

**Access to Health Care for Persons with Disabilities  
in rural Madwaleni, Eastern Cape, South Africa**

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## **DECLARATION**

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## ABSTRACT

Global research suggests that persons with disabilities face barriers when accessing health care services. Yet, information regarding the nature of these barriers, especially in low-income and middle-income countries is sparse. Rural contexts in these countries may present greater barriers than urban contexts, but little is known about access issues in such contexts. There is a paucity of research in South Africa looking at “triple vulnerability” – poverty, disability and rurality. The current study provides a local case study of these issues with the aim of informing future interventions to improve the lives of persons with disabilities.

This study explores the challenges faced by persons with disabilities in day-to-day living and in accessing health care in Madwaleni, a poor rural isiXhosa-speaking community in South Africa. The study includes a quantitative survey with interviews with 773 participants in 527 households. Comparisons between persons with disabilities and persons with no disabilities were explored.

Results suggest that persons with disabilities in Madwaleni generally experience more problems in terms of daily living as well as health issues (including access to health care) compared to persons with no disabilities. In terms of access to health care there were primarily three types of barriers – physical barriers, attitudinal barriers and communication barriers – for persons with disabilities in Madwaleni. Persons without disabilities living in households with persons with disabilities did not, however, experience more barriers to health care than did those in households without disabilities.

Implications and recommendations for the future are discussed in order to make some concrete and practical solutions in the area of disability in Madwaleni.

## OPSOMMING

Wêreldwye navorsing dui daarop dat persone met gestremdhede hindernisse in die gesig staar wanneer hulle poog om toegang tot gesondheidsorgdienste te verkry. Desnieteenstaande is inligting rakende die aard van hierdie hindernisse, veral in lae- en middel-inkomste lande, skaars. Landelike omgewings in hierdie lande mag moontlik groter hindernisse daarstel as stedelike omgewings, maar daar is min kennis oor toegangskwessies in sulke omgewings. Daar is 'n tekort aan navorsing wat die “driedubbelde kwesbaarheid” – armoede, gestremdheid en landelikheid – in Suid-Afrika ondersoek. Die meegaande studie verskaf 'n plaaslike gevallestudie rakende hierdie kwessies, wat ten doel het om toekomstige intervensies toe te lig ten einde die lewens van persone met gestremdhede te verbeter.

Hierdie studie verken die uitdagings wat persone met gestremdhede in hul daaglikse bestaan en in die verkryging van toegang tot gesondheidsorg in Madwaleni, 'n arm, landelike isiXhosa-sprekende gemeenskap in Suid-Afrika, in die gesig staar. Die studie sluit 'n kwantitatiewe opname met onderhoude met 773 deelnemers in 527 huishoudings in. Vergelykings tussen persone met gestremdhede en persone sonder gestremdhede is verken.

Resultate dui daarop dat persone met gestremdhede in Madwaleni oor die algemeen meer probleme in hul daaglikse bestaan sowel as met gesondheidsorgkwessies (insluitend toegang tot gesondheidsorg) ervaar as persone sonder gestremdhede. Wat toegang tot gesondheidsorg aanbetref, was daar vir persone met gestremdhede in Madwaleni hoofsaaklik drie tipes hindernisse – fisiese hindernisse, houdingshindernisse en kommunikasie hindernisse. Persone sonder gestremdhede, wat in huishoudings met persone met gestremdhede leef, het egter nie meer hindernisse tot gesondheidsorg beleef as huishoudings sonder gestremdhede.

Implikasies en aanbevelings vir die toekoms word bespreek ten einde konkrete en praktiese oplossings op die gebied van gestremdheid in Madwaleni te bied.

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## **LIST OF ABBREVIATIONS**

DPSA- Disabled People South Africa

EU- European Union

ICF- International Classification of Functioning, Disability and Health

NGO- Non-government Organisation

OSDP- Office on the Status of Disabled Persons

RDP- Reconstruction Development Programme

RCT- Randomised Control Trial

SAHRC- South African Human Rights Commission

UN- United Nations

UNCRPD- United Nations Convention on the Rights of Persons with Disabilities

WHO- World Health Organization

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# **CHAPTER ONE**

## **INTRODUCTION**

Investment in research about how to improve policies, systems and services to ensure disabled people access health care on an equal basis with others is a pressing priority.

(Tomlinson, Swartz et al., 2009, p. 1862)

This dissertation explores access to health care issues for persons with disabilities in a remote rural part of South Africa. Chapter 1 introduces the dissertation by looking briefly at the key concepts of disability and access to health care. Chapter 2 focuses on disability issues and how disability is understood in terms of models, definitions, measurement and prevalence. Chapter 3 is a literature review on access to health care and issues of health care access for persons with disabilities. Chapter 4 reviews the literature on rural health and disability. Chapter 5 focuses on the methodology of the study and on the study site, Madwaleni, a rural community in the Eastern Cape province of South Africa. Chapter 6 reports the quantitative results of the survey carried out in Madwaleni. Finally, Chapter 7 discusses the results of the study and looks at the implications and recommendations drawn from the results.

### **DISABILITY**

The number of people in the world with disabilities is growing (World Health Organization (WHO), 2011). WHO and the World Bank jointly produced the first world report on disability. This report suggests that over a billion people globally today experience some form of disability (WHO, 2011), about 15% of the world's population. The vast majority of

people living with disabilities live in low-income countries and most of them are very poor (MacLachlan & Swartz, 2009).

The United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD) is a human rights instrument on an international level intended to protect persons with disabilities' dignity and rights. Promotion, protection and insurance of the full enjoyment of human rights by persons with disabilities, as well as full equality under the law, is what the convention sets out (United Nations, 2008).

There are eight guiding principles that underlie the Convention:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

(United Nations, 2008.)

## **Disability Movements in South Africa**

Disability movements in South Africa have a relatively short but rich history. A “number of influential events took place in South Africa and internationally in the early eighties” (Howell, Chalklen, & Alberts, 2006, p. 49) that initiated the Disabled People South Africa (DPSA) organisation within South Africa in the 1980s. Disability activists ensured that disability became part of transformation agenda of South Africa in the early 1990s. A number of advocacy campaigns and groups within DPSA were created and helped with its expansion. These included the Disability Rights Charter Campaign, and the establishment of the Rural Disability Action Group, Disabled Children’s Action Group, and Women’s Programme. In 1992 the new South African Federal Council on Disability was launched. Post 1994 (after the first democratic elections in the country in 1994) saw an upsurge in the number of activities and programmes launched by the disability rights movement. These

have laid a structural and ideological basis for the recognition of disability as a human-rights and development issue and the creation of equal opportunities for disabled people. (Howell, et al., 2006, p. 65)

A Disability Desk was set up within the Reconstruction Development Programme (RDP) in the President’s office at the beginning of 1995. The Office on the Status of Disabled Persons (OSDP) was officially established in 1997 and was situated in the Presidency.

A Ministry and Department of Women, Children and Persons with Disabilities was set up in 2009 in South Africa but ended in 2014 after alleged underperformance and inefficiency. Following the end of this ministry and department, the Department of Social Development became responsible for disability matters in the country and the Hon. Hendrietta Bogopane-Zulu, a leading disability rights campaigner, became Deputy Minister in this Department,

having previously served in this capacity in the Department of Women, Children and Persons with Disabilities. On the one hand, disability issues can be seen to have been mainstreamed in South Africa, but some disability organisations have criticized what they view as the downgrading of disability issues over time – from the Presidency to a department shared with women’s and children’s issues, to being in a department with a very broad brief for social development. There is also concern that disability is seen purely or primarily as a “social development” or “welfare” issue, whereas, as will be seen later in this dissertation, disability issues are far broader.

## **ACCESS TO HEALTH CARE**

Under the constitution of South Africa, access to health care is a recognized right, within Section 27. A statutory body was set up by the South African Human Rights Commission (SAHRC) in 1997, to evaluate the realisation of access to health care and to hold a public enquiry. According to Meyer (2010) a preliminary report published in April 2009 by the SAHRC, based on a public enquiry into the current health services provided, found it to be in a “lamentable state”. According to the report there are a number of challenges that make the progressive realisation of access to health care more difficult. These include the fact that the country is currently in recession; a huge burden is placed on the public health due to the HIV / AIDS rate being among the highest in the world; the country has the highest income inequality internationally; and the gap between public and private health care remains a problem (Meyer, 2010).

## **DISABILITY AND ACCESS TO HEALTH CARE**

International academic communities, clinical experts, and activists for people with disabilities agree on the importance of access to health care services, and they argue that appropriate

health care should be guaranteed for the entire population (Clancy & Andresen, 2002; Tomlinson, Swartz et al., 2009). Yet, disability and access to health care has received relatively little attention, despite it being important in terms of providing equal opportunities (Jeon, Kwon, & Kim, 2015). There is relatively sparse data on how persons with disabilities access health care. Mostly it is accepted that persons with disabilities are faced with challenges – including physical access to buildings as well as access to information, services, care and support. They generally are confronted with barriers when faced with getting health care. What are the disabling barriers? According to the WHO (2011, p. 262), the barriers are:

- Inadequate policies and standards.

Policy design does not always take into account the needs of people with disabilities, or existing policies and standards are not enforced.

- Negative attitudes.

Beliefs and prejudices constitute barriers to education, employment, health care, and social participation.

- Lack of provision of services.

People with disabilities are particularly vulnerable to deficiencies in services such as health care, rehabilitation, and support and assistance.

- Problems with service delivery:

Poor coordination of services, inadequate staffing, and weak staff competencies can affect the quality, accessibility, and adequacy of services for persons with disabilities.

- Inadequate funding:

Resources allocated to implementing policies and plans are often inadequate. The lack of effective financing is a major obstacle to sustainable services across all income settings.

- Lack of accessibility:

Many built environments (including public accommodations, transport systems and information) are not accessible to all. Lack of access to transportation is a frequent reason for a person with a disability being discouraged from seeking work or prevented from accessing health care.

- Lack of consultation and involvement:

Many people with disabilities are excluded from decision-making in matters directly affecting their lives, for example, where people with disabilities lack choice and control over how support is provided to them in their homes.

- Lack of data and evidence:

A lack of rigorous and comparable data on disability and evidence on programmes that work can impede understanding and action.

Understanding the numbers of people with disabilities and their circumstances can improve efforts to remove these barriers and allow for interventions that people with disabilities can participate in.

This dissertation will explore access to health care for persons with disabilities in a remote rural area in South Africa and the primary research question that will be addressed is:

Do persons with disabilities in rural Madwaleni, South Africa, experience more access barriers to health care than persons with no disabilities?

This dissertation was part of a larger international project – the EquitAble Project (see [www.sintef.no/Projectweb/Equitable](http://www.sintef.no/Projectweb/Equitable)). This international project was a four-year collaborative research project comprised of researchers from Ireland, Norway, Sudan, Namibia, Malawi and South Africa looking at access to health care for vulnerable people in resource poor settings in Africa.

The project included both a qualitative and a quantitative component. The qualitative component looked at health care users' and providers' perceptions of the facilitators and barriers to equitable and universal access to health care for persons with disabilities while the quantitative component was a large scale survey to examine the relationship between access to health care services and disability.

Within each of the four African countries there were four sites. This dissertation is about one of the South African sites – Madwaleni – and was part of the quantitative component of the broader study.

## **CHAPTER TWO**

### **UNDERSTANDING DISABILITY**

#### **INTRODUCTION**

Despite disability being around for centuries, it is only since the 1950s and 1960s that disability studies has become a distinct discipline. It hence has a relatively short history (Goodley, 2011). Disability studies is thus a relatively new enterprise (Gleeson, 1997) emerging as a systematic discourse in the 1950s but gaining momentum since the 1970s. Despite disability issues (with their concerns of medical, health and rehabilitation) within the academic sphere not being new (Hemingway, 2008), disability studies in recent years has become a distinct international academic discipline with much energy and vibrancy (Priestley, 2006; Roulstone, Thomas, & Watson, 2012; Shildrick, 2012). According to Hughes and Paterson (1997) the key conceptual distinction at the heart of the transformation of disability discourse is from seeing disability as a medical problem to engaging with an emancipatory politics of disability. However, according to Gleeson (1997, p. 181-182), the disability debate still suffers the “legacy of theoretical deprivation” or “theoretical underdevelopment”. Given that most persons with disabilities live in low- and middle-income countries, there is a particular need for empirical disability research in these contexts and to strengthen and support research on disability (Graham et al., 2014).

#### **DISABILITY MODELS**

The many models of disability that have been developed may reflect the multidimensional character of disability (Mitra, 2006), as well as different ideological and scientific positions. The disability models provide an understanding to the way in which people with impairments

experience disability (Mitra, 2006). As noted by Pfeiffer (2001), many disability academics concur that no single model can fully explain disability.

### **Individual Disability Models**

The understanding of disability has its roots in individual models which saw disability as a function of the individual who had bodily differences or defects. Disability was the concern of the individual and because of the emphasis on deficits, this individualistic approach has been termed the “personal tragedy theory” (Oliver, 1986). Theorising in this individualistic, deficit-oriented, way, however well-intentioned, has been argued to compound discrimination and to increase prejudice against disabled individuals and the notion that they were the “other”.

This traditional and dominant view of disability in the past was causal – an individual disability was caused by impairment; or that the bodily impairment alone constituted the entire experience of disability. Terminology such as “care” and “cure” and notions of “normality” as the ideal for all people (Finkelstein, 1997) were used, leading to a “medical interpretation of disadvantage” (Titchkosky, 2000). Everything was based on biological and impairment differences. The “personal tragedy” approach to disability regarded the person with an impairment as victim of their functional limitations and policies gave preference to medical treatment and rehabilitation on an individual basis as well as state social welfare benefits (Mercer & Barnes, 2004).

The best known Individual Models comprise the Medical Model and the Psychological Model. The main approach in the past to understanding disability arose from the Medical Model – “disabilities occur because of physical impairments which have resulted from the underlying disease or disorder” (Johnston, 1996, p. 205). Issues of a medical “condition”

become important in this model. A central challenge in this model was how to correctly diagnose the condition of the person who then needs appropriate “treatment” (Llewellyn & Hogan, 2000). The Medical Model considers disability as an individual, physiological, condition which can be treated and in some instances cured. It fails to acknowledge the role of cognitions and emotions in shaping the experience of disability.

The Psychological Model focuses on the individual who has failed to adjust to or overcome their impairment. This model is often criticised as being victim-blaming. Here disability is defined in behavioural terms and regarded to be influenced by physiological, environmental, social, cognitive and emotional factors. Some psychological models deal with the psychological and emotional consequences while others deal with the determinants of impairments and disability (Johnston, 1997). Individual psychology approaches are evident in many studies of disability with its origins in the 1960s (Gleeson, 1997). In early psychological theorizing about disability it was considered almost inevitable that people would experience psychological problems as a result of their impairment (Watermeyer, 2012).

### **Social Model**

Ideas about disability moved from an emphasis on the physical condition of persons with disabilities towards an emphasis on tackling the oppression that persons with disabilities experience in society (Priestley, 2006). A social representation of disability relocates the focus from the individual to society – from an individual model (biological causes of impairment) to a social model (societal causes of exclusion and oppression). The Social Model has been “codified as the central tenet of the self-organised disability movement” (Shakespeare & Watson, 1997, p. 293). This development within the sociological realm has

been considered by some as disability studies' most significant contribution (Barnes, Oliver, & Barton, 2002) and has “undoubtedly been the dominant paradigm in researching and understanding disability in recent years” (Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, 2004, p. 145).

A strength of the Social Model lies in its simplicity, with its most pertinent aspect in that it perhaps raises a consciousness amongst persons with disabilities, analysing policies and explaining the process of disability (Campbell, 2008). It offers a new basis and rhetoric of identifying, understanding and responding to disability (Roulstone, 2004). As Humphrey (2000, p. 63) states, “the social model harbours a number of virtues in redefining disability in terms of a disabling environment, repositioning disabled people as citizens with rights, and reconfiguring the responsibilities for creating, sustaining and overcoming disablism”.

The Social Model of disability differentiated between *impairment* as bodily difference and *disability* as the social and ideological implications of having an impairment. Disadvantage comes from the social and political aspects of disability and not only from the bodily impairments. In fact, stronger versions of the social model would ascribe disadvantage to sociopolitical oppression alone, or almost exclusively. To try and deal with disability in its complex political context, the social model argues, we need to tackle the social level and not only the individual level. Disability is not an outcome of bodily pathology, but of social organisation: “it was socially produced by systematic patterns of exclusion that were – quite literally – built into the social fabric” (Hughes & Paterson, 1997, p. 328).

The “new” disability studies, influenced by the Social Model challenges the idea that disability is determined by biology, or that it is the property of the individual (Thomas, 1999).

The model puts the problem back into society as a whole and where the individual becomes less important (Llewellyn & Hogan, 2000). The Social Model of disability has moved away from notions of impairment and focuses instead of the ways in which disability is a result of social, economic, political, cultural and psychological exclusion of people with impairments (Goodley & Lawthom, 2006).

In light of the Social Model, disability is now more critically defined as the limitation or loss of opportunities to participate in the mainstream life of the community on an equal level with others due to physical as well as social barriers (Disabled People's International, 1982). Moving away from the traditional individual model of disability we are also moving away from the medical profession at the centre of improving the lives of disabled people, towards social transformation as the primary driver of change. There is also recognition now that disabled people are not simply individuals, but people who are oppressed with many disadvantages in society. By adopting a social interpretation of disability one allows persons with disabilities to both challenge the notion that their segregation was in any way inevitable and to focus on social change strategies (Hemingway, 2008). Disability studies, according to the Social Model, might include the study of oppressive social structures, as well as environmental barriers together with economic relationships and power (Hemingway, 2008).

This led to a social interpretation of disability in the 1970s redefining disability as that which is created socially and that is based on attitudinal, environmental and social barriers and which is experienced by an individual (Hemingway, 2008). According to Hemingway (2008, p. 3) two distinct terms therefore emerged; "impairment", which is the biological, functional attribute or condition of the individual and "disability" which is the experiences of social disadvantage.

The Social Model first gained momentum in the UK in 1970s, with increased politicisation of disabled people. The Open University launched the initial curriculum to deal primarily with disability, naming the course *The Handicapped Person in the Community* (Brechin & Liddiard, 1981), then changing the name at the end of the 1980s to *The Disabling Society* (Finkelstein, 1997). The development of this discipline was seen in the establishment of a dedicated journal in 1986 known as *Disability, Handicap and Society*. This journal changed titles and is now known as *Disability and Society*. This journal provided the opportunity for academic debate around disability with an emphasis on the Social Model of disability (Barton & Oliver, 1997).

It is contended that the model is a practical tool to address and identify the disabling barriers that prevent people with impairments from participating equally within society in a mainstream level (Cameron, 2008). It is not a complete theory of disability (Oliver, 1996) but simply provides a differing understanding of what is meant by disability compared to the dominant Individual Model. This social model focuses on the social structures in which certain physical, emotional and intellectual “differences” are diagnosed and managed. The Social Model focuses on the impact of the environment on disability and how it discriminates against and disables certain “impaired” individuals (Marks, 1999a).

The Social Model identifies disability as:

The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical limitations and thus excludes them from participation in the mainstream of social activities. (Barnes, Mercer, & Shakespeare, 1999, p. 28)

The model provides a mechanism for the structural assessment and explanation of the poverty and disadvantages experienced by people with impairments in a society that is disabling (Cameron, 2008). It has developed a powerful and significant political agenda (Oliver, 1996) and has become a force in influencing social policy (Beckett & Wrighton, 2000).

In conclusion, according to Dewsbury et al. (2004, p. 156) the Social Model, “in whatever form, has the great merit of producing an interactionist account of disability, wherein disability is seen as a construction and thus necessarily a responsibility shared by all parties”. It is not “random or natural but a social accomplishment or creation” (Watermeyer & Swartz, 2006, p. 3).

Table 1 summarises the key differences between the two main models in disability studies (Burger & Burger, 2010). These two models “passively coexist rather than actively engage with one another” (Thomas, 2004, p. 570).

Table 1

*Differences between the Medical Model and the Social Model (source: Burger & Burger, 2010)*

<b>Medical Model</b>	<b>Social Model</b>
Disability is a deficiency or abnormality.	Disability is a difference.
Being disabled is negative.	Being disabled, in itself, is neutral.
Disability resides in the individual.	Disability derives from interaction between the individual and society.
The remedy for disability-related problems is	The remedy for disability-related problems

cure or normalisation of the individual.	is a change in the interaction between the individual and society.
The agent of remedy is the professional.	The agent of remedy can be the individual, an advocate, or anyone who affects the arrangements between the individual and society.

### **The Capability Model**

The Capability Model developed by A.K. Sen is a useful framework for defining disability as it attempts to understand its economic causes and consequences (Mitra, 2006). Disability is understood as a deprivation in terms of capabilities or functioning. This results from the interaction of an individual's personal characteristics (e.g., age and impairment) and a collection of available goods (assets and income) and environmental factors (social, economic, political and cultural). In relation to the level of personal characteristics, impairment rather than disability is used. When it comes to capabilities and functionings, deprivation is the result of the interaction among the resources available to the person, personal characteristics and the environment. Disability is the result of an individual's deprivation of practical opportunities as a result of an impairment. Under the Capability Model, disability may be analysed on two separate levels, as a deprivation of capabilities (potential disability) or as a deprivation of functionings (actual disability). Understanding the economic burden and environment of disability is part of understanding disability (Mitra, 2006). The capability framework allows us to understand that poverty and disability affect one another in a circular relationship (Braithwaite & Mont, 2009).

### **The Human Rights Model**

The Human Rights Model can be seen as the most recent development of the Social Model. It states that:

- 1) all human beings are equal and have rights that should be respected without distinction of any kind;
- 2) people with disabilities are citizens and, as such, have the same rights as those without impairments; and
- 3) all actions to support people with disabilities should be “rights based”, for example, the demand for equal access to services and opportunities as a human right (Digital Campus, n.d.).

Like the Social Model, the Human Rights Model places responsibility for addressing the problems of disability on society rather than on the person with disabilities. It also places responsibility on one to ensure that appropriate legislation designed by the government is complied with at a local level (Digital Campus, n.d.).

According to Rioux and Carbert (2003, p. 11) a human rights framework is “empowering”. The human rights approach compels governments to make sure that there are societies that are inclusive and that anticipate and respond to differences in human characteristics that are inherent to the human condition. Human rights should be enjoyed by all people with disabilities.

### **Criticisms of the Individual Models**

The Medical Model is viewed as problematic in that it reduces the understanding of disability to the conditions of the individual “patient” while ignoring wider social and environmental influences that result in disability (Imrie, 1997). This, according to Imrie (1996, p. 3),

portrays people with disabilities as “inferior, dependent, and by implication of little or no value”. Research highlights that the medicalisation of disability is a significant factor in society’s marginal treatment of disability issues (Oliver, 1990). It further developed into the conceptualization of the “rehabilitation role”, where the individual must “accept” their condition, and make the most of their abilities to achieve “normality” (Dewsbury et al., 2004, p. 147). It views people as somehow “lacking” and unable to play a “full role” in society (Dewsbury et al., 2004, p. 147).

The Medical Model treats disability as uniform and homogenous, reinforcing the myth that there are two types of people – able-bodied and disabled. Disabled are by implication then, not normal. Yet, as Oliver (1990) and Abberley (1993) have noted, if the notion of disability is placed in a different context of society and not the individual, then we enter a different understanding of normality.

The traditional individual models offer a deficient basis for understanding disability with its focus entirely on impairment and not on issues of culture and physical environment (Barnes et al., 1999; Oliver, 1990; Swain, French, & Cameron, 2003).

### **Criticisms of the Social Model**

It is widely recognized that the Social Model criticisms of individualisation, medicalisation and pathologisation have made an important contribution to a seismic shift in how disability was understood. The social model itself, though, has been questioned and critiqued (Oliver, 2013). Historically, the model was developed by activists, most of them men, many with mobility impairments, and living in wealthier countries. There have been concerns that the Social Model defocuses from the lived reality of the experience of impairment, and that the

model in its original formulation defocused from other social divisions such as age, ethnicity, gender and sexuality (Hemingway, 2008). Concern has also been expressed that the model has tended in practice, to people who may experience challenges in being viewed as credible self-advocates, such as people with learning difficulties and those with mental health issues. There are also concerns about the practical implementability of the social model, and its openness to empirical exploration of social processes of exclusion (Shakespeare, 2014).

Bickenbach, Chatterji, Badley and Ustun (1999) conclude that the Social Model:

is provocative, but not operationalisable. It does not give us the tools we need to amass the evidence to substantiate claims about the social construction of the disadvantages of disablement. And in this sense it fails the two aspirations of the social model of disablement – first, to provide a workable model for research and second to provide advocates with hard data they need to convince legislators to pass new laws and change old ones. (Bickenbach et al., 1999, p. 1178)

Marks (1999a) mentions three criticisms of the Social Model. Firstly, the Social Model has been challenged in that it ignores differences that various disabled people experience as a consequence of gender, sexuality, race, culture or other distinctions. Secondly the model has been challenged for adopting values of capitalism that prioritises work and independence. Finally there have been a number of challenges in the way it identifies whether a person is disabled or not.

Oliver (2004, p. 8-9) identifies five main criticisms of the Social Model:

- 1) that the Social Model ignores or is unable to deal adequately with the realities of impairment;
- 2) that it ignores our subjective experiences of the pains of both impairment and disability;
- 3) that it is unable to incorporate other social divisions such as ethnicity, age, gender, sexuality;
- 4) that it cannot be used in order to describe the way that disabled people are socially positioned as “other”;
- 5) and that it is inadequate as a social theory of disability.

Riddle (2013) states that the Social Model of disability does not accurately reflect what the experience of disability actually is, as there is no causal link between impairment and disability. Social Model theorists are only acknowledging part of the phenomenon of disability and underplaying the visceral experience of impairment.

### **The Way Forward**

We need to be avoid placing the Individual and Social Models in neat juxtaposition. Indeed, there may be room for overlap or synergy between both. As Oliver (2013, p. 1024), a major proponent of the Social Model and critic of the medical model states, “at no point did I suggest that the individual model should be abandoned, and neither did I claim that the social model was an all-encompassing framework”. Anastasious and Kauffman (2013, p. 441) state, “people will benefit most by recognizing both the biological and the social dimensions of disabilities”. A more comprehensive and integrating model would be more useful as opposed to competing models. Opposing models can create a “destructive polemic” if the

Social Model is believed to negate or cancel out any Individual Model of disability (Munn, 1997).

There is a role for the Individual Models as well as the Social Model in the management of disability. The advantages of Individual models should be encapsulated in the newer Social Model and the models should feed off one another. This would help to understand subjective experiences of people with disabilities and it would help us to understand how to ameliorate disability through social practices (Munn, 1997).

Thus enters the new paradigm of looking at disability – within a continuum and not a single model. This follows the International Classification of Functioning, Disability and Health (ICF) framework conceptualising disability along a continuum (IFHIMA, n.d.). Within public health, the ICF model is the most accepted model of disability. (Iezzoni & Freedman, 2008). The ICF is a classification of health and health-related domains. This is applying the most recent international thinking which conceptualises disability along a continuum of functioning. The ICF looks at impairment involving an organ or body part (Medical Model), activity limitation involving the whole body or person and participation restrictions involving the person in the environment (Social Model). The ICF acknowledges that every human being experiences some degree of disability during their lifespan and thus recognises that disability is a universal experience and not just one that happens to a minority of the population. According to Schneider, Hurst, Miller, and Ustun (2003), the ICF provides a framework for understanding the interplay between a person's health condition and the context of that person.

In light of the fact that 80 percent of the world's people with disabilities are in low- and middle- income countries we need to look at theories that are more pertinent to what some

term the developing world. Theories in the past have predominantly come from wealthy countries in the United States of America and the United Kingdom. However, in the developing world, the dynamics are different. This is where looking at disability along a continuum becomes more important and useful. Disability is not only about impairment (Medical Model) but also about social oppression (Social Model) and it is this spectrum that makes it necessary to look at the new paradigm of a continuum.

In a given context each disability model may bring a useful perspective on disability (Mitra, 2006), but the history of disability models has recently come to a crossroads in that the models are now being replaced with a continuum of functioning. We can no longer talk of isolated models of disability but rather of a more comprehensive and extensive continuum with disability at one end of the spectrum and functioning as a full member of society at the other end. There has been an attempt to shift thinking about disability and how it is understood in today's context – especially in the context of developing countries. It is not appropriate to think of disability only in terms of Medical or Social Models but rather in a more sophisticated approach that mirrors the complexity of its place in developing societies. We need to move away from thinking of disability in separate models but rather to a continuum of functioning.

In summary, according to Gulley, Rasch, and Chan (2014, p. S9), “the scientific understanding of disability has undergone a paradigm shift” from a simpler conception of functional limitations as a direct consequence of medical pathology to a much more sophisticated view of disability as a complex and multidimensional phenomenon as reflected in the ICF. As Meade, Mahmoudi and Lee (2015) state, models of disability have increasingly recognized the role of factors related to the context of the individual and have

explicitly included contingencies in the links between pathology and disability. From this new perspective, the health of people with disabilities is not determined by the biological makeup of the individual alone but also by equitable access to health care services (Becker, 2006). In this regard, it is important in addition to recognise that disability is not just a question of individual bodies but also of how households and others are affected by the social consequences of impairment.

### **Individual versus Household Disability**

Although most of the work in disability studies focuses on individual level data, we need to understand the relationship between disability and household structures (Altman & Blackwell, 2014). Not much is known about how disability affects the conditions of households with persons with disabilities (Parodi & Sciulli, 2012). There is a paucity of work done in this area of disability. Yet, to understand the demographic structure of households containing members with disabilities is key in policy development (Fujiura, 2010). As Shandra, Avery, Hogan, and Msall (2012) highlight in their article, disability is a household affair.

Most of the work looking at households and disability has focussed on the economic factors with particular reference to poverty. According to Shandra et al. (2012), the likelihood of a household living in poverty will increase if there are more members in the household with a disability. They found in their study that higher occurrence of disability in households is linked to less advantageous household resources, and household with multiple disabilities have fewer social resources in addition to their lower financial resources. Parodi & Sciulli

(2008) mention that the economics of disability needs to analyse the person with disability in the household context rather than in isolation.

More research needs to take place in this area of disability as it is important that policy developers understand the complicated relationship between living arrangements and disability (Altman & Blackwell, 2014). For instance, do living arrangements and disability affect access to health care?

## **DISABILITY DEFINITIONS**

There is no universal definition of disability in the literature (Loeb, Eide, & Mont, 2008; Meade et al., 2015). This is partly, but not solely a product of the fact that there are so many theoretical approaches to understanding disability (Barnes, et al., 1999). Differences in perceptions, various models and classification systems, and variations in understandings in different national and cultural contexts all may result in different definitions of disability (Parnes et al., 2009). Disability is complex, dynamic, multidimensional and contested (Officer & Groce, 2009; WHO, 2011) and has not been defined, measured, or analysed in a consistent manner (Altman & Bernstein, 2008).

Because disability covers many contexts each with their own perspectives – e.g., social, economical, health, political – “causes conflict, contradiction, and confusion among terms” even within particular contexts themselves (Altman, 2001, p. 98). A further challenge is that we tend to view disability as a permanent and dichotomous entity, but it is more “fluid and continuous” (Pfeiffer, 1999, p. 394). Definitions seem to be purpose-specific (Altman, 2001).

Disability has “been subject to many definitions in different disciplines and for different purposes” (Mitra, 2006, p. 236). Gronvik (2007) believes that these problems originate from inadequate theorising within the field of disability research. As Shildrick (2012) states, disability remains very complex and difficult to define. Understandings of disability have also shifted considerably over time (Graham et al., 2014).

According to the United Nations Convention on the Rights of People with Disabilities (UNCRPD), disability remains as “an evolving concept”. According to Altman (2014) disability is a word without a specific single meaning because it has been used to represent many different things.

According to the ICF, functioning and disability are seen within a dynamic interaction between health conditions as well as personal and environmental contextual factors. Disability is the overarching term for impairments, activity limitations and participation restrictions. These refer to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors) (Goodley 2011; Leonardi, et al., 2006; WHO, 2002).

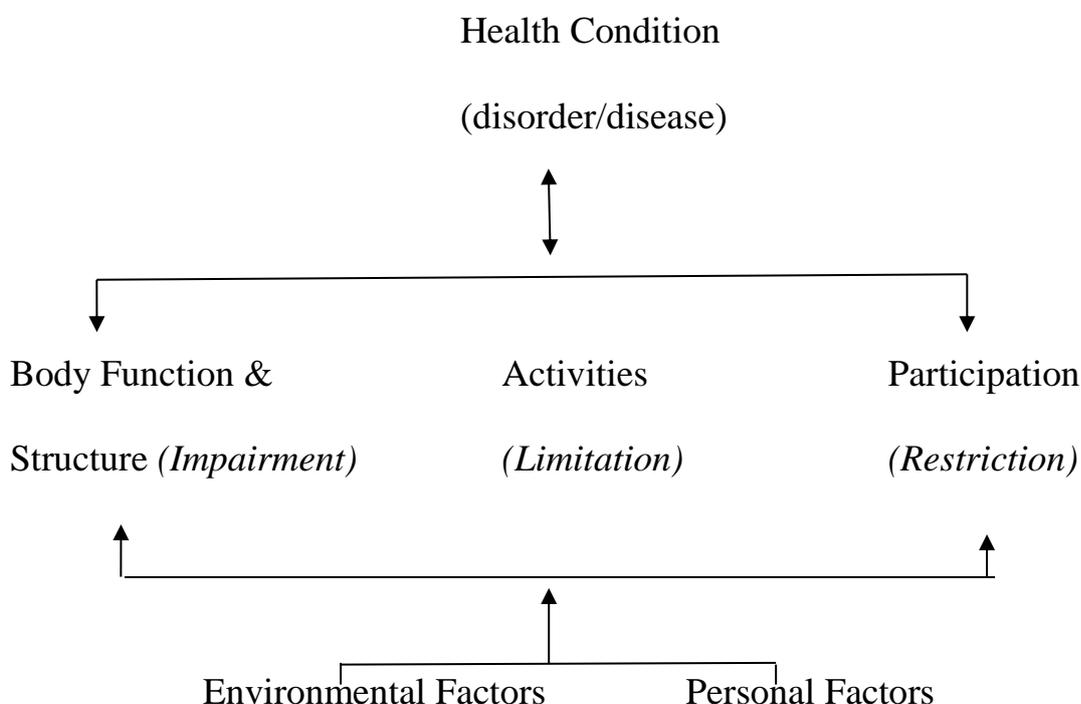
- An impairment is a problem in body function or structure;
- An activity limitation is a difficulty encountered by an individual in executing a task or action;
- A participation restriction is a problem experienced by an individual in involvement in life situations (WHO, 2011, p. 5).

Hence disability is a complicated issue in that it looks at an interaction between features of a person’s body as well as aspects of the society in which he/she finds him/herself.

As argued by Imrie (2004), the resulting ICF represents the integration of the Medical and Social models to form a Bio-psychosocial model. The ICF emphasised the universality of disability (Iezzoni & Freedman, 2008).

The Preamble to the UNCRPD stresses that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others” (WHO, 2011, p. 4). Defining disability as an interaction means that “disability” cannot be attributed to the individual alone. The potential barriers that affect persons with disabilities can be addressed by improving social participation (WHO, 2011).

Figure 1 is a summary of the ICF Model.



*Figure 1. The ICF Model*

According to (Leonardi et al., 2006), to be able to stand up to scrutiny, a definition of disability should be:

applicable to all people, without segregation into groups such as “the visually impaired” or “wheelchair users” or those with a chronic illness, and be able to describe the experience of disability across many areas of functioning. The definition should allow comparison of severity across different types of disability, be flexible enough for different applications (e.g., statistical or clinical use), be able to describe all types of disability, and recognise the effects of the environment on a person’s disability. Finally, the definition should not include stipulations about the causes of any disability. (Leonardi et al., 2006, p. 1219)

The proposed definition put forward by these authors is:

Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors. (Leonardi et al., 2006, p. 1220)

However a complicating factor in definition and measurement is that there is no clear distinction between those with disabilities and those without disabilities (Altman, 2014). Although disability is primarily seen as a dichotomous situation – either a person is disabled or not – this is not the reality. People may experience disability in one specific situation but not in another, depending on what is required of them. The environmental situation and what

the objective of the definition used to describe the situation become important (Altman, 2014).

The problems with defining disability have repercussions on

- 1) how it is measured; and
- 2) the resultant prevalence rates, amongst other statistics.

As Gronvik (2007) mentions, the complex theories and models of terms such as disability can make empirical representations rather difficult. There is, however, a need for empirical disability research in low- and medium-income countries and to strengthen and support research on disability (Graham et al., 2014).

Lastly, according to Krahn, Walker and Correa-De-Araujo (2015, p. S199) definition differences also reflect an “evolution in our understanding of disability and its relationship to health, the relative value society has placed on people with disabilities, and how program eligibility or legal protections have been addressed”. This creates some difficulties for researchers and it must be acknowledged that whatever definition is used must be provisional, the freezing of complex debates into a narrow set of categorizations which may be the most practical to use at a particular time.

## **DISABILITY MEASUREMENT**

According to Kostanjsek et al. (2013), counting disability is a challenge for a number of reasons. Firstly, disability is complex and is experienced on various levels. Secondly, operational definitions and measures of disability vary widely from situation to situation. Thirdly, for many years measuring disability has been a somewhat neglected public health

topic. As McDermott and Turk (2014) state, measuring disability has become a difficult task. Debates are raging about how it should be measured (Officer & Groce, 2009). To base comparative studies on data that used different definitions for the same terms is methodologically unacceptable (Krahn et al., 2015).

According to Schneider (2009, p. 43), “measurement of disability is integrally linked to defining disability”. She distinguishes between broad definitions (which emphasise the environment in disability) and narrow definitions (which focus on medical impairment and ignore environmental factors). As narrow definitions only consider persons with severe disability, these estimates of disability prevalence will be small. The result of these narrow definitions can be that people with disabilities become marginalised. This narrow approach to defining disability does not recognise everyday functioning difficulties but does not identify individuals as disabled. Thus, according to Schneider (2009), narrow definitions lead to exclusive measures that can result in under estimates of disability in populations.

Continuing, Schneider (2009) states that the WHO’s ICF uses a broad definition. This takes into consideration both the role of individual and environmental factors in creating the experience of disability. This encourages the point that disability is a universal experience and not that of a marginalised group. This latter breadth approach leads to a definition of disability which is inclusive of all forms of difficulty on a day-to-day basis. These people may not experience the discrimination and marginalisation that people with severe disability do, but it is still important to consider them in policy management. This broader definition thus results in a more inclusive measure of disability and much higher prevalence estimates. Measures using this broader definitional approach can eliminate use of the words “disabled” or “disability” in questions and rather focus on issues of “difficulties” (Schneider, 2009).

### **Measurement and the Washington Group on Disability Statistics**

The ICF of the WHO (WHO, 2001) and the proposal by the United Nations Washington Group of Disability Statistics (Mont, 2007) are seen as attempts, or recommendations, to standardise the measurement of disability (Molden & Tøssebro, 2012). There is agreement that the way forward is to use broader and more inclusive definitions and measures for disability prevalence estimates (Schneider, 2009). The necessity to make comparisons on disability measures for individual countries and for international comparisons was recognized in June of 2001 at the United Nations International Seminar on the Measurement of Disability. This recognition emerged from the lack, and general poor quality of, information on disability, especially in developing countries. There is also a shortage of internationally comparable measures, even among developed countries. The Washington Group on Disability Statistics was created to look into this (Madans, Loeb, & Altman, 2011). The Washington Group on Disability Statistics has developed a Short Set of questions for use in Censuses, which aims to provide an internationally comparable measure of disability and difficulty. This better reflects “the current disability paradigm based on functional limitations rather than on impairments and is deemed suitable for the international comparison of prevalence rates” (Loeb et al., 2008, p. 33). The Washington Group questions were designed to provide data that is comparable across nations for populations living in a varying cultures and economies (Madans et al., 2011). They are consistent with the ICF. Testing has now shown that they can have a production of internationally comparable data (Miller, Mont, Maitland, Altman, & Madans cited in Madans et al., 2011). In contrast to basing measures on impairment or deviations or loss in bodily structures, we can now focus on measuring functioning in core domains (Madans et al., 2011).

The six core questions developed by the Washington Group for use on censuses are:

The next questions ask about difficulties you may have doing certain activities because of a

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- a. Do you have difficulty seeing, even if wearing your glasses?
- b. Do you have difficulty hearing, even if using your hearing aid?
- c. Do you have difficulty walking or climbing steps?
- d. Do you have difficulty remembering or concentrating?
- e. Do you have difficulty with self-care, such as washing all over or dressing?
- f. Because of a physical, mental, or emotional health condition, do you have difficulty communicating, (for example, understanding or being understood by others)?

The response options are “no difficulty”, “some difficulty”, “a lot of difficulty” and “unable to do”.

According the South African Census of 2011, using the Washington Group Questions, disability is defined as follows: “If an individual has ‘Some difficulty’ with two or more of the 6 categories then they are disabled and if an individual has ‘A lot of difficulty’ or is ‘Unable to do’ for one or more categories they are classified as disabled” (Statistics South Africa, 2012, p. 51). This is the definition that this dissertation is going to use in its data analysis.

None of these questions uses the word “disability”. The strong negative and stigmatising association relating to the word disability has made people reluctant to answer these questions on disability. It is important to understand how people understand the concept of disability, as this will affect how they answer questions that use the word “disability” or

“disabled”, and how their response might vary if “difficulty” was used (Schneider, 2009, p. 43). The Washington Group approach is not centrally concerned with disability as an identity or self-ascription, but with how people function in their own social context.

To summarise, there is little agreement on how disability should be understood, conceptualised and measured empirically in quantitative research settings (Loeb & Eide, 2006). As Molden and Tøssebro (2012) point out, operational measurement of disability varies considerably and there is as yet no consensus on an international standardisation of disability measures. However, the Washington Group has made tremendous progress in terms of disability measurement and it is their criteria that will be used in this dissertation.

## **DISABILITY PREVALENCE**

Partly because of the methodological challenges discussed above, reported disability prevalence rates vary widely. Censuses and surveys globally take very different approaches to measuring disability and have faced methodological issues for decades giving reasons for concern regarding measured prevalence rates (Krahn et al., 2015; Molden & Tøssebro, 2012). In fact, the same country can record very different rates of disability with different instruments. (Mont, 2007).

### **Worldwide**

According to the WHO (2011, p. 29), about 15% of the world’s population lives with some form of disability – of whom 2-4% experience significant difficulties in functioning. This prevalence is higher than previous estimates of 10% dating back to the 1970s. This global estimate for disability, according to WHO, is on the rise due to the ageing population, the

increase in chronic diseases, as well as improvements in the methods used to measure disability.

### **South Africa**

There are proportionally and numerically more persons with disabilities in the southern hemisphere (Stone, 1999). However, in South Africa, there is a serious lack of reliable information about the nature and prevalence of disability in South Africa (Office of the Deputy President, South Africa, 1997). This is primarily because there is as yet little consistency regarding definitions and what is included as a disability (Heap, Lorenzo, & Thomas, 2009). The data collected in the 1996 census indicated that 6.7% of the population had disabilities while in the 1998 baseline national survey on disability the data counted for 5.9% of the population. The 2001 census came up with a 5 % national prevalence. This is an under-representation due to varying definitions, measurements and interpretations of disability in South Africa. For instance, the wording of the census disability question in 1996 was different to the census 2001 question. In the South African 1996 census the disability question read as follows: Does the person have a serious sight, hearing, physical or mental disability? While in the South African 2001 census the question read as follows: Does the person have any serious disability that prevents his/her full participation in life's activities? They were asking different questions about disability and this fact makes comparison between prevalence of the two censuses problematic. The 2011 South Africa census used the Washington Group questions (discussed above) and came up with a disability prevalence of 7.5% of South Africans five years and older. This prevalence cannot be compared to the previous census in 2001 as the wording was different.

Quite correctly, according to Van Staden (2011), the exact percentage of prevalence cannot be agreed upon in South Africa in that there have been inconsistent results in the census and other studies.

It is likely that disability is more prevalent in rural areas due to harsh living conditions and increased poverty but, according to the 1998 survey on disability carried out in South Africa (Schneider et al., 1999), the prevalence of disability in rural areas is lower, but more likely to be severe (5.1%), than that of urban areas (6.3%). This is unlike international findings where rural prevalence is higher than that of its urban counterparts.

### **Eastern Cape**

The prevalence of disability in the Eastern Cape province of South Africa is estimated at 9.6% (Statistics South Africa, 2012), using the Washington Group questions, while disability statistics in the Amatole district (wherein the study was conducted) are unknown (Grut, Mji, Braathen, & Ingstad, 2012).

### **Summary of Chapter**

This chapter explored issues of disability in terms of models, definitions, measurement and prevalence.

The models that were discussed included the dominant Individual and Social Models on disability. A brief look at the Capabilities Model and the Human Rights Model was also done. Strengths and limitations of the dominant models were then investigated. The new and alternative ICF model was then introduced as a move forward to disability models development and for creating more accurate measures.

Disability definitions were then explored, and these showed that there is no universal definition of disability. It was portrayed that this is a complex and intricate issue that depends on many factors. The ICF model was then again discussed as a more effective approach to disability definition issues.

The difficulties of defining disability impact on the measurement of disability. The work of the Washington Group on Disability Statistics was then discussed as a useful tool to help address these measurement difficulties.

Finally, we looked at how obtaining disability prevalence was affected by disability definitions and measurement issues discussed earlier. International, national and local prevalence rates were then investigated.

Having looked comprehensively at one of the key terms (i.e., disability) in this dissertation it is now appropriate to look at the second key concept in this dissertation, i.e. access to health care.

## **CHAPTER THREE**

### **ACCESS TO HEALTH CARE**

#### **INTRODUCTION**

The chapter will start by looking at how the word “access” is understood in the health care context. It will then explore the literature on access to health care in general. The focus will then turn to access to health care issues in South Africa. The literature review will then narrow its focus and look at the relationship between disability and access to health care in general, in low-income countries and then in South Africa. A discussion on disability and barriers to health care will follow with a look at multiple barriers and then at specific impairments and access to health care.

#### **ACCESS TO HEALTH CARE**

Access to health care is a major health and development issue (Obrist et al., 2007) and plays a major role in the performance of health care systems globally (Levesque, Harris, & Russell, 2013). It is an important concept in the study of the organisation, financing and delivery of health care services (Ricketts & Goldsmith, 2005). While the literature on access to health care is large, diverse and complex (Dixon-Woods et al., 2006), there are no global criteria on how to define and measure access (Oliver & Mossialas, 2004). Racher and Vollman (2002) mention how access as a concept was “nebulous and obscure” to most of the public as well as policymakers and practitioners while Obrist et al. (2007, p. 1587) state that equitable access “remains an empty formula” for politicians and experts.

Despite the focus and attention that is placed on access to health care services it is surprising that there is still a degree of ambiguity in defining access (Sibley & Weiner, 2011). A review

of the literature reveals diverse uses of the word "access" (Norris & Aiken, 2006) while the conceptualisation and operationalisation of the term is not consistent (Dixon-Woods et al., 2006; Gulzar, 1999; Levesque et al., 2013). It is not a simple undifferentiated category (Heap et al., 2009).

Access to health services is a complex concept (Guillford et al., 2002; Hjortsberg & Mwikisa, 2002; Levesque et al., 2013), it is difficult to define (Al-Taiar, Clark, Longenecker, & Whitty, 2010) and there are hence many definitions (Peters et al., 2008). The concept of access to health care has become somewhat of a "catch all" phrase, and the meaning varies significantly with whoever uses it (Norris & Aiken, 2006). As Karamitri, Bellali, Galanis, and Kaitelidou (2013, p. 36) state, accessibility to health services is a "complex and multifaceted" issue with researchers exploring accessibility from different points of view. Access to health care incorporates "a variety of nuanced definitions" (Meade et al, 2015, p. 633). It is a multidimensional concept (Cabieses & Bird, 2014; Nemati et al., 2014).

For example, to analyse access to health care one may consider the narrow domain – from the moment the patient seeks care to the moment attention is first received – or the broad domain – from perceiving the need for health care through to the use of services, including all contact throughout the episode (Frenk, 1985 cited in Garcia-Subirats et al., 2014). Some have extended the latter to include satisfaction with care received and incorporate aspects of quality and health outcomes (Anderson, 1995). However, according to Garcia-Subirats et al. (2014), most studies on access to health care tend to focus on initial contact and on specific type of barriers related to the services or the population.

To come up with a comprehensive definition of access has been a problem. Although there have been attempts in the past to clarify its complexities, access to health care has remained a rather vague concept, thus preventing the work of health care policymakers and professionals in making meaningful health care reform (Khan & Bardwaj, 1994). The components or aspects of access to health care are not very well understood (Gulzar, 1999). In being able to access health care raises issues about the meaning and measurement of access to health care (Guillford et al., 2002).

A highly cited contribution to the effort to define and measure access to health care is the work of Penchansky and Thomas (1981), published over thirty years ago. They proposed that the specific areas, the dimensions of access, are as follows:

- **Availability**, the relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs. It refers to the adequacy of the supply of physicians, dentists and other providers; of facilities such as clinics and hospitals; and of specialised programmes and services such as mental health and emergency care.
- **Accessibility**, the relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost.
- **Accommodation**, the relationship between the manner in which the supply resources are organised to accept clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the clients' ability to accommodate to these factors and the clients' perception of their appropriateness.
- **Affordability**, the relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health

insurance. Client perception of worth relative to total cost is a concern here, as is clients' knowledge of prices, total cost and possible credit arrangements.

- **Acceptability**, the relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients. In the literature, the term appears to be used most often to refer to specific consumer reaction to such provider attributes as age, sex, ethnicity, type of facility, neighbourhood of facility, or religious affiliation of facility or provider. In turn, providers have attitudes about the preferred attributes of clients or their financing mechanisms. Providers either may be unwilling to serve certain types of clients (e.g., welfare patients) or, through accommodation, make themselves more or less available.

Following the work of Penchansky and Thomas, Guillford et al. (2002) claim access is a multi-dimensional concept that should be measured on at least four dimensions: 1) service availability, 2) utilisation of services and barriers to access including personal, financial and organisational barriers, 3) relevance and effectiveness, and 4) equity.

Likewise, Peters et al. (2008, p. 162) argue that access is a multidimensional process that includes quality of care, geographical accessibility, availability of the right type of care for those who need it, financial accessibility, and acceptability of service. Their conceptual framework for assessing access to health services is as follows:

- **Geographic accessibility** – the physical distance or travel time from service delivery point to the user;

- **Availability** – having the right type of care available to those who need it, such as hours of operation and waiting times that meet demands of those who would use care, as well as having the appropriate type of service providers and materials;
- **Financial accessibility** – the relationship between the price of services (in part affected by their costs) and the willingness and ability of users to pay for those services, as well as be protected from the economic consequences of health costs;
- **Acceptability** – the match between how responsive health service providers are to the social and cultural expectations of individual users and communities.

A relevant recent contribution to defining and measuring access to health care is the work of Amin et al. (2012). The designers of this Equitable framework, basing their approach on existing literature, state that equitable access services are those that meet the needs of all people and are measured using the following indicators:

- **Accessibility** refers to the need for health facilities, goods and services to be accessible to everyone without discrimination, and within the jurisdiction of the State. This first element of accessibility has been further broken down into the related dimensions of Non-discrimination; Physical Accessibility; Economic Accessibility (affordability); and Information Accessibility.
- **Availability** concerns the quantity of service available; functioning public health and health care facilities, goods and services, as well as programmes, have to be available to the general public in sufficient quantity.
- **Acceptability** stresses that all health facilities, goods and services must be respectful of medical ethics, be culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned.

- **Quality**, by which is meant that health facilities, goods and services must be scientifically and medically appropriate to provide services of good quality.

This final element is perhaps the least well developed but one of the most important. We need to understand that there are different kinds of barriers when accessing health care. For example, Lagu, Iezzoni, and Lindenauer (2014, p. 1847) state that barriers to access are the result of a variety of physical, policy, procedural and attitudinal factors and “we need to begin to characterise these barriers and identify domains (or axes)” that will help improve and achieve access to health care. Some of these barriers overlap with one another and have been referred to interchangeably by different authors. The literature on access to health care includes reference to physical barriers (Iezzoni, Kilbridge, & Park, 2010; O’Day, Dautel, & Scheer, 2002; West, Luck, & Capps, 2007), programmatic barriers (Yee & Breslin, 2010), structural barriers (Hwang et al., 2009; McColl, 2005), procedural barriers (Hwang et al., 2009), physician barriers (Harrington, Hirsch, Hammond, Norton, & Bockenek, 2009; O’Day, et al., 2002), environmental barriers (Centers for Disease Control and Prevention (CDC), 2006; Kroll, Jones, Kehn, & Neri, 2006), process barriers (Kroll et al., 2006) and financial barriers (Callahan & Cooper, 2006; Krahn, Farrell, Gabriel, & Deck, 2006; O’Day, et al., 2002; Sommers, 2006). These barriers can occur in isolation or, more commonly, in an interaction with one another.

Examples of the different kinds of barriers found in the literature are in Table 2.

Table 2

*Different Kinds of Barriers to Accessing Health Care*

Physical	transportation issues and physical inaccessibility to offices and equipment
Programmatic	litigation and settlement negotiations
Structural	lack of ramps and parking spaces at buildings where services are held
Procedural	difficulty scheduling appointments, problems obtaining insurance coverage
Physician	deficits of physicians' knowledge of disability as well as attitudes of physicians
Environmental	the physical, social and economic environments in which health care is offered
Process	patient-provider communication, personal motivation
Financial	lack of financial resources from the patient; health care systems under financial constraints

Despite these efforts to formulate an understanding of access to health care, “there are few comprehensive studies available on barriers encountered from the initial seeking of health care through to the resolution of the health problem; in other words, on access in its broad domain” (Garcia-Subirats, et al., 2014, p. 204).

In summary, research on access to health care has been done widely for several years within many countries including using methodological approaches and disciplines, but definitions vary significantly across populations depending on broad social, economic and cultural components (Cabieses & Bird, 2014).

### **ACCESS TO HEALTH CARE IN SOUTH AFRICA**

The right to access health care services in South Africa is guaranteed by Section 27 of the Constitution. However in South Africa, little is known about access barriers to health care for the population in general (Harris et al., 2011). Although health care access is supported by the constitution, considerable inequities still remain largely due to discrepancies in resource allocation (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009, Gilson & McIntyre, 2007). Access barriers also include vast distances and high travel costs, especially in rural areas (Harris, et al., 2011), high out of pocket payments for care (Goudge et al., 2009), long queues (Nteta, Mokgatlhe-Nthabu, & Oguntibeju, 2010), and disempowered patients (Schneider, et al., 2010). According to Harris et al. (2011), these barriers are the result of uneven social-power relationships. Their study on access to health care in South Africa concurs with previous South Africa studies, confirming that poor, uninsured, Black Africans and rural groups have poorer access to health care than do other members of South African society (Coovadia et al., 2009; Gilson & McIntyre, 2007; Goudge et al., 2009; Schneider et al., 2010).

### **DISABILITY AND ACCESS TO HEALTH CARE**

Health care needs that are not met and that exacerbate health disparities are experienced disproportionately by people with disabilities (Pharr, 2014). The WHO emphasizes that

people with disabilities require access to health care, as do the general population, and recommends their needs be met by primary health care, with specialist referral where necessary (WHO, 2011). They go on to state that often people with disability commonly need to be able to access appropriate mainstream health care and rehabilitation to a greater extent than people without disability, because in addition to having the same health needs as others they may have higher levels of need related to their impairments, health conditions, or the lifestyle consequences of these. Yet, inequity in accessing health care for people with disability is a global issue – in general, people with disabilities have poorer health care access (Ali et al., 2013), despite access to health care being of added importance to individuals with disabilities (Centers for Disease Control and Prevention, 2013). Emerson (2011) identifies five key factors in the health inequalities of people with disabilities of which poor access to health care is one. Other factors relate to the social determinants of poor health, the intrinsic health vulnerabilities, communication difficulties and level of health literacy and lifestyle risk factors (Emerson, 2011).

Despite the fact of further access needs, and possibly increasing the gap between need and services offered, persons with disabilities, however, constitute a marginalised group in health services research. Their experiences within the health care system are not well understood, and research-based health service improvement interventions commonly exclude people with disabilities (Scheer, Kroll, Neri, & Beatty, 2003). They have only recently been included as a categorical group in some health service research projects (Davis & O'Brien, 1996; Gold et al., 1997). Persons with disabilities are also often marginalised socially and belong to the poorest sectors of society (United Nations, 2008). There is an association between poverty and increased need for health care.

There seems to be some consensus in the conclusions drawn when it comes to work done regarding access to health care for persons with disabilities. According to Tomlinson, Swartz et al. (2009), there is international evidence that people with disabilities face distinctive barriers when accessing health care services, while The World Report on Disability (WHO, 2011), published in 2011 by the World Health Organization and the World Bank, amassed a wide range of evidence confirming that, across the globe, disabled people have poorer access to health care and poorer health outcomes than nondisabled people. Gulley, Rasch, and Chan (2011) concluded that people with disabilities also experienced much greater health care access problems despite the greater need for health care services, while Mudrick, Breslin, Laing, and Yee (2012, p. 159) summarise that there is “a large and growing literature that documents that people with disabilities experience barriers when accessing primary healthcare”.

More recent studies provide contemporary evidence to support the view that persons with disabilities have less access to health care. Jeon et al.’s (2015, p. 357) findings in a study in South Korea “strengthen existing evidence” that people with disabilities are “facing significant health gaps compared to people without disabilities”. Mahmoudi and Meade (2015) conclude that, over the last decade, there has been minimal progress in increasing access to medical care among people with disabilities, while Danquah et al. (2015, p. 1082) mention that “large gaps existed in access of services for people with disabilities”. According to Shakespeare and Officer (2014), while disability cannot be seen solely or even mainly as a medical issue, people living with disability cannot perform at the optimal or full potential because of unequal access to health and rehabilitation services. This may also lead to them having shorter lifespans as well as more difficulties in their lives. Other more recent studies that support the idea that persons with disabilities have less access to health care are

Mulumba et al. (2014), Mc Doom, Koppelman, and Drainoni (2014), Lagu et al. (2014), Gudlavalleti et al. (2014), Mirza et al. (2014) and Popplewell, Rechel, & Abel (2014).

In summary, there are still disparities in health care on the basis of disability (Smith, 2008) with people with disabilities more likely to report barriers to seeing a health professional (Cannell et al, 2011). As Saulo, Walakira, and Darj (2012) state, disabled persons have been discriminated against in health care services and are a globally marginalised group. Because of this, there is still a need in research to identify barriers for persons with disability in accessing health care (Eide et al., 2015).

## **DISABILITY AND ACCESS TO HEALTH CARE IN LOW-INCOME COUNTRIES AND CONTEXTS**

Even though the disability prevalence is much higher in lower- and lower-middle-income countries compared to high-income countries (Mitra & Sambamoorthi, 2014), according to Elwan (1999), information on disability and access to health care in low-income countries is very limited.

More recently however, there is an accumulation of evidence that barriers to health care access exist for people with disabilities in developing countries. According to MacLachlan and Mannan (2014), access to health care, even in wealthy countries, is often difficult for people with disabilities, but in poorer countries the challenges are exacerbated, combining physical, financial, and attitudinal components. The EquitAble Project (see [www.sintef.no/Projectweb/Equitable](http://www.sintef.no/Projectweb/Equitable)) has documented a number of barriers to health care experienced by people with disabilities in resource-poor settings in Africa (Braathen, Vergunst, Mji, Mannan, & Swartz, 2013; Kritzinger, Schneider, Swartz, & Braathen, 2014; Van Rooy et al., 2012)

and uses a model of access which will be presented later in this dissertation. Also, according to Trani et al., (2011) there has been pioneering work on access to health care for disabled persons in low-income countries. For them the principle of equal access to health services stated in Article 25 of UNCRPD will not be achieved unless the general health needs of persons with disabilities in low-income countries are met. They found in their study in a low-income country that “as expected . . . people with severe disabilities had less access to public healthcare services than non-disabled persons” (2011, p. 1477).

### **DISABILITY AND ACCESS TO HEALTH CARE IN SOUTH AFRICA**

Loeb, Eide, Jelsma, Ka Toni, and Maart (2008) stated that there are not enough data on the situation of people with disabilities in South Africa and in particular for the poor majority. However, according to Eide et al. (2011), it is now well documented that people with disabilities in South Africa are less likely to have adequate access to health care services and health information.

A study by Graham et al. (2014) in South Africa, looking at poverty and disability, showed that people with disabilities were more likely to report difficulties with accessing health services. This finding suggests that disabled people’s organisations’ calls for greater focus on people with disabilities in the health care system, particularly with regard to access and education, should continue.

Maart and Jelsma (2014) found that people with disabilities in South Africa appear to have difficulty accessing medical rehabilitation and home care services but not necessarily general health services. This is because, according to the authors, there were a large number of community health clinics in the study area – a deprived area of Cape Town. This is an

interesting finding in that unlike most international studies, access to general health services does not seem to be an issue in this study in an urban South African context.

Findings by Moodley and Ross (2015) found inequities in health outcomes and access to health services for people with disabilities in South Africa. They go on to emphasize a need for health care policies that are disability-friendly and that reduce barriers to accessing health care.

Further South African studies looking at barriers to health care and disability are by Braathen, et al. (2013) and Kritzinger et al. (2014). Braathen et al. (2013) presented a case study of someone in a rural area who suffered from a psychosocial impairment and how she struggled with access to health care. Kritzinger et al. (2014), in a qualitative study in South Africa with a Deaf community, found that not only communication difficulties were a barrier to health care but also interpersonal factors such as lack of independent thought and a non-questioning attitude by the health care user, as well as overprotectedness and lack of familial communication within the family of the user. These interpersonal factors together with the communication barriers interact to further hamper access to health care.

## **UNDERSTANDING BARRIERS TO HEALTH CARE FOR PEOPLE WITH DISABILITIES**

Patients with disabilities face barriers when they attempt to access health care (Lagu et al., 2013). Most studies in the disability arena have identified multiple barriers when it comes to access to health care. Because of this it has been easier to group barriers into different categories. Scheer et al. (2003) did so when they grouped barriers into environmental, structural and process barriers. Likewise Hwang et al. (2009) state that population based surveys have consistently demonstrated that people with disabilities face many barriers to

accessing quality primary preventative services, ranging from structural to procedural barriers.

Understanding the context of the impairment in which people face barriers to access health care is crucial (Cabieses & Bird, 2014).

## **SPECIFIC IMPAIRMENTS AND ACCESS TO HEALTH CARE**

According to O'Day et al. (2002), little information exists from the perspective of people with disabilities about health care barriers they face, while even less is known about what barriers people with specific impairments encounter, while a study by Iezzoni, Frakt, and Pizer (2011) found that certain types of disability appear especially associated with experiencing access barriers. For instance, they found that upper body functional difficulties and being blind were not significantly associated with barriers but that cognitive impairments, hearing deficits and lower body functional difficulties had strong associations with reports of access barriers.

As Horner-Johnson, Dobbertin, Lee, Andresen, and the Expert Panel on Disability and Health Disparities (2014, p. 1995) mention, the population of people with disabilities is “quite heterogeneous” and that people with different types of disabilities may encounter differing barriers to health care. This point is supported by McDoom et al. (2014). Let us look at some specific impairments and how the people with them experience barriers to health care.

### **Physical Impairments**

There have been a few studies looking at access to health care for persons with physical impairments. There is evidence that people with physical impairments are less likely to have

access to and /or utilize certain primary preventative health care services when compared with the general population (Branigan, Stewart, Tardif, & Veltman, 2001; Kroll et al., 2006; Morrison, George, & Mosqueda, 2008; O'Day et al., 2002; Veltman, Stewart, Tardiff, & Branigan, 2001).

The main barrier for people with physical impairments seems to be physical access to health care providers. For example, the study by Iezzoni et al. (2010) identified physical barriers (such as inaccessible equipment, including mammography machines, examining tables, and weight scales) to care for diagnosis and treatment of breast cancer among women with mobility impairments. The authors found that doctors preferred to examine patients in their wheelchairs and that patients had to sometimes insist on being transferred to an examining table. When they were transferred to tables, patients feared injury. Even when health care centres had accessible equipment, this equipment was sometimes unavailable for the appointment.

Hence physical access is about more than ramps (Iezzoni, Killeen, & O'Day, 2006). The inability to enter a building is rarely the reason that patients cannot be accommodated (Lagu, et al., 2013) – it is more about inaccessible equipment that is a far more common barrier (Lagu et al., 2014; Story, Schwier, & Kailes, 2009).

Further, according to Kim, Nam, Hwang, and Shin (2014), environmental barriers caused people with spinal cord injury to experience limited accessibility to health services. They also identified inaccessible transportation as a major barrier to health services which according to them confirms previous studies showing transportation as the main barrier to people with severe physical disabilities (e.g., Hwang, Chun, Park, & Shin, 2011). It was concluded that

these environmental and physical barriers could be different according to the characteristics or types of disability.

### **Sensory Impairments**

There have been some studies found that looked at sensory impairments and access to health care specifically. Cupples, Hart, Johnston, and Jackson (2012) state that people with visual impairment are likely to have limited access to information and health care facilities while Saulo et al. (2012) found that access to health care is limited for persons with blindness seeking HIV testing.

Ubido, Huntingdon, and Warburton (2002) found inequalities in access to health care faced by people who have hearing impairments, while Steinberg et al. (2006) conclude that Deaf patients face particular challenges regarding communication when dealing with health care providers. According to Iezzoni et al. (2011), process as well as physical barriers pose problems for persons who are deaf or hard of hearing in health care encounters. For example, if a woman cannot hear and no accommodation is made to ensure communication, she may not know when to hold her breath as a mammography technician takes the image of her breast (Iezzoni, O'Day, Killeen, & Harker, 2004).

The South African qualitative study with a Deaf community mentioned earlier by Kritzinger et al. (2014) is also relevant here.

### **Intellectual Impairment**

Inequalities in access to health care for people with intellectual/learning impairments are being recognized (Ali et al., 2013; Cooper et al., 2011; Krahn, Hammond, & Turner, 2006; Redley, Banks, Foody, & Holland, 2012; Webb & Stanton, 2009).

According to Ruddick (2005, p. 559) it is frequently cited that people with intellectual disabilities while vulnerable to many health problems have poor access to health care. There are many factors that can potentially act as these barriers to people with intellectual disabilities having good health and accessing services. These include:

- (a) a lack of clarity regarding responsibilities for ensuring that health policies are operationalised;
- (b) social and residential aspects of life being emphasised within the quality of life framework for evaluating services for people with intellectual disabilities, with health as an under-represented domain;
- (c) a lack of reliable and valid measures that can be used with carers and people with intellectual disabilities to explore health, particularly in comparison to literature on the general population; and
- (d) potential communication difficulties (between the person with intellectual disabilities, their carers and health staff) that can impact on decision making processes from early identification of health problems through to stage of gaining appropriate treatment.

A study by Tracy and McDonald (2015, p. 24) found that people with intellectual disabilities continue to experience “multiple, complex and interrelated barriers” to health care. These barriers include attitudes, knowledge and skills of doctors. They go on to recommend

strategies to reduce these barriers to health care which include the education of doctors and other health professionals.

### **Psychosocial Impairments**

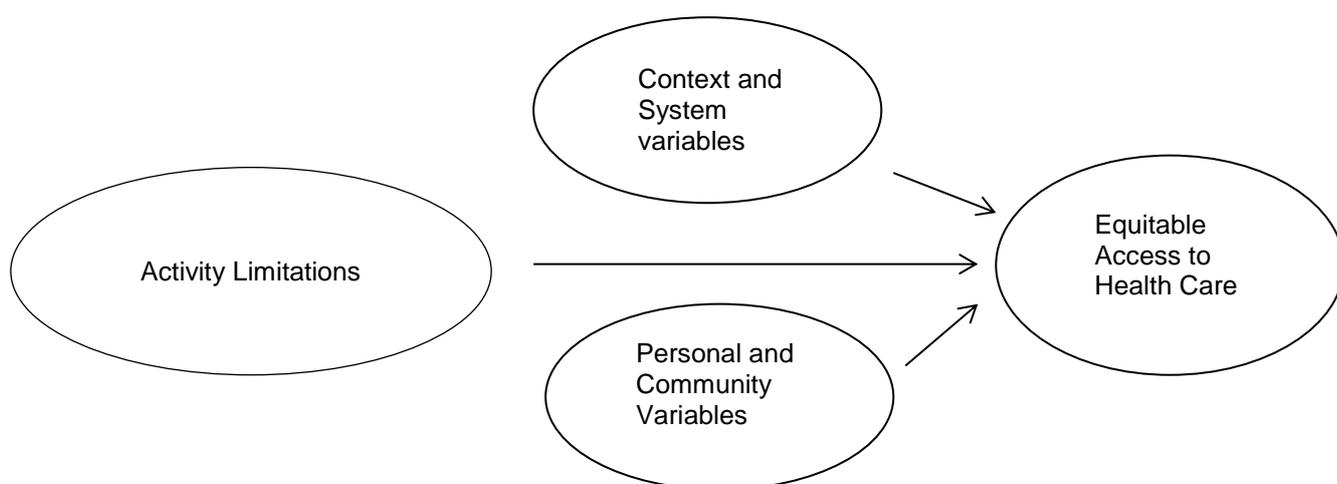
A study by Coomer (2013) in Namibia found that parents of children with mental health disabilities and disorders experience a multitude of barriers that make access to health care services more difficult. People with serious mental illness are less likely to utilize general, preventive, and specialty health care services (Borba et al., 2012). With psychosocial disability, Pahwa, Chatterjee, Tallen, and Brekke (2010), cited in Mesidor, Gidugu, Rogers, Kash-McDonald, and Boardman (2011), identified system and provider level barriers, environmental and individual level barriers to health care and also found stigma to be a barrier to accessing health care. Stigma was identified by Van Den Tillaart, Kurtz, and Cash (2009) as a factor in the incomplete and inconsistent health care provided to individuals with psychosocial disabilities. Negative attitudes towards individuals with psychosocial disabilities have been cited as an important factor, leading to poor communication with primary care providers and the provision of less than adequate care (Van Den Tillaart et al., 2009). The study by Braathen et al. (2013) mentioned earlier, looking at a case study and access to health care for a person with psychosocial impairments, is also relevant here.

In a recent study which echoes many earlier findings, Horner-Johnson et al. (2014) looked at differences in access to health care by type of disability among working-age adults with disabilities. They found that adults with vision impairment or with multiple types of limitations are at especially high risk of reduced access to health care while adults with cognitive and physical disabilities also experienced significant disparities in access. They end with the statement that more in-depth research is needed “to identify the specific causes of

these disparities and develop interventions to address the barriers faced by these particularly vulnerable groups” (p. 1995).

### **Access within the Context of this Study**

Taking into account the various positions regarding access mentioned above, the current study uses the access framework based on the ICF developed for the larger study of which this dissertation forms a part (Amin et al., 2012). The framework suggests that the relationship between activity limitations and access to health services is influenced by factors such as the context that people live in (highly dispersed, displaced, chronic poverty, relative – but unequal – wealth) and the existing health system (the distribution of resources between different services, the emphasis on primary care, the extent of service integration) (WHO, 2001). The link between activity limitations and access is also influenced by personal factors (coping skills, extent of activity limitation, type of bodily impairment, experience of secondary health problems, gender, age, ethnicity) and community variables (cultural understandings of disability, extent of family support, opportunities for inclusion). The Equitable Model is depicted in Figure 2:



*Figure 2.* The Equitable Framework for Access to Health Care

## **Summary of Chapter**

This chapter has focussed on access to health care, one of the main concepts of this dissertation. The chapter began by looking at access to health care in general before looking at general health care access issues in South Africa. Focus was then on access to health care issues for persons with disabilities in general, in low-income countries and in South Africa. Barriers to health care and disability was then briefly explored before ending the chapter on specific impairments (including physical, sensory, intellectual and psychosocial impairments) and access to health care issues.

Bearing in mind that the point that this dissertation is looking primarily at, namely access to health care for persons with disability in a rural context within South Africa, it is appropriate for the next chapter to first focus on rural health in general and how this potentially impacts health care access and disability.

## **CHAPTER FOUR**

### **RURAL HEALTH**

Rural health has generally been a relatively neglected area of health research. Interest has however grown in the past several years (Muula, 2007). In the past, rural health was generally seen as a “vague idea” that basically looked at medical work outside of mainstream urban areas, but is now becoming more well-known and better understood (Reid, 2006). The conceptualisation and measurement of the construct is becoming increasingly important to research and policy in the field of rural health (Hewitt, 1989 cited in Miller, Farmer, & Clarke, 1998).

#### **Defining Rural Health**

A minimum of three primary domains have historically been central to the definition of what is rural. These are the ecological, occupational and sociocultural components (Bealer, Willis, & Kuvlesky, 1965). The ecological component refers to the spatial apportionment of the population. This is conventionally employed to signify a delimited geographical area characterized by a population that is small, relatively sparse, and isolated, to varying degrees, from metropolitan hubs. The occupational dimension is probably the most well-defined referring to people who get their income from agriculture, mining, fishing, forestry, etc. The sociocultural dimension of rurality is the most complicated but generally refers to values and ideals that underlie human interactions in a rural setting. This domain seems to be the most appropriate for this study.

There is however no clear specific definition of what is meant by “rural”. It is a “theoretically rich” construct (Miller et al., 1998, p. 5) and has a multidimensional character in terms of its

conceptualization and measurement (Redfield, 1947; Sorokin & Zimmerman, 1929). There is no consensus on the definition of what constitutes a rural area and there are many definitions of the term (Muula, 2007). It is difficult to reach agreement about the definition of rural (Couper, 2003). There is a need in the future for universal definitions so that we can compare studies and carry out future collaborative research (Wilson et al., 2009). Muula (2007) however states that it is not possible to have a universal definition. The key however is what purpose the term is used for (Couper, 2003). In most instances authors assume readers have specific knowledge on what is being referred to as rural. Most definitions, according to Couper (2003) take issues such as service, access and distance into account. The way that rural health in the South African context is understood addresses issues of poverty and inequity and hence has a strong social justice, social responsibility and advocacy component, going beyond the common technicalities of geography and distance (Reid, 2006). In South Africa there is no standardized definition of rurality, and various stakeholders use a variety of criteria to define rural – or do not use rural as a variable at all (Gaede & Versteeg, 2011).

### **Rural Access to Health Services**

Concern over the availability of health services in rural areas has existed for decades (Cordes, Doeksen, & Shaffer, 1998) and “rural communities have long struggled to maintain access to quality health care services” (Weisgrau, 1995, p. 1). However, it is not enough, by itself, that a system of primary care be available in rural areas – the services must also be accessible (Davis, McAdams, & Tilden, 1998). Intuition expects that rural populations have reduced access to health care services compared to their urban counterparts but, according to Sibley and Weiner (2011), studies have been contradictory and inconclusive.

According to Bourke, Humphreys, Wakerman, and Taylor (2012), people living in rural and remote areas face multiple challenges in accessing appropriate health services. There is much research literature that looks at barriers to health care for the rural population (Brems, Johnson, Warner, & Weiss Roberts, 2006; Chipp et al., 2011; Goins, Williams, Carter, Spencer, & Solovieva, 2005; Iezzoni et al., 2006; Ricketts & Savitz, 1994). Rural communities share certain characteristics that affect both health and health care (Rosenblatt, 2002) and “do without ready access to the dense net of services – including health services – that characterises the urban environments” (2002, p. 3).

It is a pertinent issue to ensure equitable access to health care is at a policy level. A large body of research and policy analysis has focused on highlighting access problems for vulnerable populations and suggesting how policies can eliminate access barriers (Aday, 1993, 1998 cited in Ricketts, 2002). Rural populations have often been viewed as especially vulnerable with respect to access to health care because of:

- 1) poorly developed and fragile health infrastructures;
- 2) high prevalence rates for chronic illness and disability;
- 3) socioeconomic hardships; and
- 4) physical barriers such as distance and availability of transportation, including a lack of public transportation (Rowland & Lyons, 1989 cited in Schur & Franco, 1999, p. 25).

Access to quality health services becomes the single biggest issue, if not the defining issue, in rural health (Reid, 2006). Rural communities have thus limited access to health care (Muula, 2007).

*Rural Health in South Africa*

Rural care health practice, like virtually every other activity in South Africa, has been deeply shaped and impacted on by the political situation in the country over the last 50 years (Reid, Couper, & Noble, 2002) and longer. Rural health in South Africa is synonymous with the health of the deliberately underdeveloped areas of the country, inhabited largely by Black communities. Since the election in 1994 there have been plans for sweeping changes to the health care system and the priority principle of the plan was that of equity. Equity has direct implications for rural health care and practice in South Africa. Now the quality of rural health care services can be seen as a barometer of success of the broader social reforms undertaken by the government. The South African government has prioritised the needs of persons living in rural areas, with increasing attention being paid to social and economic development (Coovadia et al., 2009).

In South Africa, 52% of the total population and 75% of poor South Africans live in rural areas (Reid, 2006). South African society is a society in transition and this is reflected in its morbidity, mortality and disability profiles (Reid et al., 2002). The health status of rural people in South Africa is similar to that of people in many developing nations around the world. The diseases of poverty are common including chronic disability. Access to health care for rural people is difficult: the high cost of transport and the large distances involved lead to late presentations of disease, particularly in rural areas. This is further complicated by traditional beliefs regarding illness: unregulated traditional healers of various levels of experience and skill make their services available to a somewhat fearful and tradition-bound public in rural areas (Reid et al., 2002). According to Gaede and Versteeg (2011, p. 99) rural communities in South Africa experience “significant barriers to accessing healthcare”,

including financial barriers, inadequate transport, and distance to the nearest facility as well as limited resources available.

The public health care system in rural areas has been delivered through a system of rural hospitals and clinics, many of which were built and operated as mission hospitals until the 1970s when most of them were taken over by the apartheid government in an effort to centralise planning. These same hospitals now form the infrastructure for the new National Health System, the aim of which is to decentralise to a district based health system. The infrastructure and facilities available in rural hospitals are relatively good, although diagnostic services are limited. Most rural hospitals offer a comprehensive service where doctors with general training are employed and who are largely foreign-qualified (Reid, 2006).

How an elderly woman with disability living in a rural area can access quality health care will act as a barometer of South Africa's progress towards a more just, fair and civilized society, until a more objective measurement is developed (Reid, 2006). Little research has been conducted into the experiences, needs and challenges of those living in rural areas in South Africa, particularly among persons with disabilities (Neille & Penn, 2015).

### *Disability and Rurality*

There is a higher prevalence of disability in rural areas compared to urban areas (WHO, 2011). Roughly four of every five disabled persons live in rural areas in developing countries (UN Enable, 2006). It has been estimated that 88% of persons living with disability live in the world's poorest countries and 90% of those in rural areas (Marks, 1999b).

Any administrator of rural health services must plan to serve people with disabilities in their need for a continuum of services and for access to special services (Beaulieu, 1998). Yet disability and access to health care among the poor rural populations has received little attention. There is scarce data on their health needs (Lishner, Richardson, Levine, & Patrick, 1996). What little literature there is suggests that persons with disabilities in rural areas have more problems and issues regarding their health care than persons with no disabilities in rural areas – especially when it comes to health care access (Lishner et al., 1996).

Lishner et al. (1996) conducted a literature review on access to primary health care among persons with disabilities in rural areas. They focused on the following rural populations affected by disabilities: children and adolescents, working-age adults, the elderly, the mentally ill and people with AIDS. Substantial barriers in accessing health care were documented for all of these rural populations. According to Lishner et al. (1996) there is a consistent emphasis in the literature that the health care systems fail in rural areas for persons with disabilities.

Hamdan and Al-Akhras (2009) carried out a prevalence study of disability in a rural community in the north of the West Bank. Physical (34%), mental (15.9%) and speech (11.4%) were the most common disabilities where economic conditions were seen as the main barrier to receiving care. Only 49.3% of the disabled sample received some form of care. Pressing needs included medical care, support equipment and educational, physiotherapy and rehabilitation services.

A similar study was done in rural Spain where a door-to-door screening survey explored the distribution of disability and its major determinants (de Pedro-Cuesta et al., 2010) as well as

in Peru where it was found that disabled persons had generally low health status in the area (Rohrer et al., 2010).

In the study by Van Rooy et al. (2012, p. 774) it was found that people with disabilities in rural northern Namibia had perceived barriers to accessing health services. This confirms research in other countries showing that people with disabilities have a “whole host of barriers pertaining to both service delivery process and structural environment”.

Ahmad (2013) assessed health care for rural people with physical disabilities and identified barriers in accessing such services in Pakistan. Public health care for both males and females with physical disabilities in the rural areas of Pakistan was found to be poor. The main barriers identified in this study were built environments, health care delivery processes and financial barriers. These findings are very similar to the study by Van Rooy et al. (2012) who also found process and structural barriers as important in making health care access problematic for persons with disabilities in rural areas.

#### *Disability in Rural Communities in South Africa*

There has been little research looking at disability issues in rural South Africa. Neille and Penn (2015), Braathen et al. (2013), Grut et al. (2012), Maart, Eide, Jelsma, Loeb, and Ka Toni (2007) and Jelsma, Maart, Eide, Ka’Toni, and Loeb (2007) were the only studies found that looked at this issue. Neille and Penn (2015) in a qualitative study found that barriers to service provision extend beyond physical obstacles and include a variety of sociocultural and sociopolitical barriers. Braathen et al. (2013) looked at a case study of someone in a rural area who suffered from a psychosocial impairment and how she struggled with access to health care. Grut et al. (2012) also using a case study of a person with a disability in rural South Africa showed how people with disabilities who live in poverty-stricken areas experience

multiple barriers. They state that people with disabilities who live in poor rural societies experience unique problems in accessing health services. Maart et al. (2007) found that persons with disabilities in the rural areas of the Eastern Cape perceived fewer barriers within their environment (with the exception of attitudes) than those residing in informal urban settlements in the Western Cape. The study by Jelsma et al. (2007) looked at people with disabilities in rural Eastern Cape. They conclude that a rural setting seemed to contribute to a worse perceived health-related quality of life.

Hence only a few studies in rural South Africa focused specifically on disability and access to health care (of which most were qualitative and case studies) –despite there being international evidence that people with disabilities face barriers when accessing health care services. More research contributing to assessing and improving access to health care for people with disabilities needs to be prioritised – especially in South African rural areas.

### **Chapter Summary**

This chapter introduced the idea of rural health in general, a pertinent issue in that this dissertation focuses on disability and access to health care in a rural area within South Africa. The chapter started by attempting to define what it means to be “rural” before looking at rural access to health services. Focus of this chapter then turned to rural health in South Africa. Disability and its relationship with ruralness was then explored before again incorporating a South African perspective.

Having now explored the three basic concepts in this dissertation – disability, access to health care and rurality – in the three preceding chapters, it is now useful to look at the methodology of the dissertation.

## **CHAPTER FIVE**

### **METHODOLOGY**

#### **BACKGROUND TO METHODS**

This chapter discusses the research methodology of the dissertation. The chapter will start by contextualising the methodology used by looking at paradigms and approaches to research methodology. Two important paradigms – the positivist and interpretivist – will be explored in some detail to ascertain which paradigm is most appropriate for this dissertation. The two approaches to research – quantitative and qualitative – will also be explored in order to understand the approach more useful for this dissertation.

Once the study methodology has been contextualised, the chapter will look at the research survey – the method of data collection for this dissertation followed by data analysis techniques useful in the management of the data collected.

Focus will then narrow down to the research methodology, research problem, research question, research hypotheses and research design of the dissertation.

Finally a discussion on ethical considerations for the study will be discussed.

#### **PARADIGMS OF SOCIAL SCIENCE RESEARCH**

Paradigms of social science research are “all-encompassing systems of interrelated practice and thinking that define for researchers the nature of their enquiry along three dimensions:

ontology, epistemology and methodology” (Terre Blanche & Durrheim, 2011, p. 6). Ontology is a branch of philosophy dealing with the nature of reality that is to be studied, epistemology is a branch of philosophy dealing with the nature of knowledge, while methodology looks at the practical aspects of a research study. There are a number of different paradigms including the positivist, the interpretivist, the critical, the feminist, the postmodern and the postcolonialist paradigms. Piergiorgio (2003) maintains that there are primarily two basic underlying paradigms in social science research – the positivist paradigm and the interpretivist paradigm.

The positivist paradigm believes that social realities can be discovered and that these relationships are structured in logical ways in a stable and unchanging external reality (Terre Blanche & Durrheim, 2011). It believes in a deductive approach – observed data leads to theoretical development – and that empirical data will support or refute previously formulated theories. According to Piergiorgio (2003) systematic analysis of the literature takes on a very important role since it is this that provides the theoretical hypotheses on which fieldwork will be based.

The interpretivist paradigm, on the other hand, believes that the reality to be studied consists of or is filtered through people’s subjective experiences of the external world (Terre Blanche & Durrheim, 2011, p. 7). There is a subjective relationship between researcher and subject. Unlike positivism, interpretivism follows an inductive approach – observation precedes theory – the researcher starts with a set of vague speculations and tries to make sense of the phenomenon by observing a set of particular instances (Terre Blanche & Durrheim, 2011, p. 7). Table 3 shows the differences between two basic paradigms in Social Science Research.

Table 3

*Differences between Two Basic Paradigms in Social Science Research*

	<b>Positivism</b>	<b>Interpretivism</b>
Ontology	Naïve realism: social reality is “real” and knowable (as if it was a thing)	Constructivism: the knowable world is that of meanings attributed by individuals  Relativism: these constructed realities vary in form and content among individuals, groups and cultures
Epistemology	Dualism: objectivity  True results  Experimental science in search of laws  Goal: explanation  Generalisations: “natural” immutable laws	Non-dualism: non objectivity  Researcher and object of study are not separate but interdependent  Interpretive science in search of meaning  Goal: comprehension  Generalisations: opportunity structures, ideal types
Methodology	Experimental: manipulative	Empathetic interaction between scholar and object studied

	Observation	Interpretation
	Observer-observed detachment	Observer-observed interaction
	Mostly deduction	Induction
	Quantitative techniques	Qualitative techniques
	Analysis by variables	Analysis by cases

(Source: Adapted from Piergiorgio, 2003)

## **APPROACHES TO SOCIAL SCIENCE RESEARCH**

Social scientists commonly contrast two major approaches to research – quantitative and qualitative approaches.

Quantitative research is all about numbers. It is about measurement and how much of something there is. Good quantitative research allows us to make comparisons of different situations (Durrheim & Painter, 2011). Most, though not all, quantitative research is conducted at a “macro level”, where the interest is in explaining and predicting aggregate behaviour and characteristics (Williams, 2003). It is rooted in the scientific studies of the social world and depends on statistical techniques (Williams, 2003). Preference is given to the following methods and techniques:

- Conceptualisation of concepts that can be operationalised through measuring instruments.
- Data-collection techniques, such as structured questionnaires and schedules.

- Data-analysis techniques, varying from simple cross-tabulation of the data to complex analysis techniques (Neser, Joubert, & Sonnekus, 1995, p. 53).

The evolution of the quantitative social science approach has been the move away from the experimental method, where the researcher manipulates one or more variables in order to study their effects on other variables, to a broader range of approaches including non-experimental method and design, where the researcher studies relationships between naturally occurring phenomena (Punch, 2003).

### **Qualitative Research**

Qualitative research is all about collecting data, not by numbers, but commonly by written or spoken language or by observation of behaviour in context (Durrheim, 2011b). The analysis of the data is not by statistical analysis, but by identifying and categorising themes. Qualitative research looks at issues in depth, openness and detail. It focuses on aspects such as meaning, experience and understanding. Streubert Speziale and Carpenter (2003, p. 15) identify six principles of qualitative research:

1. believing in multiple realities;
2. a commitment to identifying an approach to understanding that supports the phenomenon under study;
3. being committed to the participants' viewpoint;
4. conducting a research in a way that limits disruption of the natural context of the phenomenon of interest;
5. acknowledgement of participants in the research process; and
6. reporting data in a literary style rich with participants' commentaries.

Table 4 highlights the primary differences between quantitative and qualitative research.

Table 4

*Differences between Quantitative and Qualitative Research*

	<b>Quantitative Research</b>	<b>Qualitative Research</b>
<b>Research Planning</b>		
Theory-Research Relationship	Structured: logically sequential phases Deduction: Theory precedes observation	Open: Interactive Induction: Theory emerges from observation
Function of the Literature	Fundamental in defining theory and hypotheses	Auxillary
Concepts	Operationalised	Orientative, open, under construction
Relationship with the environment	Manipulative approach	Naturalistic approach
Psychological researcher-subject interaction	Neutral, detached, scientific observation	Empathetic identification with the perspective of the subject studied
Physical researcher-subject interaction	Distance, detachment	Proximity, contact
Role of subject studied	Passive	Active
<b>Data Collection</b>		

Research Design	Structured, closed, precedes research	Unstructured, open, constructed in the course of research
Representativeness	Statistically representative sample	Single cases not statistically representative
Recording Instrument	Standardised for all subjects Objective: data matrix	Varies according to subjects' interests. Tends not to be standardised
Nature of the Data	Hard: objective and standardised (objectivity vs subjectivity)	Soft: rich and deep (depth vs superficiality)
<b>Data Analysis</b>		
Object of the analysis	The variable (analysis by variables)	The subject (analysis by subjects)
Aim of the analysis	Explain variation in variables	Understand the subjects
Mathematical and statistical techniques	Used extensively	Not used
<b>Production of Results</b>		
Data presentation	Tables (relationship perspective)	Extracts from interview and texts (narrative perspective)
Generalisations	Correlations, causal models, laws, logic of causation	Classifications and typologies, ideal types, logic of classification
Scope of results	Generalisability	Specificity

(Source: Piergiorgio, 2003)

Having focussed on the differences it must be remembered that having differing strengths and weaknesses they are alternative and not opposing research approaches (Durrheim, 2011b).

This dissertation will follow the positivist paradigm and use the quantitative approach in its collecting, analysing and interpretation of data. This is primarily because the study of the dissertation involves a survey – one principal form of the quantitative method is the social survey (Williams, 2003) and quantitative research is inspired by the positivist paradigm (Piergiorgio, 2003).

## **RESEARCH SURVEY**

The research survey can be defined as a

style that involves systematic observation or systematic interviewing to describe a natural population and, generally, draw inferences about causation or patterns of influence from systematic covariation in the resulting data. (Sapsford, 2007, p. 14)

The survey is the most widespread quantitative social research technique (Payne & Payne, 2004; Piergiorgio, 2003), and has been a “central strategy” in social research (Punch, 2003, p. 1). Surveys are carried out primarily to explain things rather than describe things (Williams, 2003). They are not about causal relationships but rather associations between variables.

Survey is a technique of gathering information by:

- questioning those individuals who are the object of the research belonging to a representative sample through a standardised questioning procedure with the aim of studying the relationships among the variables.

(adapted from Piergiorgio, 2003)

Surveys involve systematic observation or interviewing in a standardised manner (Sapsford, 2007, p. 7) and have developed into “exercises in measurement”. According to Sapsford (2007), most surveys are about describing populations, testing hypotheses and making comparisons between groups. Research surveys have typically three characteristics:

1. they collect data in a standardised way from
2. a sample of respondents
3. enabling the data to be codified, normally into a quantitative form

(Payne and Payne, 2004, p. 219).

## **METHODS USED IN THIS STUDY**

### **STUDY CONTEXT**

The context of this study is the catchment area of Madwaleni Hospital, South Africa. The hospital is situated in a deeply rural and impoverished area of the Eastern Cape province, 220 km up the coast from East London, 100 km from Mthatha, 30 km from Elliotdale and 16 km from the Wild Coast. The Madwaleni area is situated in the rolling hills of the Amatole District within the Mbashe Municipality. This rural area is defined by poor infrastructure, lack of basic service provision, low levels of literacy, high levels of unemployment, limited access to health care and education, high incidence of communicable diseases and high mortality rates (Watermeyer & Barratt, 2013 cited in Neille and Penn, 2015). Figure 3 is a summary of the Administrative Structure of Madwaleni.



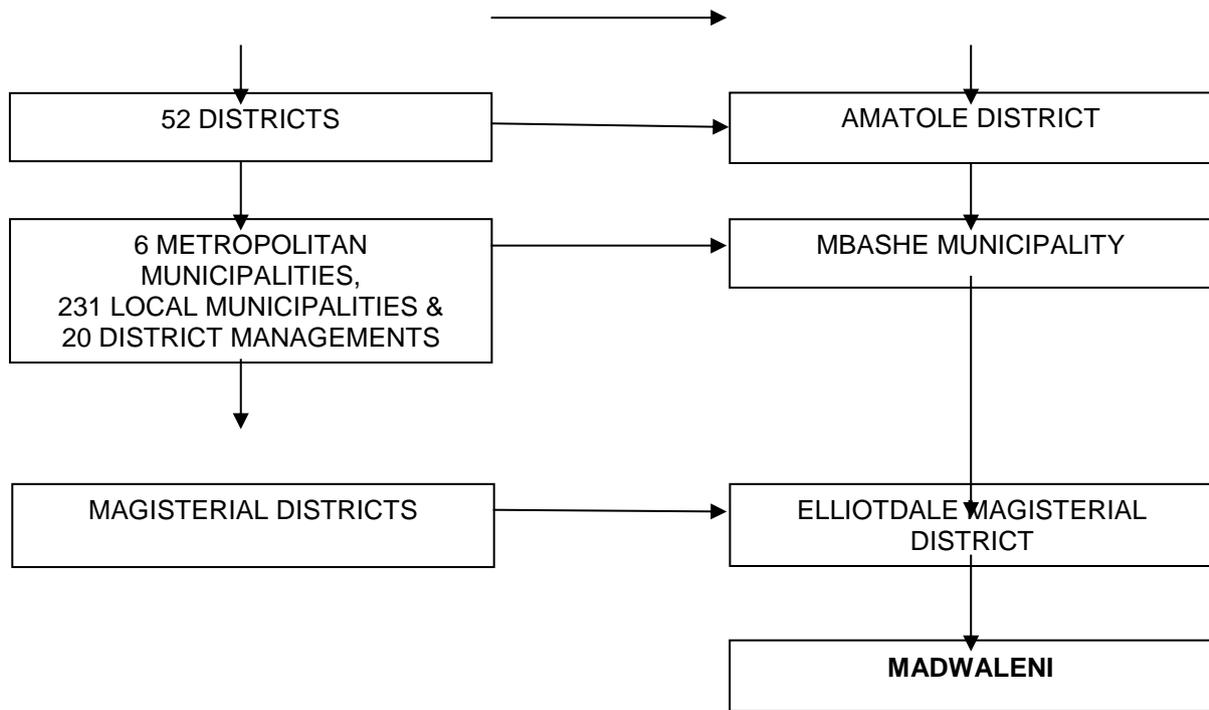


Figure 3. Administrative Structure of Madwaleni

The studied Madwaleni area is situated in the Eastern Cape province, falling under the administration and jurisdiction of the Amatole district and the Mbashe municipality and under the authority of the Elliotdale magisterial district. Figure 4 shows where Madwaleni is situated within the borders of South Africa. It is situated 200 km above East London near Elliotdale in the Eastern Province of South Africa.

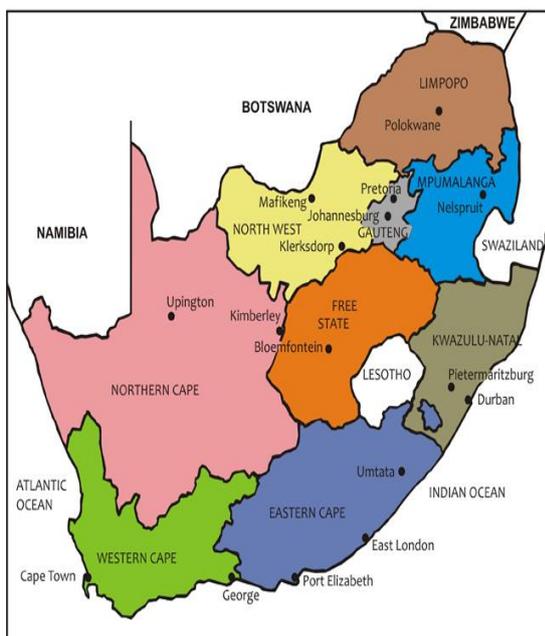




Figure 4. Madwaleni in South Africa

The deeply rural isiXhosa-speaking community within Madwaleni comprises 120 000 impoverished people of whom 89% are unemployed. There are about 20 villages scattered around the catchment area which has a 35 km radius from the hospital. There is scarcity of sewage systems, running water and electricity to the general Madwaleni community and these are limited to the hospital and the local hotels. The Madwaleni area is characterized by rugged hills, valleys, rivers, forests, gravel roads, free running animals and grass thatched rondawels scattered sporadically over the hills.

As well as the hospital, the area is also served by eight health centres: Hobeni; Nkanya; Bomvana; Molitafa; Soga; Xhora; Mqhele; and Vukukanya. There are two major rivers and several other tributaries and streams. The major rivers are Mbashe and Xora. Vukukanya Bomvana, Hobeni, Nkanya, Molitafa and Soga are in between the two major rivers while Xhora and Mqhele are outside of the Xora river. Figure 5 is a detailed map of the Madwaleni area with its hospital and eight health centres.

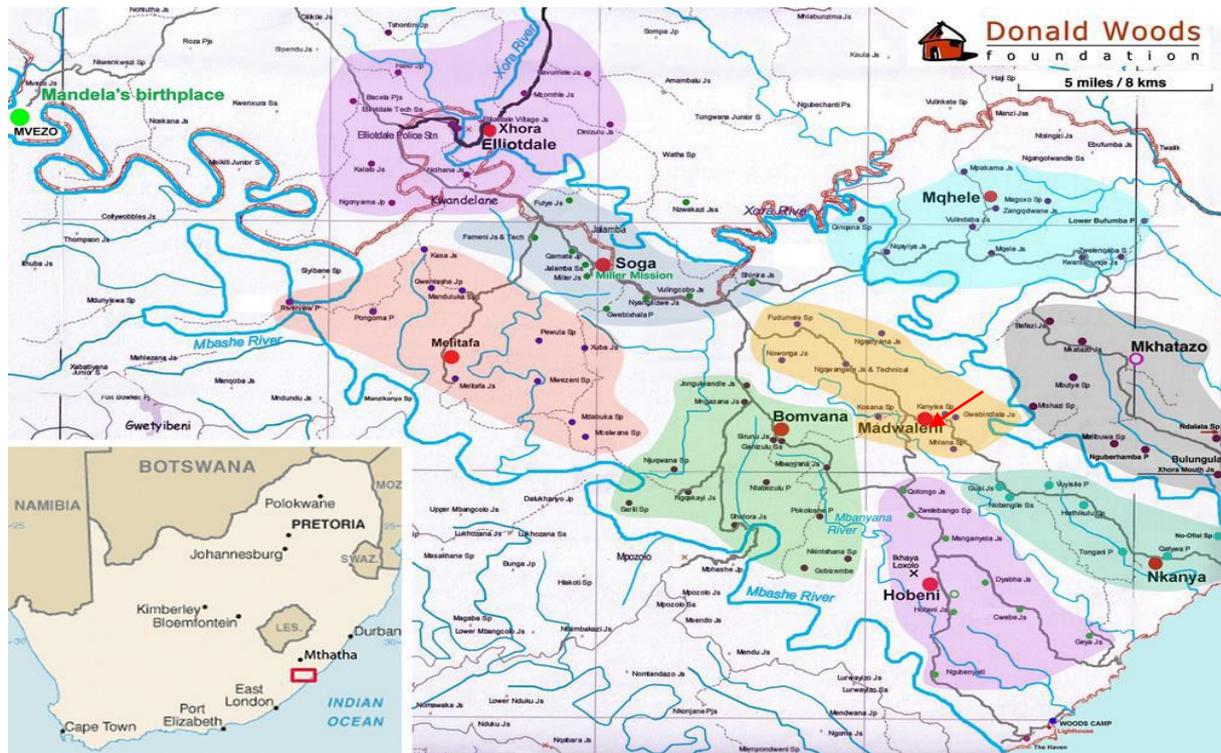


Figure 5. Madwaleni Area

## DATA ANALYSIS

Statistical methods are used to analyse quantitative data (Durrheim, 2011b). Statistics use mathematical formulas and tools which allow researchers to make claims about the world using a statistical argument (Durrheim, 2011b).

As Walter and Andersen (2013) state, statistics systematically collect numerical facts, summarise reality in numbers, make interpretations about reality and influence the way we understand society.

The approach to data analysis for this dissertation included quantitative data analysis using descriptive and inferential statistics. Frequency and cross tabulation, comparing and contrasting the frequency of different phenomena between persons with disabilities and

persons with no disabilities were used. Chi-squared tests (comparison by percentages) and Analysis of Variance (ANOVA) tests (comparison by means) were then incorporated into the analysis.

## **RESEARCH METHODOLOGY**

Research methodology is a way to solve the research problem systematically (Kothari, 2004). It helps a researcher in identifying the problems, formulating problems and hypotheses, gathering information, participating in the field work, using appropriate statistical tools, considering evidences and drawing inferences from the collected information (Kumar, 2010).

## **RESEARCH PROBLEM**

According to Kaniki (2011), we need a research problem in order to to conduct research. The research problem, to be practical, has to be clearly stated with explicit parameters (Kaniki, 2011). All research begins with a question – it is simply a statement of what it is we want to know (Williams, 2003).

The research problem of this dissertation covers the issue of access to health care – in particular, it is about disability and access to health care issues in a rural area of South Africa.

## **RESEARCH QUESTION**

The main research question for this dissertation is the following:

Is there a difference in access to health care for people with and people without disabilities in Madwaleni, a deeply rural and impoverished community in South Africa?

“Access” for this dissertation, fundamentally, refers to real or perceived barriers or facilitators in getting health care for people with disabilities, and are these different compared to those experienced by people without disabilities? Barriers and facilitators refer to issues such as transport, terrain, costs, distance, time and attitudes, etc.

A second research question is whether in Madwaleni, as a whole, households with a person with a disability have poorer access to health care than those households who do not have a person with a disability.

## **RESEARCH HYPOTHESIS**

A research hypothesis is an educated guess or expectation about differences between groups in the population or about relationships among variables (Durrheim, 2011b).

The main research hypothesis is that in rural Madwaleni, people with disabilities have more barriers to health care than people without disabilities.

The second research hypothesis is that households including a person with a disability in Madwaleni have more barriers to health care than households where there is no disability.

In other words, this research study is looking at an individual as well as a household level when it comes to disability and access to health care.

## **RESEARCH DESIGN**

A research design is a “strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research” (Durrheim, 2011a, p. 34) while the aim of a research design is to structure a project in such a way that the eventual validity of the research findings is maximised (Mouton & Marias, 1990). The planned nature of research designs is important. In developing a research design, the researcher must make a series of decisions along four dimensions:

1. the purpose of the research;
2. the paradigm informing the research;
3. the context or situation within which the research is carried out; and
4. the research techniques employed to collect and analyse data

(Durrheim, 2011a, p. 37).

The research design for this dissertation is an observational cross sectional study.

For the purposes of the study we use the term “cases” for persons with disabilities and “controls” for persons without disabilities. There were two types of controls in this study – in house controls (person with no disability living in the same household as a person with a disability) and neighbourhood controls (member of household where nobody in the household has a disability). Given the exploratory nature of the study, the controls were unmatched on variables such as age and gender.

As discussed before, there are differing ways of defining and measuring disability – and hence defining case and controls. This dissertation used the Washington Group Questions using a 4 point scale ranging from (1). No impairment to (4). Unable to do. Hence a score of 2 or more showed the individual to have some impairment (2), a lot of impairment (3) or

unable to do (4). The definition and measurement set out by StatsSA using the WG questions will be used in this study. Here disability is defined as follows: “If an individual has ‘Some difficulty’ with two or more of the 6 categories then they are disabled and if an individual has ‘A lot of difficulty’ or is ‘Unable to do’ for one or more categories they are classified as disabled” (Statistics South Africa, 2012, p. 51).

Data for the study were collected in the Madwaleni area in October-November 2011. A total of 17 data collectors were trained by members of the Equitable research team for a week before spending three weeks in the field collecting data using mobile phone technology. Local chiefs of the area were contacted and told about the study and they all gave permission to have access to their communities. Data collectors were local community health workers from the area and were well aware of the dynamics of the community.

Four health centres (Hobeni, Xhora, Nkanya, and Vukukanya) in the Madwaleni catchment area were strategically selected as base points from which to go out into the communities. Hobeni was chosen as it was the most southern health centre in the area as well as the newest health centre; Xhora is the most northern health centre in the area and also closest to Elliotdale, the nearest town to the Madwaleni area; Nkanya the most eastern health centre and also the most isolated in terms of access; and Vukukanya the most central as it is based on the grounds of Madwaleni hospital. Villages in and around each of the health centres were randomly selected using a random table. Every fifth household was then selected within each village. Households were then approached.

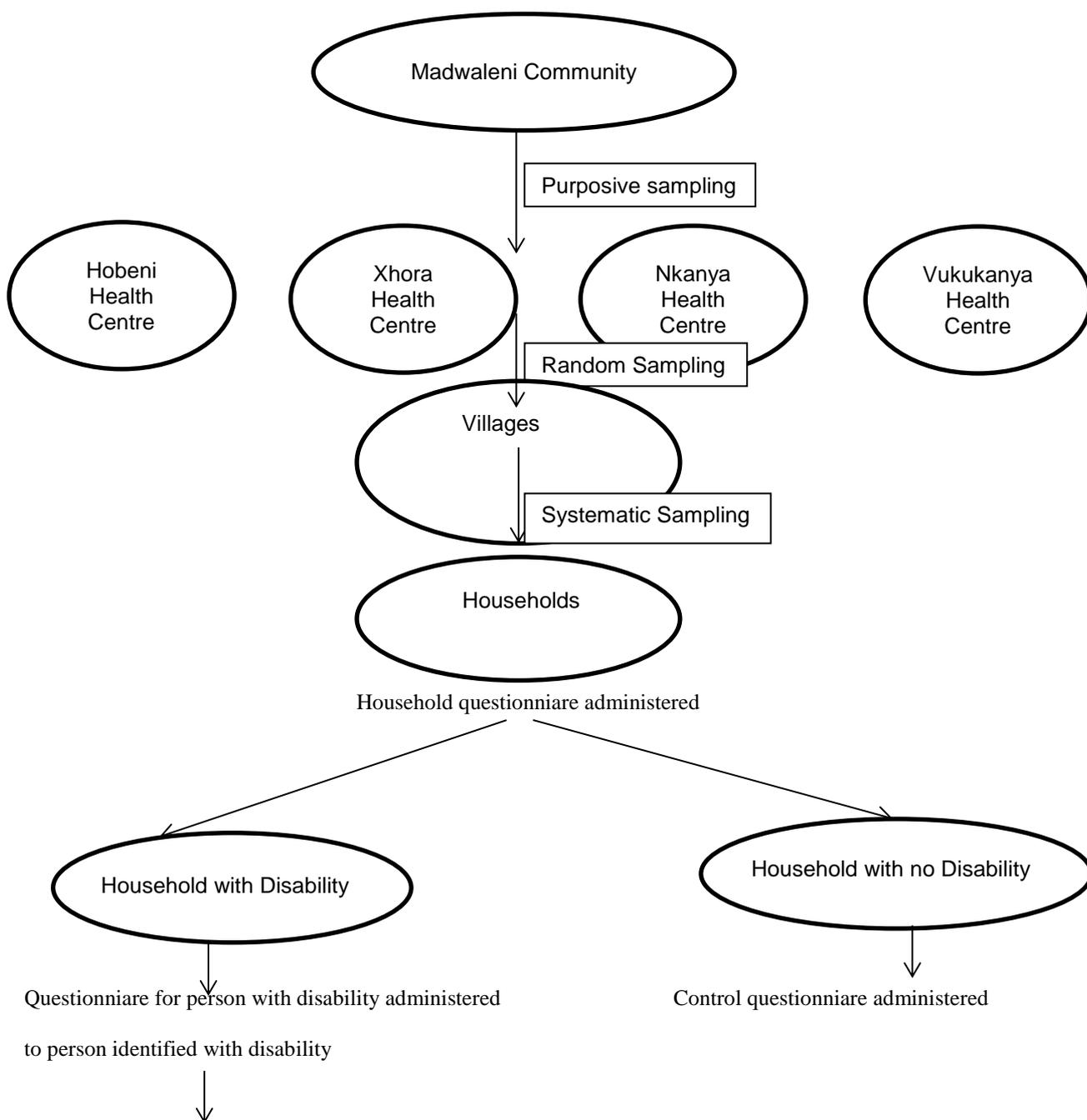
The head of each household, by asking the members in the household, was identified and asked to answer a Household questionnaire. If they agreed to do so, consent forms were

completed and an interview using mobile phone technology was carried out. The Household questionnaire ascertained the composition of the household, i.e., the members of the household, and if they had disability or not using the Washington Group Questions on disability. If a person with a disability was identified in the household with the Household questionnaire then that person was subsequently also interviewed (after consent forms were completed) using the questionnaire for persons with disabilities. If there were more than one person with a disability in a particular household then the person with the most severe disability was interviewed. This was ascertained by the disability rating scale in the household questionnaire where a higher total disability score according to the Washington Group method depicted more severe disability. A third interview (after completion of consent forms) was carried out in the same household with a person without disability (in house controls) matched to the person with disability by age and gender using a Control questionnaire. If no matched non-disabled control was found in the household then no control interview was carried out in that household.

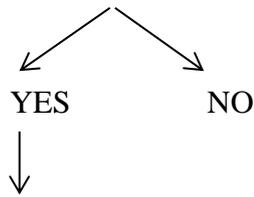
If the household did not have a person with disability living in the house then this household became a neighbourhood control household. The head of the household would complete the Household questionnaire and a randomly selected person (using random tables) in the control household would complete the control questionnaire – in other words, a neighbourhood control household would have two interviews completed instead of the possible three in a disabled household.

In all situations, parents or guardians were interviewed for children under the age of 18.

Two sets of controls (persons without disabilities) were created – in house controls and neighbourhood controls. These controls are then compared to cases (persons with disabilities). We are thus also able to look on a household level (households with disability and households without disability) as well as on an individual level (individuals with disability and individuals without disability) and see if there are access issues that are different at both levels. Figure 6 is a flow chart of the research design and sampling methods.



Control individual identified based on gender or age



Control questionnaire administered

**Figure 6.** Research Design and Sampling Methods

## **POPULATION OF STUDY**

The population of this study is the Madwaleni community in the Eastern Cape province of South Africa.

## **SAMPLE OF STUDY**

The sample comprised of 773 individuals – 322 cases with disability and 451 controls (without disability) – covering 527 households. Children under the age of five were excluded from the sample.

## **INSTRUMENTS**

Interviews using three questionnaires, depending on circumstances, were used in the study:

1. A Household questionnaire
2. A Questionnaire for a person with a disability
3. A Control questionnaire

The Household questionnaire is a 12 page questionnaire administered to the head of the household in each household. It identifies the household and then starts with looking at the

household composition for all persons in the household-relationship to head of household, sex, age marital status, any illness/injury data is collected. Each household member's level of impairment ranging from "no difficulty" (1), "some difficulty" (2), "a lot of difficulty" (3) and "unable to do" (4) is then ascertained. Level of education and employment issues, income and expenses, ownership, population displacement, and use of health facility information is then obtained.

The second questionnaire was administered to a person with a disability in a household. This is a 20 page questionnaire focused on functional difficulties and access to health issues. It once again asks the individual his/her level of difficulties again ranging from (1) "none" to (4) "unable to do". Issues of pain, fatigue, health conditions, participation restriction, assistive devices, environmental factors, health service awareness, health care utilization and attitudes towards health services are asked. The last question asks the participant if they consider themselves having a disability or not.

The third questionnaire is one that is asked to control subjects in the study – either in house controls or neighbourhood controls – i.e., participants with no disability. This questionnaire is a shortened version and has 14 pages. Once again it asks the individual his/her level of difficulty again ranging from (1) "none" to (4) "unable to do" followed by issues of fatigue, health conditions, participation restriction, environmental factors, health service awareness, health care utilization and attitudes towards health services.

The questionnaires used in the survey for this dissertation were developed by the Equitable research team as part of this international research project. Some of the questions from the questionnaires were developed and adapted from the Living Conditions studies by SINTEF

(e.g., Eide & Kamaleri, 2009), updated with more recent literature, workshopped and piloted at all sites, then adapted as necessary. Part of the questionnaires included the Washington Group Questions on disability as well as the General Health Questionnaire (GHQ-12). The GHQ-12 is the most extensively used screening instrument for common psychological disorders or for non-specific psychiatric morbidity. The response set for the GHQ-12 is normally a 4-point Likert Scale but in this study a Yes/No option was given instead for ease of administration in this study. This will not make any substantial differences to the results of the questionnaire.

The survey questionnaires which were originally in English were translated into isiXhosa and back translated to make them more appropriate for the study site and its community members. The 17 data collectors/interviewers made use of cell-phone technology (the translated questionnaires was programmed into the cell phone). The data capturing was recorded directly into the cell phone and these data were then sent to a central data base where it was collated and analysed. This method provided more accurate data, minimal missing data, was easier to monitor locally and remotely, and had built in quality checks. For example, the system will not allow contradictory answers and uses branching software – for example, in a study on cancers, as soon as a participant has been identified as male he will not be asked questions concerning cervical cancer. This method of data collection is supported by Tomlinson, Solomon et al. (2009) who conclude that real time quality control and data collector supervision make it a preferable option to a paper-based methodology.

## **DATA ANALYSIS**

A central database was used to analyse the data using the SPSS statistical programme. To identify differences between groups (persons with and without disability), crosstabs were

used together with chi-square analysis to calculate significance levels from percentages. In some instances, the averages or means of multiple questions were analysed between two groups using t-tests. The indexes were also used as dependent variables in linear multiple regression analysis to incorporate and to take into account correlations between the independent variables.

## **ETHICAL CONSIDERATIONS**

I obtained ethical approval for the larger research study from the ethics committee of the University of Stellenbosch. I also obtained ethical approval for doing research in Madawaleni from the Department of Health, Eastern Cape Province, South Africa. These two letters of approval are found in Appendix A. Each participant in the study was treated with confidentiality and underwent an informed consent procedure.

## **CHAPTER SIX**

### **RESULTS**

This chapter will be in two parts. Part 1 will look at the results of the Individual Survey while Part 2 will cover the Household Survey results.

Part 1 will have four sections. The first section, “Sample Characteristics”, will first look at the study sample demographics which will include age, gender, marital status, education, employment. Section 2, “Disability Issues”, will then focus on disability status of the subjects in the survey with attention being drawn to the same demographics. A comparison between persons with no disabilities and persons with disabilities will then be made. Having set up the premise for comparing persons with no disabilities and persons with disabilities we will then move on to Section 3, “Disability and Daily Living in Madwaleni”, where the focus will be on participation in the environment on a day-to-day basis for persons with no disabilities and persons with disabilities. Section 4, “Disability and Health Issues in Madwaleni”, will then focus on issues of health looking specifically at General Physical Health, General Mental Health, Needing and Receiving Health Care, Getting Health Care, Attitudes towards Health Care, Access to Health Care and Waiting Times for Health Care. Again, comparisons between persons with no disabilities and persons with disabilities will be made in terms of these health care issues.

Part 2 will have two sections. Section 1, “Household Density”, will look at issues of household density while Section 2, “Household and Access to Health Care”, will focus on how households have an impact on access to health care in terms of disability status.

## **PART 1 – INDIVIDUAL SURVEY**

### **1.1 Sample Characteristics**

There were 773 participants who took part in the individual survey.

#### **Age**

Only persons aged five and above were included in the survey due to the study's decision that it would be difficult to assess disability in children younger than five years old. It was decided to look at three age categories: 5-17 who were labelled financially dependent, 18-60 who were given the economically active label and those 61 and over who were potentially on a pension grant. A percentage of 6.3% of the sample were aged between 5-17, 70.9% of the sample was between the ages of 18-60 and 22.8% of the sample was 61 years or over. The average age of the sample is 42 years with an age range of 93, the youngest being five years old and the oldest 98 years.

#### **Gender**

In terms of gender there were 209 males (27%) and 512 females (66.2%) in the sample with 52 missing data (6.8%). Missing data occurred despite our efforts to obtain no missing data with the mobile phone methodology of data collection. A particular skewed gender balance found in Madwaleni is assumed to be due to a high proportion of a male migrating workforce from rural areas to the cities in South Africa.

Looking at age and gender together we find fairly similar age distributions among the males and females. Table 5 presents the age and gender distribution of the study sample.

Table 5

*Age and Gender Distribution*

	<b>Male</b>	<b>Female</b>	<b>Total</b>
<b>5-17</b>	11% (23)	3.9% (20)	5.9% (43)
<b>18-60</b>	70.3% (147)	71.6% (367)	71.3% (514)
<b>61+</b>	18.7% (39)	24.5% (125)	22.8 % (164)
<b>Total</b>	100% (209)	100% (512)	100% (721)

**Marital Status**

When it comes to marital status, 253 of the subjects in the sample were never married or not cohabiting (32.7%), while 413 subjects were currently married or cohabiting (53.5%), 0.6 % divorced or separated and 2.7% widowed. Overall 81 (10.5%) subjects had missing data.

**Education Levels**

When looking at the educational levels of persons aged 18+, 40.7% of the sample had no formal education while 40.8% had less than primary school. 15.2% had primary school education, 2.7% secondary school education and 0.6% tertiary level education.

**Employment**

The statistics on employment with our sample (aged 18-60) show high levels of unemployment – 35.9% of the sample are officially unemployed with a further 42.6% who are unpaid but keeping home and 2.1% having non-paid work – hence, a total of 80.6% of the sample had no fixed income. Only 5.7% of the sample has some form of fixed income, either having paid work or being self-employed.

Table 6 presents summary statistics for the full sample of the study.

Table 6

*Sample Variables*

<b>Variables</b>	<b>N</b>	<b>%</b>
<b>Age:</b>		
5-17	49	6.3
18-60	548	70.9
61 and over	176	22.8
Total	773	100.0
<b>Gender:</b>		
Male	209	27.0
Female	512	66.2
Missing data	52	6.8
Total	773	100.0
<b>Marital Status:</b>		
Never Married (and not cohabiting)	253	32.7
Currently Married (or cohabiting)	413	53.5
Divorced/separated	5	0.6
Widowed	21	2.7
<b>Education level (18+):</b>		
No formal education	162	31.5%

Less than primary school	244	47.5%
Primary school	87	16.9%
Secondary school	18	3.5%
Tertiary level education	3	0.6%
<b>Employment (18-60):</b>		
Unemployed	184	35.9%
Unpaid and keeping home	219	42.6%
Non-paid work	11	2.1%
Fixed Income	29	5.7%

## 1.2 Disability Issues

When it comes to disability status in the sample, 58.2% of the sample were persons with no disabilities (in house and neighbourhood controls<sup>1</sup>) and 41.8% of the sample were persons with disabilities (cases). This is due to the study design and is not a prevalence value. Table 7 presents the percentages of persons with no disabilities and persons with disabilities in the sample.

Table 7

### *Disability Status*

<b>No Disability</b>	450	58.2%
<b>Disability</b>	323	41.8%

<sup>1</sup> We checked to see if there were significant differences between in-house and neighbourhood control individuals, and there were not, so we are able to consider the controls as a single group.

<b>Total</b>	773	100%
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### Disability and Age

Within persons with disabilities, 4.6% were aged 5-17, 54.5% were aged 18-60 and 40.9% were aged 61+. Within persons with no disabilities, 7.6% were aged 5-17, 82.7% were aged 18-60 and 9.8% were aged 61+. Table 8 presents the disability status together with the age distribution.

Table 8

#### *Disability by Age Distribution*

	<b>No Disability</b>	<b>Disability</b>
<b>5-17</b>	7.6% (34)	4.6% (15)
<b>18-60</b>	82.7% (372)	54.5% (176)
<b>61+</b>	9.8% (44)	40.9% (132)
<b>Total</b>	100% (450)	100% (323)

### Disability and Gender

In this survey 70.9% of persons with disabilities were females and 29.1% were males. Table 9 presents the disability status with the gender distribution while Table 10 presents the disability status together with both the age and gender distribution.

Table 9

#### *Disability by Gender Distribution*

	<b>No Disability</b>	<b>Disability</b>
<b>Male</b>	28.9% (121)	29.1% (88)

<b>Female</b>	71.1% (298)	70.9% (214)
<b>Total</b>	100% (419)	100% (302)

Table 10

*Disability by Age and Gender Distribution*

	<b>Male</b>	<b>Female</b>	<b>Total</b>
<b>No Disability 5-17</b>	9% (11)	5.7% (17)	6.7% (28)
<b>18-60</b>	78.5% (95)	84.9% (253)	83.1% (348)
<b>61+</b>	12.5% (15)	9.4% (28)	10.2% (43)
<b>Total</b>	100% (121)	100% (298)	100% (419)
<b>Disability 5-17</b>	13.6% (12)	1.4% (3)	4.9% (15)
<b>18-60</b>	59.1% (52)	53.3% (114)	54.9% (166)
<b>61+</b>	27.3% (24)	45.3% (97)	40.2% (121)
<b>Total</b>	100% (88)	100% (214)	100% (302)

**Disability and Marital Status**

69.8% of persons with disability within our study are married while 23.7% had never married. Table 11 presents the disability status together with the marital status.

Table 11

*Disability by Marital Status*

	<b>No Disability</b>	<b>Disability</b>

<b>Married</b>	51.95% (208)	69.8% (203)
<b>Never Married</b>	45.9% (184)	23.7% (69)

This higher rate of marriage for persons with a disability may be owing to the fact that they were an older group; unfortunately we did not collect data on age at marriage so it is not possible to compare directly.

### **Disability and Education**

With persons aged 18+, 60.6% of persons with a disability had no formal education, while 28.9% of persons with a disability had less than primary school education- this together makes 89.5% of persons with a disability having no or less than primary school education compared to 75.7% of persons with no disability having the comparable levels of education.

In terms of having primary school education, 21% of persons with no disability and 7.3% of persons with disability had achieved this level of education. The percentages for obtaining the level of secondary school education were 3.1% for persons with no disability and 2.1% for persons with disability. Table 12 presents the level of education (aged 18+) with disability status.

Table 12

*Level of Education (aged 18+)*

	<b>No Disability</b>	<b>Disability</b>
<b>No Formal Education</b>	26.3% (103)	60.6% (174)

<b>Less than Primary School</b>	49.4% (193)	28.9% (83)
<b>Primary School</b>	21% (82)	7.3% (21)
<b>Secondary School</b>	3.1% (12)	2.1% (6)
<b>Tertiary Education</b>	0.3% (1)	1% (3)
<b>Total</b>	100% (391)	100% (287)

### Disability and Employment

The majority of the sample aged 18+ did not have paid employment – a combination of only 6.3% of persons with no disability had paid employment compared to 4.2% of persons with disability. Of persons with no disability 24.8% were unemployed while 59.0% of persons with disability were unemployed. Of persons with no disabilities 18.1% were students while only 1.8% of persons with disabilities were students. Chi-squared tests showed that these three relationships were all statistically significant ( $p < 0.000$ ). Table 13 presents the employment status (aged 18-60) together with disability status.

Table 13

#### *Employment Status (aged 18-60)*

	<b>No Disability</b>	<b>Disability</b>
<b>Paid work</b>	5.2% (18)	3.0% (5)
<b>Self employed</b>	1.1% (4)	1.2% (2)
<b>Non paid work</b>	2.9% (10)	0.6% (1)
<b>Student</b>	18.1% (63)	1.8% (3)
<b>Unpaid homemaker</b>	46.8% (163)	33.7% (56)
<b>Retired</b>	0.3% (1)	0.6% (1)
<b>Unemployed</b>	24.8% (86)	59.0% (98)
<b>Casual/Seasonal</b>	0.6% (2)	0% (0)

<b>Other</b>	0.3% (1)	0% (0)
<b>Total</b>	100% (348)	100% (166)

### Difficulties

Following our definition of disability as set out in Chapter 2 we have the following statistics concerning specific difficulties in the study sample. These are proportions within the persons with disabilities sample.

In terms of difficulty in seeing, 10.3% of people with disabilities stated that they had problems seeing (either a lot or unable). Looking within age categories, 10.2% had problems seeing in the 5-17 age category, 7.5% in the 18-60 category and 18.8% in the 61+ category. Table 14 presents visual difficulties by age distribution.

Table 14

#### *Problems Seeing*

<b>Age</b>	<b>Percentage</b>
5-17	10.2% (5)
18-60	7.5% (41)
61+	18.8% (33)
Total	10.3% ( 79)

In terms of difficulty in hearing, 10.3% of people with disabilities stated that they had problems hearing (either a lot or unable). Looking within age categories, 14.3% had problems hearing in the 5-17 age category, 6% in the 18-60 category and 22.7% in the 61+ category. Table 15 presents hearing difficulties by age distribution.

Table 15

*Problems Hearing*

<b>Age</b>	<b>Percentage</b>
5-17	14.3% (7)
18-60	6.0% (6)
61+	22.7% (40)
Total	10.3% (80)

In terms of difficulty in walking, 13,8% of people with disabilities stated that they had problems walking (either a lot or unable). Looking within age categories, 8.2% had problems walking in the 5-17 age category, 10% in the 18-60 category and 27.3% in the 61+ category.

Table 16 presents physical difficulties by age distribution.

Table 16

*Problems Walking*

<b>Age</b>	<b>Percentage</b>
5-17	8.2% (4)
18-60	10.0% (55)
61+	27.3% (48)
Total	13.8% (107)

In terms of difficulty in remembering, 4.9% of people with disabilities stated that they had problems remembering (either a lot or unable). Looking within age categories, 10.2% had

problems in remembering in the 5-17 age category, 3.6% in the 18-60 category and 7.4% in the 61+ category. Table 17 presents memory difficulties by age distribution.

Table 17

*Problems Remembering*

<b>Age</b>	<b>Percentage</b>
5-17	10.2% (5)
18-60	3.6% (20)
61+	7.4% (13)
Total	4.9% (38)

In terms of difficulty with self care, 3.6% of people with disabilities stated that they had problems with self care (either a lot or unable). Looking within age categories, 8.2% had problems with self care in the 5-17 age category, 2.6% in the 18-60 category and 5.7% in the 61+ category. Table 18 presents self care difficulties by age distribution.

Table 18

*Problems with Self Care*

<b>Age</b>	<b>Percentage</b>
5-17	8.2% (4)
18-60	2.6% (14)
61+	5.7% (10)
Total	3.6% (28)

In terms of difficulty communicating, 1.7% of people with disabilities stated that they had problems communicating (either a lot or unable). Looking within age categories, 8.2% had problems communicating in the 5-17 age category, 1.1% in the 18-60 category and 1.7% in the 61+ category. Table 19 presents communication difficulties by age distribution.

Table 19

*Problems Communicating*

<b>Age</b>	<b>Percentage</b>
5-17	8.2% (4)
18-60	1.1% (6)
61+	1.7% (3)
Total	1.7% (13)

It must be noted that some participants had multiple difficulties.

### **1.3 Disability and Daily Living in Madwaleni**

#### **Daily Living Activities**

It is important to explore the issues of disability and how these impact on daily living in Madwaleni. This is especially important due to Madwaleni's remoteness, ruralness and topography. Hence, questions were asked in the individual survey about the subject's environment and daily living activities. Statements needed to be responded using a 0-4 coding system – 0= no problem, 1= mild problem, 2= moderate problem, 3= severe problem and 4= complete problem (unable to perform).

The first daily living activity had to do with shopping and how subjects were able to get goods and services for themselves and others. There were 95.1% of persons with no disabilities who stated that they had no problem with shopping compared to 71.8% of persons with disabilities who had no problem in this area of their lives. When it came to shopping being a severe problem, 1.1% of persons with no disabilities and 9% of persons with disabilities experienced severe problems when shopping. These findings were all statistically significant (Chi-squared test,  $p < 0.000$ ). Table 20 presents the daily living activity of shopping in terms of difficulty by disability status.

Table 20

*Daily Activity of Shopping by Disability Status*

		No disability	Disability
<b>Shopping</b>	No Problems	95.1% (428)	71.8% (232)
	Severe Problems	1.1% (5)	9.0% (29)

When it came to preparing or cooking food as well as doing housework we find similar results. In terms of having no problem in preparing food, 95.3% of persons with no disabilities and 66.6% of persons with disabilities stated that they had no problems compared to 0.9% and 9.3% respectively who stated that they had severe problems in preparing food. Housework chores were similar – 95.6% of persons with no disabilities had no problems compared to 63.5% of persons with disabilities stating that they had no problems. When it came to housework chores being a severe problem, 1.1% of persons with no disabilities and 11.5% of person with disabilities experienced severe problems with home chores. These findings are all statistically significant (Chi-squared test,  $p < 0.000$ ). Table 21 presents the daily living activities of preparing food and housework chores in terms of difficulty by disability status.

Table 21

*Daily Activities of Preparing Food and Household Chores by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Preparing Food</b>	No Problems	95.3% (429)	66.6% (215)
	Severe Problems	0.9% (4)	9.3% (30)
<b>Housework Chores</b>	No Problem	95.6% (430)	63.5% (205)
	Severe Problems	1.1% (5)	11.5% (37)

In terms of taking care of personal objects as well as taking care of others we find again that the differences between persons with no disabilities and persons with disabilities are statistically significant (Chi-squared test,  $p < 0.000$ ). 95.8% of persons with no disabilities and 68.1% of persons with disabilities experienced no problems in taking care of personal objects while 1.1% and 9.3% respectively had severe problems in this respect of their lives. Similar findings were found when it comes to caring for others- 96.4% of persons with no disabilities and 69.7% of persons with disabilities experienced no problems in taking care of others while 0.9% and 7.7% respectively had severe problems in taking care of others. Table 22 presents the daily living activities of taking care of personal objects and of others in terms of difficulty by disability status.

Table 22

*Daily Activities of Taking Care of Personal Objects and Others by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Taking Care of Personal Objects</b>	No Problems	95.8% (431)	68.1% (220)
	Severe Problems	1.1% (5)	9.3% (30)

<b>Taking Care of Others</b>	No Problems	96.4% (434)	69.7% (225)
	Severe Problems	0.9% (4)	7.7% (25)

Social life seems also to be experienced differently depending on disability status. Making and maintaining friendships, interacting with persons in authority, interacting with strangers, creating and holding family relationships, making and maintaining intimate relationships were all statistically (Chi-squared test,  $p < 0.000$ ) different depending on disability status – people with disabilities experiencing more severe problems in all of these aspects of social life. Table 23 presents the daily living activities of social relationships in terms of difficulty by disability status.

Table 23

*Daily Activities of Social Relationships by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Difficulty with friends</b>	No Problems	97.1% (437)	76.4% (247)
	Severe Problems	0.7% (3)	5.6% (18)
<b>Difficulty with authority</b>	No Problems	97.1% (437)	76.8% (248)
	Severe Problems	0.9% (4)	6.8% (22)
<b>Difficulty with strangers</b>	No Problems	97.1% (437)	78.3% (253)
	Severe Problems	0.7% (3)	5.0% (16)
<b>Difficulty with families</b>	No Problems	97.3% (438)	79.3% (256)
	Severe Problems	0.4% (2)	4.6% (15)
<b>Difficulty with intimacy</b>	No Problems	93.8% (422)	66.9% (216)
	Severe Problems	1.6% (7)	12.1% (39)

Getting an education as well as getting and keeping employment were also statistically different (Chi-squared test,  $p < 0.000$ ) when comparing persons with no disabilities and persons with disabilities. In terms of getting an education, 85.3% and 59.4% respectively had no problem in getting an education while 6.2% and 14.6% respectively had severe problems in getting an education. The results were similar when it came to employment opportunities – 90.2% of persons with no disabilities and 60.7% of persons with disabilities had no problem with employment opportunities while 3.3% and 16.4% respectively had severe problems when it came to employment opportunities. Table 24 presents the daily living activities of getting an education and finding employment in terms of difficulty by disability status.

Table 24

*Daily Activities of Getting an Education and Finding Employment by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Getting an Education</b>	No Problems	85.3% (384)	59.4% (192)
	Severe Problems	6.2% (28)	14.6% (47)
<b>Employment Opportunities</b>	No Problems	90.2% (406)	60.7% (196)
	Severe Problems	3.3% (15)	16.4% (53)

When it comes to the management of one's finances, we again see statistically significant differences (Chi-squared test,  $p < 0.000$ ) between persons with no disabilities and persons with disabilities. 92.0% of persons with no disabilities and 72.1% of persons with disabilities had no financial management problems while 1.1% and 6.8% respectively has severe problems handling income and payments in their day-to-day-life. Table 25 presents the daily living activities of financial management in terms of difficulty by disability status.

Table 25

*Daily Activities of Financial Management by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Finance Management</b>	No Problems	92.0% (414)	72.1% (233)
	Severe Problems	1.1% (5)	6.8% (22)

In terms of taking part in day-to-day activities we again find differences between persons with no disabilities and persons with disabilities. Taking part in clubs and organisations (community life), taking part in recreation and leisure, taking part in religious and spiritual activities as well as taking part in political life and citizenship were all statistically different (Chi-squared test,  $p < 0.000$ ) depending on disability status with people with disabilities experiencing more severe problems in all of these day-to-day activities. Table 26 presents taking part in day-to-day activities in terms of difficulty by disability status.

Table 26

*Taking Part in Day-to-Day Activities by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Taking part in community life</b>	No Problems	95.6% (430)	72.4% (234)
	Severe Problems	0.7% (3)	7.4% (24)
<b>Taking part in recreation and leisure</b>	No Problems	94.0% (423)	73.7% (238)
	Severe Problems	1.3% (6)	7.1% (23)
<b>Taking part in spiritual activities</b>	No Problems	96.2% (433)	78.0% (252)
	Severe Problems	0.9% (4)	5.9% (19)
<b>Taking part in political</b>	No Problems	95.1% (428)	72.8% (235)

<b>life and citizenship</b>	Severe Problems	2.2% (10)	8.0% (26)
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### Barriers to Daily Living

Barriers when participating in daily activities in Madwaleni were then also explored. These barriers were rated on a 6 point scale – daily, weekly, monthly, less than monthly, never and not applicable. They were also asked if the particular barrier was a big problem or little problem.

Transport in Madwaleni is a big barrier in terms of day to day living. This is primarily because of the rugged terrain of the region and the vast distances. Our study found that a higher percentage of persons with disabilities use private transport compared to persons with no disabilities. This was statistically significant (Chi-Squared test,  $p < 0.000$ ). Table 27 presents the mode of transport used by disability status.

Table 27

#### *Mode of Transport Used by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Mode of Transport</b>	Private Vehicle	2.4%	11.5%
	Public Transport	48.7%	43.1%
	Walk	46.9%	43.0%
	Other	2.0%	2.4%

Availability and accessibility of transportation on a monthly basis was more of a barrier for persons with disabilities (8.7%) compared to persons with no disabilities (1.8%). However, on a daily basis, there was a higher percentage of persons with no disabilities (12.2%) that

had barriers than persons with disabilities (8.7%). 70.7% of persons with no disabilities and 66.9% of persons with disabilities never had transport issues as barriers. All these findings were significant (Chi-squared test,  $p < 0.000$ ). Table 28 presents the availability and accessibility of transport by disability status.

Table 28

*Availability and Accessibility of Transport by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Transport Barriers</b>	No Problems	70.7% (318)	66.9% (216)
	Daily Basis	12.2% (55)	8.7% (28)
	Weekly Basis	4.9% (22)	7.1% (23)
	Monthly Basis	1.8% (8)	8.7% (28)

The natural environment (e.g., temperature, terrain, climate) and how it impacts on persons in Madwaleni was also explored in terms of barriers of daily living. More persons with disabilities, compared to persons with no disabilities, had the natural environment making it difficult for them to do what they wanted or needed to do on a daily, weekly and monthly basis. 74.4% of persons with no disabilities never had natural environment barriers while 60.1% persons with disabilities never had these barriers. All these findings were significant (Chi-squared test,  $p < 0.000$ ). Table 29 presents the natural environment barriers by disability status.

Table 29

*Natural Environment Barriers by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Natural Environment</b>	No Problems	74.4% (335)	60.1% (194)

<b>Barriers</b>	Daily Basis	4.0% (18)	7.7% (25)
	Weekly Basis	4.2% (19)	9.3% (30)
	Monthly Basis	1.3% (6)	8.4% (27)

Likewise, the surroundings (e.g., lighting, noise, crowds) was also a significant factor when it came to barriers in activities between persons with disabilities and persons with no disabilities. Again, there were higher percentages of persons with disabilities who had barriers than persons with no disabilities when it came to surroundings and daily living. 78.7% of persons with no disabilities never had barriers to surroundings compared to 64.1% of persons with disabilities. All these findings were statistically significant (Chi-squared test,  $p < 0.000$ ). Table 30 presents the surrounding barriers by disability status.

Table 30

*Surrounding Barriers by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Surrounding Barriers</b>	No Problems	78.7% (354)	64.1% (207)
	Daily Basis	3.6% (16)	7.1% (23)
	Weekly Basis	4.9% (22)	8.0% (26)
	Monthly Basis	0% (0)	6.2% (20)

Information wanted or needed in the format one can use or understand was also significantly different between persons with no disabilities and persons with disabilities. There were higher percentages of persons with disabilities who required information on a daily, weekly and monthly basis. 78% of persons with no disabilities never had information barriers compared to 67.5% of persons with disabilities. All these findings were statistically

significant (Chi-squared test,  $p < 0.000$ ). Table 31 presents the information barriers by disability status.

Table 31

*Information Barriers by Disability Status*

		No disability	Disability
<b>Information Barriers</b>	No Problems	78.0% (351)	67.5% (218)
	Daily Basis	4.4% (20)	8.0% (26)
	Weekly Basis	2.7% (12)	7.4% (24)
	Monthly Basis	1.1% (5)	6.2% (20)

Regarding social barriers to participation, the comparisons of the experience of prejudice and discrimination by others between persons with no disabilities and persons with disabilities were also statistically different. Higher percentages of persons with disabilities experienced prejudice and discrimination on a daily, weekly and monthly basis compared to persons with no disabilities. 81.1% of persons with no disabilities never/not applicable experienced prejudice or discrimination while 77.4% of persons with disabilities never/not applicable experienced prejudice or discrimination. All these findings were statistically significant (Chi-squared test,  $p < 0.000$ ). These findings were also statistically significant when it was asked if prejudice and discrimination was a big problem or not – higher percentages of persons with disabilities experienced “big problems”. Table 32 presents the prejudice and discrimination barriers by disability status.

Table 32

*Prejudice and Discrimination Barriers by Disability Status*

		No disability	Disability
<b>Prejudice and Discrimination Barriers</b>	Never/not applicable	81.1% (365)	77.4% (250)
	Daily Basis	0.9% (4)	5.0% (16)
	Weekly Basis	2.0% (9)	7.4% (24)
	Monthly Basis	0.7% (3)	7.4% (24)

**Daily Living and the Environment**

When it comes to living with ease in their environments, subjects were asked to respond to “yes” or “no” on nine environmental factor statements. The first statement asked about positive attitudes from others on the participant and found that persons with disabilities had significantly less positive attitudes towards them from others. Table 33 presents positive attitudes from others by disability status.

Table 33

*Positive Attitudes from Others by Disability Status*

		No disability	Disability
<b>Positive Attitudes from others</b>	Yes	77.8% (350)	58.2% (188)
	No	22.0% (99)	41.5% (134)
	Did not answer	0.2% (1)	0.3% (1)

Support from others was also perceived differently depending on disability status. Persons with disabilities perceived less support from others compared to persons with no disabilities. 42.1% of persons with disabilities stated that they did not get support from others when needed compared to 34.9% of persons with no disabilities. This was not statistically

significant (Chi-square test,  $P < 0.091$ ). Table 34 presents support from others by disability status.

Table 34

*Support from Others by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Support from Others</b>	Yes	64.9% (292)	57.9% (187)
	No	34.9% (157)	42.1% (136)
	Did not answer	0.2% (1)	0% (0)

Accessibility of buildings, transport and information were also statistically different (Chi-squared test,  $P < 0.000$ ) when persons with disabilities were compared to persons with no disabilities. Table 35 presents accessibility of buildings, transport and information by disability status.

Table 35

*Accessibility of Buildings, Transport and Information by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Accessibility of Buildings</b>	Yes	63.8% (287)	45.2% (146)
	No	36.2% (163)	54.8% (177)
<b>Accessibility of Transport</b>	Yes	68.7% (309)	52.6% (170)
	No	31.3% (141)	47.4% (153)
<b>Accessibility of Information</b>	Yes	66.4% (299)	49.8% (161)
	No	33.3% (150)	50.2% (162)
	Did not answer	0.2% (1)	0% (0)

When it came to terrain and ease to carry out daily activities we find again that there is a statistically significant difference (Chi-squared test,  $P < 0.000$ ) in the two compared groups based on disability status. Table 36 presents ease of terrain by disability status.

Table 36

*Ease of Terrain by Disability Status*

		No disability	Disability
<b>Ease of terrain</b>	Yes	64.4% (290)	47.1% (152)
	No	34.9% (157)	52.6% (170)
	Did not answer	0.7% (3)	0.3% (1)

In terms of favourable environmental conditions (heat, cold, rain, noise, pollution, crowding, etc.) we find that persons with disabilities perceive to have less favourable conditions and that this relationship is statistically significant (Chi-squared test,  $p < 0.000$ ). Table 37 presents perceived favourable environmental conditions by disability status.

Table 37

*Perceived Favourable Environmental Conditions by Disability Status*

		No disability	Disability
<b>Favourable environmental conditions</b>	Yes	62.7% (282)	49.8% (161)
	No	37.3% (168)	50.2% (162)

Service provisions (refers to the way inputs such as money, staff, equipment and drugs are combined to allow the delivery of health interventions) were also perceived to be different

depending on disability status. Persons with disabilities perceiving less service provision compared to persons with no disabilities. This relationship is statistically significant (Chi-squared test,  $p < 0.000$ ). Table 38 presents perceived service provisions by disability status.

Table 38

*Perceived Service Provisions by Disability Status*

		No disability	Disability
<b>Perceived Service Provisions</b>	Yes	66.0% (297)	50.8% (164)
	No	33.8% (152)	49.2% (159)
	Did not answer	0.2% (1)	0% (0)

**1.4 Disability and Health Issues in Madwaleni**

After having explored issues of disability and daily living, the focus turns in particular to disability and health issues in Madwaleni.

Asked about their general physical health on a scale of 1 (poor) to 4 (very good), there was also a significant difference (Chi-squared test,  $p < 0.000$ ) between persons with disabilities and persons with no disabilities. Persons with disabilities have poorer perceived health when compared to persons with no disabilities. 18% of persons with disabilities rate their physical health as poor, while 26.3% rate it as not very good. In comparison there were 4% of persons with no disabilities who rated their physical health as poor and 14.4% who rated it as not very good. Table 39 presents participants' ratings of general physical health and their disability status.

Table 39

*General Physical Health Rating*

	<b>No Disability</b>	<b>Disability</b>
<b>Poor</b>	4% (18)	18% (58)
<b>Not very good</b>	14.4% (65)	26.3% (85)
<b>Good</b>	41.1% (185)	39% (126)
<b>Very good</b>	40.2% (181)	16.7% (54)
<b>Do not know</b>	0.2% (1)	0% (0)

Asked about their general mental health on a scale of 1 (poor) to 4 (very good), there was also a significant difference (Chi-squared test,  $p < 0.000$ ) between persons with disabilities and persons with no disabilities. Table 40 presents participants' ratings of general mental health and their disability status.

Table 40

*General Mental Health Rating*

	<b>No Disability</b>	<b>Disability</b>
<b>Poor</b>	1.8% (8)	4% (13)
<b>Not very good</b>	6.2% (28)	15.5% (50)
<b>Good</b>	50.9% (229)	64.1% (207)
<b>Very good</b>	41.1% (185)	16.4% (53)

Further to assessing subjects' mental health, questions from the General Health Questionnaire (GHQ-12) were also part of the individual survey. A maximum score of 12 indicated the highest level of reported psychological problems and a minimum score of 0 indicating no psychological problems. Persons with disabilities scored a mean of 4.24 while persons with

no disabilities scored a mean of 2.85. This finding was significant (ANOVA test<sup>2</sup>,  $p < 0.000$ ) and thus supports the General Mental Health Rating discussed above. Table 41 presents the GHQ-12 mean findings for persons with disabilities and persons with no disabilities.

Table 41

*Mean Score for GHQ-12 by Disability Status*

No Disability	Disability
2.85	4.24

When we look at the specific questions asked in the GHQ-12 we find the following results:

With concentration issues, persons with disabilities were more likely not able to concentrate – 46.7% stated that were not able to concentrate compared to 19.1% of persons with no disabilities who stated that they were not able to concentrate. This was statistically significant (Chi-squared test,  $p < 0.000$ ).

In terms of feeling that they were playing a useful part in things, 47.1% of persons with disabilities felt that they did not, compared to 23.6% of persons with no disabilities. This was statistically significant (Chi-squared test,  $p < 0.000$ ).

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<sup>2</sup> There are differing conventions for using ANOVA versus Students' t test for comparison of two means. For purposes of this study, given that we were basing many of the questions on instruments first developed by SINTEF Norway, we follow their convention of using the ANOVA as opposed to the t test for two means. There is ample evidence that for practical purposes the two tests yield the same results. Some see the t test simply as a special case of ANOVA; others argue that an advantage of the ANOVA is that there is reduced chance of committing a Type 1 error – see <http://www.differencebetween.net/miscellaneous/difference-between-t-test-and-anova/>; Brown and Melamed (1990).

The capability of making decisions was also statistically different (Chi-squared test,  $p < 0.000$ ) between the two comparison groups. Persons with disabilities found it more difficult to make decisions with 39.6% stating that they were not capable of making decisions about things, compared to 19.8% of persons with no disabilities stating the same thing.

Not being able to enjoy normal day-to-day activities was also statistically different (Chi-squared test,  $p < 0.000$ ) – 38.6% of persons with disabilities were not able to enjoy activities compared to 21.6% of persons with no disabilities.

Not being able to face up to your problems was more of a factor for persons with disabilities (39.6%) compared to 20.7% of persons with no disabilities. This was statistically significant (Chi-squared test,  $p < 0.000$ ).

While 39% of persons with disabilities have not been feeling reasonably happy, all things considered, 27.8% of persons with no disabilities had similar feelings. This was statistically significant (Chi-squared test,  $p < 0.001$ ).

When it came to not having much sleep over worry, feeling constantly under strain, not overcoming difficulties, been feeling unhappy and depressed, losing confidence in oneself, and thinking of yourself as a worthless person, these were all not significant relationships when it came to mental health and comparing persons with disabilities and persons with no disabilities.

### **Needing and Receiving Health Care**

Eighteen percent of the sample did not receive health care when they needed it. Within that, 58.9% of persons who did not receive health care had a disability while 41.1% of persons who did not receive health care did not have a disability. This is statistically significant (Chi-squared test,  $p < 0.001$ ).

In terms of needing and receiving health care when having specific difficulties we see that 22.5% of persons with seeing difficulties did not receive health care compared to 17.7% of persons with no seeing difficulties. This is statistically significant (Chi-squared test,  $p < 0.000$ ). When it comes to persons with hearing difficulties, 28.8% of them did not receive health care with 17% of persons with no hearing difficulties receiving no health care. This is statistically significant (Chi-squared test,  $p < 0.000$ ). 28% of persons with walking difficulties did not receive health care compared to 16.7% of persons with no walking difficulties not receiving health care. This is statistically significant (Chi-squared test,  $p < 0.000$ ). The other three types of difficulties, namely remembering, self care and communication did not show similar significant results.

### **Availability of Health Care**

The issue of availability of health care services and if this was a problem was addressed. 78.4% of persons with no disabilities never had availability problems to health care compared to 70.3% of persons with disabilities who never had issues with availability of health care. On a daily basis, 6.2% of persons with no disabilities and 4.6% of persons with disabilities had health care availability issues. However on a weekly and monthly basis the trend turned to persons with disabilities having more availability issues compared to persons with no

disabilities. These findings are statistically significant (Chi-squared test,  $p < 0.000$ ). Table 42 presents the problems of availability of health care services by disability status.

Table 42

*Problems of Availability of Health Care Services by Disability Status*

		No disability	Disability
<b>Availability of Health Care Services</b>	No Problems	78.4% (353)	70.3% (227)
	Daily Basis	6.2% (28)	4.6% (15)
	Weekly Basis	2.2% (10)	9.3% (30)
	Monthly Basis	0.7% (3)	5.0% (16)

### **Actually Getting Health Care**

In terms of actually getting health care there was a statistically significant (Chi-squared test,  $p < 0.000$ ) difference between persons with no disabilities and persons with disabilities – there was a higher percentage of persons with disabilities who did not get health care (25.7%) compared to 12.9% of persons with no disabilities who did not get health care.

Reasons for not getting health care were then addressed when comparing persons with no disabilities and persons with disabilities. Cost was the only statistically significant factor that distinguished persons with no disabilities and persons with disabilities who did not get health care. Of persons with disabilities 75.6% stated cost as a factor in not getting health care while 12.9% of person with no disabilities stated cost as a factor.

### **Attitudes towards Health Care**

The attitudes of health care users towards competence of health care personnel differ significantly if they are persons with disabilities or persons with no disabilities. Persons with disabilities have less favourable attitudes towards competence of health care workers at health centres as well as at the hospital in Madwaleni. Of persons with no disabilities 79.7% strongly agree that health care personnel at health centres have competence compared to 57.6% of persons with disabilities. When it comes to attitude towards health care personnel at the hospital, the percentages were 84.4% and 63.2% respectively. These were statistically significant (Chi-squared test,  $p < 0.000$ ).

When it comes to trusting the treatment provided by the health personnel at the health centres and hospital, it was again found that persons with disabilities have less favourable attitudes at both facilities. While 84.2% of persons with no disabilities strongly agree that they can trust the treatment at health centres, 60.1% of persons with disabilities strongly agree. The comparable percentages with respect to treatment at hospital are 86.7% and 65.3% respectively. These were statistically significant (Chi-squared test,  $p < 0.000$ ).

In terms of being received in a positive manner at the health centres and hospital, it was again found that persons with disabilities experience less favourable attitudes. Of persons with no disabilities 84% strongly agree that people are received in a positive manner at health centres while 63.8% of persons with disabilities strongly agree. When it came to the hospital, the percentages were 86.4% and 68.7% respectively. These were statistically significant (Chi-squared test,  $p < 0.000$ ).

## Barriers to Health Care in Madwaleni

We now turn to barriers to health care in Madwaleni. In terms of access to health care and barriers experienced, there were once again statistically significant results. There were higher percentages of persons with disabilities who encountered barriers on a weekly and monthly basis to health care access (but not on a daily basis). Of persons with no disabilities 78.4% never had barriers to health care access compared to the 70.3% of persons with disabilities. All these findings were statistically significant (Chi-squared test,  $p < 0.000$ ). Table 43 presents the problems of access to health care by disability status.

Table 43

### *Barriers to Health Care*

		No disability	Disability
<b>Barriers to Health Care</b>	Never/not applicable	78.4% (353)	70.3% (227)
	Daily Basis	6.2% (28)	4.6% (15)
	Weekly Basis	2.2% (10)	9.3% (30)
	Monthly Basis	0.7% (3)	5.0% (16)

Eighteen potential specific barriers relating to access to health care in Madwaleni were also highlighted and addressed in one question in a questionnaire of this study. Participants were given a list of 18 potential access barriers that they were asked to rate with response options of “No Problem” (score 1), “Small Problem” (score 2), “Moderate Problem” (score 3), “Serious Problem” (score 4) or “Insurmountable Problem” (score 5). These figures were then added up. A minimum total score of 18 reflects “no problems” in terms of access. Higher scores reflect more access barriers with a possible maximum score of 90 (18x5). The list of the 18 barriers in the question are:

1. lack of transport

2. no services available
3. physical access to health facility
4. because of faith
5. negative attitudes among health workers
6. no accommodation at health facility
7. communication with health workers
8. standard of health facility
9. journey to health facility is dangerous
10. did not know where to go
11. could not afford the cost of visit
12. did not have necessary documents
13. thought you were not sick enough
14. denied health care
15. drugs and equipment were inadequate
16. could not take time off work
17. previously treated badly
18. could not afford cost of transport

When looking at the combined access barriers question together with disability status, persons with disabilities had an average of 23,3075 while persons with no disabilities had an average of 20,8228. This was statistically significant (ANOVA,  $p < 0.000$ ). This implies that there are more barriers to health care for a person with a disability in Madwaleni.

With gender, males had an average of 21,3301, while females had an average of 22,3574, showing that females generally had more barriers to access but that this was not significant.

It is interesting now to disaggregate some of the access barriers and look at how they impact on the respondents in the survey.

*Physical Barriers:*

It was found that 81.1% of persons with no disabilities had no problem with transport to health centres while 71.2% of persons with disabilities had no problem in transport issues. Hence, 18.9% of persons with no disabilities had some problems while 28.8% of persons with disabilities had some problems. This was statistically significant (Chi-squared test,  $p < 0.000$ ). Table 44 presents transport barriers to health centres by disability status.

Table 44

*Transport Barriers to Health Centres by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Lack of Transport to Health Centres</b>	No Problem	81.1% (365)	71.2% (230)
	Small Problem	5.3% (24)	13.0% (42)
	Moderate Problem	1.8% (8)	6.5% (21)
	Serious Problem	11.3% (51)	8.0% (26)
	Insurmountable Problem	0.4% (2)	1.2% (4)

Not being able to afford transport costs was also significantly different between the two groups with persons with disabilities having more barriers to transport access due to cost than persons with no disabilities (Chi-squared test,  $p < 0.000$ ). Table 45 presents affordability of transport costs by disability status.

Table 45

*Affordability of Transport Costs by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Affordability of Transport Costs</b>	No Problem	85.1% (383)	82.0% (265)
	Small Problem	4.4% (20)	6.8% (22)
	Moderate Problem	1.6% (7)	6.2% (20)
	Serious Problem	8.9% (40)	4.3% (14)
	Insurmountable Problem	0% (0)	0.6% (2)

The journey to the health centre was perceived by persons with disabilities as more dangerous compared to persons with no disabilities (Chi-squared test,  $p < 0.001$ ). 87.6% of persons with no disabilities had no problems (12.4% had some problems) while 80.2% of persons with disabilities had no problems with danger (19.8% had some problems). Table 46 presents the journey in terms to dangerousness by disability status.

Table 46

*Dangerousness of Journey by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Dangerous Journey to Health Centre</b>	No Problem	87.6% (394)	80.2% (259)
	Small Problem	2.7% (12)	8.7% (28)
	Moderate Problem	3.1% (14)	5.9% (19)
	Serious Problem	6.4% (29)	5.0% (16)
	Insurmountable Problem	0.2% (1)	0.3% (1)

Not knowing where to go in terms of health centres was also significantly different between the two groups with persons with disabilities experiencing more lack of knowledge about

where to go (Chi-squared test,  $p < 0.000$ ). Table 47 presents knowledge of where to go in terms of health centres by disability status.

Table 47

*Knowledge of Where to Go in Terms of Health Centres by Disability Status*

		No disability	Disability
<b>Not Knowing Where To Go</b>	No Problem	96.2% (433)	87.6% (283)
	Small Problem	2.7% (12)	7.4% (24)
	Moderate Problem	0.7% (3)	3.7% (12)
	Serious Problem	0.4% (2)	1.2% (4)
	Insurmountable Problem	0% (0)	0% (0)

No accommodation at health centres was also experienced differently with 94.4% of persons with no disabilities having no problems while 86.7% of persons with disabilities having no problems (Chi-squared test,  $p < 0.003$ ). Hence, 5.6% of persons with no disabilities had some problems while 13.3% of persons with disabilities had some problems. Table 48 presents accommodation issues at health centres by disability status.

Table 48

*Accommodation Issues at Health Centres by Disability Status*

		No disability	Disability
<b>No Accommodation at Health Centre</b>	No Problem	94.4% (425)	86.7% (280)
	Small Problem	3.8% (17)	7.7% (25)
	Moderate Problem	1.3% (6)	3.4% (11)
	Serious Problem	0.2% (1)	1.9% (6)
	Insurmountable Problem	0.2% (1)	0.3% (1)

When it comes to drugs and equipment provision at health centres it was found that persons with disabilities had significantly less access to drugs and equipment than persons with no disabilities – 90.2% of persons with no disabilities had no problem with this access while 78.3% of persons with disabilities had no problem in accessing drugs or equipment (Chi-squared test,  $p < 0.000$ ). Hence, 9.8% of persons with no disabilities had some problems with accessing drugs or equipment while 21.7% of persons with disabilities had access issues. Table 49 presents drugs and equipment provision at health centres by disability status.

Table 49

*Drugs and Equipment Provision at Health Centres by Disability Status*

		No disability	Disability
<b>Inadequate Drugs or Equipment</b>	No Problem	90.2% (406)	78.3% (253)
	Small Problem	3.8% (17)	8.0% (26)
	Moderate Problem	3.8% (17)	6.8% (22)
	Serious Problem	2.2% (10)	5.6% (18)
	Insurmountable Problem	0% (0)	0.3% (1)

Standard of the health centre was perceived differently between the two groups. 94.2% of persons with no disabilities had no problem (5.8% had some problems) with the standard of the health centre while 82% of persons with disabilities had no problem (18% had some problems). This was statistically significant (Chi-squared test,  $p < 0.000$ ). Table 50 presents perceptions of standard of the health centre by disability status.

Table 50

*Perceptions of Standard of the Health Centre by Disability Status*

		No disability	Disability

<b>Standard of the Health Centre</b>	No Problem	94.2% (424)	82.0% (265)
	Small Problem	3.1% (14)	8.4% (27)
	Moderate Problem	2.0% (9)	6.5% (21)
	Serious Problem	0.7% (3)	2.8% (9)
	Insurmountable Problem	0% (0)	0.3% (1)

*Attitudinal Barriers:*

Perceived negative attitudes among health workers were also significantly different – persons with disabilities experiencing more perceived negative attitudes among the health workers they had interaction with. 93.3% of persons with no disabilities experienced no problems with this while 84.5% of persons with disabilities experienced no problems with negative attitudes ( $p < 0.000$ ). 1.8% of persons with no disabilities had a serious problem with attitudes of health workers while 3.1% of persons with disabilities had serious problems (Chi-squared test,  $p < 0.000$ ). Table 51 presents perceptions of attitudes of health care workers by disability status.

Table 51

*Perceptions of Attitudes of Health Care Workers by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Negative Attitudes Among Health Workers</b>	No Problem	93.3% (420)	84.5% (273)
	Small Problem	2.2% (10)	8.4% (27)
	Moderate Problem	2.7% (12)	4.0% (13)
	Serious Problem	1.8% (8)	3.1% (10)
	Insurmountable Problem	0% (0)	0% (0)

Persons with disabilities perceived they were denied health care statistically more than persons with no disabilities (Chi-squared test,  $p < 0.000$ ). 96.4% of persons with no

disabilities had no problem when it came to denial of health care while 87.6% of persons with disabilities had no problems. Hence, 3.6% of persons with no disabilities had some problems with being denied access while 12.4% of persons with disabilities had some problems with denied access to health care. Table 52 presents perceived denial of health care by disability status.

Table 52

*Perceived Denial of Health Care by Disability Status*

		No disability	Disability
<b>Denial of Health Care</b>	No Problem	96.4% (434)	87.6% (283)
	Small Problem	1.3% (6)	6.5% (21)
	Moderate Problem	1.8% (8)	2.8% (9)
	Serious Problem	0.4% (2)	2.5% (8)
	Insurmountable Problem	0% (0)	0.6% (2)

Persons with disabilities reported having been treated worse at health centres than persons with no disabilities. This is statistically significant (Chi-squared test,  $p < 0.000$ ). 96% of persons with no disabilities were not treated badly when accessing health centres while 85.8% of persons with disabilities were not treated badly at health centres. Hence, 4% of persons with no disabilities had some problems with being treated badly while 14.2% of persons with disabilities had some problems with being treated badly at health centres. Table 53 presents perceived treatment at health centres by disability status.

Table 53

*Perceived Treatment at Health Centres by Disability Status*

		No disability	Disability
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<b>Treated Badly at Health Centre</b>	No Problem	96.0% (432)	85.8% (277)
	Small Problem	2.7% (12)	8.0% (26)
	Moderate Problem	1.3% (6)	5.3% (17)
	Serious Problem	0% (0)	0.6% (2)
	Insurmountable Problem	0% (0)	0.3% (1)

*Communication Barriers:*

Persons with disabilities also had statistically significant more communication problems with health workers at the health centres. While 93.3% of persons with no disabilities experience no communication problems with health workers, 85.4% of persons with disabilities did not experience communication problems with health workers (Chi-squared test,  $p < 0.003$ ). 6.7% of persons with no disabilities had some problems while 14.6% of persons with disabilities had some problems. Table 54 presents issues of communication with health workers.

Table 54

*Communication with Health Workers by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Communication with Health Workers</b>	No Problem	93.3% (420)	85.4% (276)
	Small Problem	3.8% (17)	9.3% (30)
	Moderate Problem	2.2% (10)	3.4% (11)
	Serious Problem	0.7% (3)	1.9% (6)
	Insurmountable Problem	0% (0)	0% (0)

When it comes to the interaction and experiences with health care providers it was found that persons with disabilities were less satisfied with waiting times than persons with no disabilities (Chi-squared test,  $p < 0.000$ ), were treated with less respect (Chi-squared test,  $p < 0.000$ ), things were not as clearly explained (Chi-squared test,  $p < 0.000$ ), they were not as

involved in their own decision making for treatment (Chi-squared test,  $p < 0.000$ ), they were not able to talk as privately with health care providers (Chi-squared test,  $p < 0.000$ ), and the ease with which they could see a health care provider they were happy with was less satisfactory (Chi-squared test,  $p < 0.000$ ). See Tables 55-60 respectively.

Table 55

*Perceptions of Waiting Time at Health Centres by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Waiting Time at Health Centres</b>	Very Good	58.4% (263)	26.9% (87)
	Good	31.3% (141)	53.3% (172)
	Moderate	6.9% (31)	11.8% (38)
	Bad	1.8% (8)	4.6% (15)
	Very Bad	1.3% (6)	3.1% (10)
	Do not know	0.2% (1)	0.3% (1)

Table 56

*Perceptions of Respect by Health Care Workers by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Treated with Respect by Health Care Providers</b>	Very Good	62.7% (282)	37.8% (122)
	Good	31.8% (143)	53.6% (173)
	Moderate	4.4% (20)	6.2% (20)
	Bad	0.7% (3)	1.5% (5)
	Very Bad	0.2% (1)	0.6% (2)
	Do not know	0.2% (1)	0.3% (1)

Table 57

*Perceptions of Explanations by Health Care Workers by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Clear Explanations by Health Care Providers</b>	Very Good	63.8% (287)	38.4% (124)
	Good	30.4% (137)	52.0% (168)
	Moderate	4.9% (22)	6.5% (21)
	Bad	0.4% (2)	1.9% (6)
	Very Bad	0% (0)	0.6% (2)
	Do not know	0.4% (2)	0.6% (2)

Table 58

*Perceptions of Involvement in Treatment and Decision Making by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Involved in Treatment Decision Making</b>	Very Good	62.4% (281)	33.7% (109)
	Good	31.6% (142)	53.9% (174)
	Moderate	5.1% (23)	8.7% (28)
	Bad	0.4% (2)	2.5% (8)
	Very Bad	0.2% (1)	0.9% (3)
	Do not know	0.2% (1)	0.3% (1)

Table 59

*Perceptions of Privacy by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Able to talk privately with health care providers</b>	Very Good	63.1% (284)	40.9% (132)
	Good	31.6% (142)	51.1% (165)
	Moderate	4.9% (22)	5.9% (19)
	Bad	0% (0)	0.9% (3)
	Very Bad	0.2% (1)	0.9% (3)
	Do not know	0.2% (1)	0.3% (1)

Table 60

*Ease to See Health Care Provider They are Happy with by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Ease to see a health care provider they are happy with</b>	Very Good	64.4% (290)	37.8% (122)
	Good	30.0% (135)	49.2% (159)
	Moderate	4.4% (20)	6.5% (21)
	Bad	0.2% (1)	4.3% (14)
	Very Bad	0.4% (2)	1.5% (5)
	Do not know	0.4% (2)	0.6% (2)

Provision of health care was perceived by persons with disabilities as less satisfactory compared to persons with no disability (Chi-squared test,  $p < 0.000$ ). They were also not as satisfied with the personnel in their area or those accessible to them (Chi-squared test,  $p < 0.000$ ). Table 61 presents perceived provision of health care by disability status while Table 62 presents satisfaction of health care personnel by disability status.

Table 61

*Perceived Provision of Health Care by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Satisfied with Provision of Health Care</b>	Very Satisfied	77.3% (348)	42.4% (137)
	Satisfied	17.1% (77)	47.7% (154)
	Neutral	3.3% (15)	2.8% (9)
	Dissatisfied	0.7% (3)	5.6% (18)
	Very Dissatisfied	1.3% (6)	1.5% (5)
	Do not know	0.2% (1)	0% (0)

Table 62

*Satisfaction of Health Care Personnel by Disability Status*

		<b>No disability</b>	<b>Disability</b>
<b>Satisfied with Personnel of Health Care</b>	Very Satisfied	74.9% (337)	41.2% (133)
	Satisfied	17.6% (79)	51.7% (167)
	Neutral	6.0% (27)	3.1% (10)
	Dissatisfied	0.7% (3)	3.4% (11)
	Very Dissatisfied	0.7% (3)	0.3% (1)
	Do not know	0.2% (1)	0.3% (1)

**Waiting Times at Health Care Centres**

Persons with no disabilities had an average waiting time of 6 hours and 10 minutes at the health centres, while persons with disabilities had an average waiting time of 3 hours and 17 minutes.

**Home Visits**

When asked if they had been visited at home in the last three years, there was a significant difference between the two groups. Persons with disabilities were more likely to report not having received a home visit in the last three years. 46% of persons with no disabilities had received a home visit while 28.2% of persons with disabilities had a home visit in the last three years (Chi-squared test,  $p < 0.000$ ).

There was a significant relationship between one type of difficulty and access to health care – remembering impairments had a statistically significant relationship (Chi-squared test,  $p <$

0.011). Persons with remembering difficulties have less access to health care. All the other difficulties did not have significant relationships with access to health care.

## **PART 2 – HOUSEHOLD SURVEY**

There were 532 households that took part in our survey. There were 360 households with at least one person with a disability (case households) – 248 of which were case control households and 112 only case households – and 172 households (control household) with no persons with disability.

In terms of specific difficulties at household level, 10.5% of households had dwellers with seeing difficulties, 7.4% of households had dwellers with hearing difficulties, 10.9% of households had dwellers with mobility difficulties, 3.6% of households had dwellers with self care difficulties, 3.7% of households had dwellers with communication difficulties, and 4.5% of households had dwellers with memory difficulties.

### **Household Size**

Households having 1-2 persons comprised 16.3% of the sample. It was found that within this category, 43.7% of the respondents were older than 60 years. Households with 3-5 persons comprised 59.2% of the sample, 6-10 person households 22.8% and households with more than 10 persons comprised 1.7% of the sample.

With persons with disabilities in our study, it was found that 19.9% live in 1-2 person households and that the majority of persons with disabilities (56.2%) live in 3-5 person households.

### **Head of Households**

There were 267 households that had a head of household with no disability, while there were 265 households that had a head of household who had a disability.

### **Household Access to Health Care**

Households with no persons with disability had a total average access score of 20,8500 while households with persons with disability had a total average score of 23,1485. This difference is not statistically significant (ANOVA test).

Within households with disability, persons with no disabilities scored on average 20,7540 while persons with disabilities scored on average 23,1485. Household with no disabilities scored an average of 20.9984. This was not statistically significant (ANOVA test). This implies that a person with no disability does not have better access compared to their housemate who has a disability. He/she also does not have better access compared to persons in a household with no disabilities.

The relationship between the total number of people in a household and access to health care showed no significant correlation. The correlation was -0.067 and was not significant (Pearson Correlation Test,  $p < 0.064$ ). Breaking this up into case households and control households we find similar patterns. Case households had a correlation of -0.071 (Pearson Correlation Test,  $p < 0.205$ ) and control households had a correlation of -0.052 (Pearson Correlation Test,  $p < 0.267$ ). In other words, size of household has no impact on access to health care in Madwaleni.

In terms of the Equitable Framework for Access to Health Care Model used in this dissertation, the results of this study support that there are context (e.g., transport), system (e.g., staff attitudes), personal (e.g., education) as well as community (e.g., poverty) variables that have an impact on access to health care in Madwaleni.

The main research hypothesis – that in rural Madwaleni, people with disabilities have more barriers to health care than people without disabilities – was supported by the current findings in this study.

The second research hypothesis – that households including a person with a disability in Madwaleni have more barriers to health care than households where there is no disability – was not supported by the current findings in this study.

The results presented in this chapter will be discussed in the following chapter.

## **CHAPTER SEVEN**

### **DISCUSSION**

This chapter will discuss the main findings of this study. It will then discuss the limitations related to the findings of the study before coming up with recommendations for future work and research in this area.

Living with disability in a rural impoverished area such as Madwaleni, South Africa, potentially has substantial implications for individuals, households and communities. These potential implications were investigated in this study and comparisons between persons with disabilities and persons with no disabilities were made. The implications were looked at fundamentally in terms of daily living and health issues. The need to understand rural poverty and disability is an important priority (as suggested by the previous South African Department of Women, Children and People with Disabilities [now incorporated into the Department of Social Development]) (Graham et al., 2014).

#### **Summary of the Findings**

Summary of the findings of this study show that persons with disabilities in Madwaleni generally experience more problems in terms of daily living as well as health issues (including access to health care) compared to persons with no disabilities.

When it comes to daily living, persons with disabilities had more problems with daily activities such as shopping, preparing food, and household chores. They had more difficulties with social issues including social relationships and social inclusion, experiencing more prejudice and discrimination. They also had more problems with education and employment

opportunities. In terms of barriers in daily life they had more problems with transportation, the natural environment, their surroundings, as well as access to information. Lastly, they had problems with their environment including attitudes from others, support from others, their terrain and lastly service provision.

In terms of health, persons with disabilities reported poorer physical and mental health, received health care less often, had less availability of health care, and perceived attitudes of health care workers were more negative. Access to health care was worse in terms of physical, attitudinal and communication barriers. Physical barriers included transport, transport costs, the actual journey to the health centre, not knowing where to go, accommodation at health centres, drugs and equipment provision and general standard of health care. Attitudinal barriers included perceptions of poorer attitudes by health care providers, perceptions of more denial of treatment by health care providers, and perceptions that they were treated worse by health care providers. Communication barriers included perceived poorer communication with health care providers, perceived poorer interaction with health care providers, perceived less respect from health care providers, perceived poorer explanations from health care providers, perceived less involvement in their own treatment, and perceived less privacy at consultations. Persons with disabilities also felt less happy with the ease that they were able to see their preferred health care provider, less satisfied with the perceived provision of health care and generally less satisfied with health care personnel. The methods in this study did not allow more in-depth exploration of particular providers' skills and attitudes, and is better dealt with through qualitative methods, which were used in a different substudy of the overall EquitAble project.

The conceptual framework of the ICF recognises that the environment has an impact on the ability of persons with disabilities to participate and contribute in the life of the community with meaning and to benefit from all services provided (WHO, 2001). This is particularly relevant for persons living in Madwaleni where there are many environmental challenges due to the topography of the area. Despite a wide range of policies, people with disabilities are considered to still fare worse than persons with no disabilities (Schneider et al., 1999). Daily living in a rural, remote and impoverished community has the potential for hardship and difficult times. Persons with disabilities may experience this more intensely due to their circumstances and the situation they find themselves in, as the data presented in this study attest.

### **Disability and Daily Living In Madwaleni**

Daily life for persons with disabilities in Madwaleni seems to be more difficult than persons with no disabilities. For instance, basic activities such as shopping, preparing food, household chores and taking care of personal objects were more commonly problems for persons with disabilities in Madwaleni. Human and financial resources are required from families and communities to support daily living for persons with disabilities (UN Enable, n.d.).

It needs to be acknowledged that in this study persons with disabilities are largely older in age. This may mean that much of their difficulties and discrimination may be based on age rather than on disability status as such. However, literature still supports the idea that their disability and not their age status is the reason why they are experiencing discrimination and disparities in health care. Smith (2008) found that the elderly population with disabilities experienced more problems when it came to accessing health care services compared to the elderly who did not have disabilities.

When it comes to social as well as community life, persons with disabilities in this study experienced more severe problems in interacting with others and participating in social activities. Findings by Mulumba et al. (2014, p. 76) showed that a “sense of community marginalisation is present” for persons with disabilities. According to Parnes et al. (2009, p. 1178), people with disabilities and their families the world over “face discrimination and are not yet fully able to enjoy their basic human rights”. Our study found that persons with disabilities reported more prejudice and discrimination. Persons with disabilities are overlooked and marginalised globally (Parnes et al., 2009; Saulo et al., 2012) and often experience exclusion from full participation in their communities (Krahn et al., 2015). A recent study by Neille and Penn (2015) found that persons with disabilities in a rural area in South Africa had barriers to service provision that extended beyond physical barriers, including sociocultural and sociopolitical barriers.

More negative attitudes towards persons with disabilities in Madwaleni were also reported in our study and that they also receive less support than persons with no disabilities. According to Lang, Kett, Groce, and Trani (2011, p. 207) people with disabilities constitute one of the “most marginalised and socially excluded groups in our society”. Largely excluded from mainstream economic and social life in their own communities, persons with disabilities are claimed to be the poorest and most isolated groups (Charlton, 2000). As Parnes et al. (2009) summarise, discrimination, stigmatisation and marginalisation are found in all areas of disability in the context of low-income countries. Yet the bulk of the literature on disability focuses almost entirely on the “failing body” and “personal troubles”, without looking at social barriers to inclusion. (Barnes, 2012). Disability should now be described in terms of

social discrimination and prejudice rather than primarily in terms of medical conditions (Roulstone et al., 2012).

Many have claimed that people with disabilities are still disproportionately represented amongst the unemployed and poor (Graham et al., 2014). We found that there were indeed higher rates of unemployment among persons with disabilities in Madwaleni compared to persons with no disabilities. This in turn has implications on their levels of poverty making them potentially poorer as well. While there were higher levels of unemployment with persons with disabilities, it was also found that these persons have more problems in getting and keeping employment. This is supported by a study by Gudlavalleti et al. (2014). Linked to employment opportunities are education opportunities and it was found that like employment, there were also discrepancies in education levels when comparing persons with disabilities and persons with no disabilities. Again we find that there were more problems in being educated for persons with disabilities. With lower levels of employment as well as education we also found that persons with disabilities have more financial management problems. These findings are partly explicable by the fact that the persons with disabilities were an older group than the rest of the population, but this may not be the full story. The World Report on Disability highlights the fact that many people with disability do not have equal education and employment access (WHO, 2011). This is all supported by Bremer, Cockburn, and Ruth (2009) as well as Stein, Stein, Weiss, and Lang (2009) who conclude that persons with disabilities are more likely to be poor and unemployed, have less education and live in rural areas.

Implementation and regulation of the transport industry in South Africa has not adequately addressed barriers of access for rural poor and persons with disabilities, despite the policies

attempting to be inclusive (South African Human Rights Commission, 2009). According to Gaede and Versteeg (2011), persons with disabilities have only a few public transport systems available to them – and even fewer in rural areas.

Generally, transport in Madwaleni is a big issue – the rugged terrain and vast distances of the region make transport a potential problem. Access to health services may be especially challenged when services must cover large geographical areas (Goodridge et al., 2015, p. 1401). There are only primarily three modes of transport in Madwaleni – private transport, public transport in the form of taxis and by foot. It was found in this study that persons with disabilities make more use of private transport compared to persons with no disabilities. This is most probably in part due to negative attitudes and stigma from others when taking public transport (Vergunst, Swartz, Mji, MacLachlan, & Mannan, 2015).

Information wanted or needed in the format one can use or understand was also significantly different between persons with no disabilities and persons with disabilities – persons with disabilities in Madwaleni experiencing more barriers on a daily, weekly and monthly basis. A study by Eide et al. (2011) found that many persons with disabilities lacked correct information and knowledge about HIV/AIDS prevention. Another study looking at families with children with disabilities found that many families were frustrated by “information obstacles” (Fisher & Shang, 2013, p. 2159). These realities are echoed in Madwaleni.

### **Disability and Health in Madwaleni**

Poverty in a community makes the right to health care a “distant dream” (Parnes et al., 2009, p. 1173). Also, according to Pharr (2014), people with disabilities experience unmet health care needs which result in health problems. According to the World Report on Disability,

doctors internationally who generally lack training about caring for persons with disabilities, frequently compromise patients' health care experiences and health outcomes (Iezzoni & Long-Bellil, 2012). As can be expected from research in other parts of the world (Gulley et al., 2011; Jeon et al., 2015; McColl, Jarzynowska, & Shortt, 2010), people with disabilities in Madwaleni were far more likely to report poor health than persons with no disabilities.

The health of persons with disabilities in developing countries has not received enough attention in the literature (Trani et al., 2011). Trani et al. (2011, p. 1483) found in their study that people with disabilities "were more likely to report poorer health status" than persons with no disabilities. Mulumba et al. (2014) found that participants viewed their disability as a barrier to good health. Shakespeare and Kleine (2013) highlighted financial and attitudinal barriers that prevent persons with disabilities from having their health needs met. This is despite some people with disabilities having increased health needs (Mannan & MacLachlan, 2013; Mji, MacLachlan, Melling-Williams, & Gcaza, 2009).

Living in poverty and having a disability can compound one's health status negatively. Disability is both a cause and consequence of poverty (Department for International Development, 2000). Disability and poverty are inherently linked (Parnes et al., 2009, p. 1172) and have a strong association with one another (Munsaka & Charnley, 2013, p. 756). The international literature has termed this the "vicious circle" of poverty and disability (Sagli, Zhang, Ingstad, & Fjeld, 2013). There is still widespread opinion that we lack data to support theories of the relationship, particularly from developing contexts (Graham et al., 2014). This is supported by Seddon and Lang (2001) who argue that the field is dominated by northern perspectives that fail to understand the context of wider developmental challenges. Added to this are the claims that the links between poverty and disability are often anecdotal

rather than evidence based (Groce, Kett, Lang, & Trani (2011). In particular, there is little understanding of how poverty and disability interact in the rural context, where access to services and employment is often more limited (Graham et al., 2014). According to Grut et al. (2012, p. 1), poor people with disabilities who live in poor rural societies “experience unique problems”. The right to health care in rural areas is further compromised by a number of health system and socio-economic barriers (Gaede & Versteeg, 2011). This “triple vulnerability” – poverty, disability and rurality – has undergone limited research. The current study provides a local case study of these issues.

### **Access to Health Care in Madwaleni in Light of International and Local Findings**

International findings on access to health care for people with disabilities have generally found that they experience a number of barriers to health care. This has been discussed in detail in Chapter 3 of this dissertation. As Ali et al. (2013) mention, inequity in accessing health care for people with disability is a global issue while Mannan and MacLachlan (2013) state that persons with disabilities are among those who have the greatest difficulties accessing health services. Mulumba et al. (2014) go on to say that political side lining, discrimination and inequitable access to health services is experienced by persons with disabilities and that this is why they have poor health.

Gudlavalleti et al. (2014), Trani et al. (2011) and Drainoni, Lee-Hood, Tobias, Bachman, Andrew, and Maisels (2006) state in their studies that people with disabilities faced significantly more or multiple barriers to accessing health care compared to persons without disability. In particular, Mulumba et al. (2014) found that persons with disabilities reported experiencing discrimination that impacted on their ability to access health services. In a study by Kim et al. (2014) it was found that persons with disabilities (in this case spinal cord

injury) had significantly more difficulties receiving medical services due to lack of accessibility compared to persons with no disabilities. McDoom et al. (2014, p. 154) state categorically that “people with disabilities are more likely than those without disabilities to experience barriers when accessing health care, often leading to unmet needs”. Van Rooy et al. (2012) summarise in saying that people living with disabilities face unique problems in dealing with conventional health care facilities.

The World Disability Report acknowledges that people with disability need to be able to access health care more than people without disability but that they have less access to health care services and therefore experience health care needs that are unmet (WHO, 2011). As Krahn et al. (2015) state, there is work that must be done to improve access to health care for people with disabilities.

Barriers to access to health care for people with disabilities in South African has also been found in a number of studies as discussed before in Chapter 3 of this dissertation. Access barriers to health care for persons with disabilities were also found in Madwaleni. These primarily included three types of barriers – physical barriers, attitudinal barriers and communication barriers.

Some of the physical barriers that were highlighted in our study were to do with transport issues. The issue of transportation with regard to health care services has received increased attention (Paez, Mercado, Farber, Morency, & Roorda, 2010). When it comes to transport to health centres we find similar results to the general transport issues. Again lack of transport was more of a problem for persons with disabilities with cost to health centres being highlighted as an issue. This is supported by Syed, Gerber, and Sharp (2013) who state that

transportation barriers are often cited as barriers to health care access. According to them studies have found that rural patients face greater transportation barriers to health care access than urban patients. However, the significance of these barriers is uncertain based on existing literature due to variation in both study populations and transportation barrier measures. Transportation barriers to health care access are common, and greater for vulnerable populations such as persons with disabilities. Generally, the more remote the area in question, “the greater the problems of access to medical care due to geographic distances, transportation problems, lack of insurance and inadequate supply of local providers” (Lishner et al., 1996, p. 48).

Transportation costs and travel distance emerged as key access barriers, especially for rural residents in South Africa (Harris et al., 2011). They found that access barriers relate to the geographic inaccessibility of health facilities, particularly in largely rural and poorly resourced provinces. Madwaleni, in the Eastern Province, is the third largest rural population in South Africa (Kok & Collinson, 2006) with a 62% rural population. A number of studies have found that greater access barriers are experienced by rural communities compared to urban communities and these barriers included distance, time and costs of accessing health services (Gaede & Versteeg, 2011, p. 101). Our study found that transport costs were a key factor for persons with disabilities. This was supported by a study by Gudlavalleti et al. (2014).

Attitudinal barriers were also highlighted in our study. According to MacLachlan & Mannan (2014), access is often difficult for people with disabilities even in wealthy countries, but in poorer countries the challenges are even greater which include attitudinal barriers. Attitudes

of health care workers towards persons with disabilities was identified as a barrier in a study in South Africa (Maart et al., 2007). This was found in Madwaleni.

In terms of communication barriers, persons with disabilities in Madwaleni had more communication barriers with health care workers than persons with no disabilities. Due to the fact that our sample included a mixture of impairments, we were not able to identify the types of impairments presented by those who had more difficulty in communication with health care workers and what the reasons for these difficulties were. A study by Kritzinger et al. (2014) found communication barriers to be a prominent barrier in accessing health care for deaf participants in Worcester, South Africa. Peters and Cotton (2015, p. 569) highlighted that women with physical disabilities in Australia screening for breast cancer were “distressed by attitudes and communication with health care professionals” and felt that they were treated in ways that did not recognise their human rights to dignity, respect and self-determination.

Our study showed that a significant number of persons with disabilities reported that they did not receive health care when they needed it and that this was statistically significant compared to persons with no disabilities. Thus, this study showed that people with disabilities had higher rates of unmet health care needs than persons with no disabilities. This is supported by the WHO (2011) who state that this occurs in both developed and developing countries. This particular finding was supported by Gudlavalleti et al. (2014) who found the same results in their study. A recent study by Casey (2015) confirms this with a longitudinal analysis on disability and unmet health care needs in Canada.

Not knowing where to go for treatment was also a potential issue (Gudlavalleti et al., 2014). This was also found in our study where persons with disabilities found it more difficult to know where to access health care.

Increased understanding of the day-to-day challenges of persons with disabilities and their needs can educate those involved in health planning and care especially “on how to incorporate various equities in order to create conditions that would enable the individuals with disabilities to achieve optimum health care” (Mahtab, 2013, p. 258).

This dissertation has highlighted that being a person with disability living in Madwaleni is not only about the “medical” issues but more importantly about social and inclusion issues. As Swartz and Watermeyer (2006) state, the story of disability in South Africa, as well as in other countries, is about social oppression. It is with this in mind that we need to shift and open our minds and ideas about disability (particularly with rural impoverished areas in South Africa), and that is a more complex situation. There is still much to do before persons with disabilities in general, and those living in rural impoverished areas in particular, can be included in all parts of society including access to health care.

### **Households and Disability**

Our study also looked briefly at the relationships between households and disability. Our study found no significant differences in access to health care for households with a person with a disability and households with no disability. This implies that a household with a person with a disability is not at an advantage or disadvantage in accessing health care compared to a household with no disability, in this context. Given the literature on household level effects of disability this finding is somewhat surprising and we need further research on

this issue. It may be the case that in a context in which all households are very impoverished, such as Madwaleni, the extra difficulties which may be associated with disability are not substantial in terms of effects on the household functioning.

### **Limitations of the Study**

This study has limitations. First, this has been a quantitative survey and hence the complexities and nuances of disability in terms of access to health care and day-to-day living have not been tapped in depth. Although we now have some ideas in terms of numbers and comparisons, this study does not reflect the intricacies and dynamics of access to health care and disability. This is particularly in Madwaleni where geographical access in terms of topography and terrain are a reality. This was unfortunately not adequately explored in the survey. Geographical access to health care facilities is known to influence health services usage (Paez et al., 2010). Geographical challenges such as remoteness, mountains, gullies, rivers, and unpaved roads present physical barriers to accessing health care (Van Rooy et al., 2012). These challenges are a reality in the Madwaleni area but were not assessed in the survey.

Second, the population of people with disabilities is quite heterogeneous (Iezzoni, 2011; Mulumba et al., 2014) and a diverse group (Krahn et al., 2015). They experience different degrees of vulnerabilities and this has not been adequately addressed in this study. For example, persons with physical impairments will potentially have differing access to health issues compared to persons with hearing impairments. This study has primarily placed all types of impairments under one disability umbrella and has hence made some generalisations. This point is supported by Rowland, Peterson-Besse, Dobbertin, Walsh, and Horner-Johnson (2014). In our study we did not have enough participants in each impairment category to

make generalisations about specific impairments and issues of access to health care. For example, within our sample, only 10.3% had seeing difficulties, 10.3% had hearing difficulties, 13.8% had physical difficulties, etc.

Third, we did not address some pertinent issues related to disability. For instance, we did not get data about the origin or duration of the disability and how these may be related to the focus of the study (Miller, Kirk, Kaiser, & Glos, 2014). As Horner-Johnson et al. (2014) put it, more research is needed to assess interventions to address health care barriers for particular disability groups.

Fourth, this study used self-reported measures. This in itself has potential limitations. These measures may be unreliable or biased. The participants, if they perceived the responses to be socially desirable, may have incorrectly reported the information (Adams, Soumerai, Lomas, & Ross-Degnan, 1999). The face-to-face interviews may have influenced the outcomes and as Saulo et al. (2012) point out, personal interaction affects the conversation. There were no independent confirmations by anybody of what the participants were reporting. This study only included community members and not health care staff or other informants, though such interviews were included in the broader study.

Related to the issue of self-reported measures is the point that participants had to score themselves to determine if they had any difficulties or not. This was thus a subjective rating. Brouwer et al. (2005) state that self-reported difficulties were higher than those derived from clinical examination or the use of a standard measure of functional capacity. This may have therefore been the case in this study. However, the opposite may also be possible – some

respondents who experience functional limitations may not self-identify as being a person with a disability. This was found in study by Casey (2015).

Still to do with self-identity is the point that the Washington Group questions measure difficulties and not self-ascription or identity, i.e., the social aspects of disability. For example, a person who is disfigured in some way may still experience disabilism but not have been able to convey these issues in the WG questions which look at difficulties and not self description. This is a limitation of this current study but the broader Equitable Project mentioned earlier looked into these issues with the qualitative studies in the project.

Fifth, the study did not distinguish between lifelong versus acquired disability. We were not able to ascertain this in our questionnaires. The dynamics for these two types of disabilities could well mean differing social repercussions. For example, a person who is born with cerebral palsy may experience stigmatisation and discrimination that is different to a person who acquires a disability late in life due to an unfortunate accident, and who may receive considerable social support. Their social experiences as well as their access to health care may be very different.

Sixth, the comprehension of the survey by the respondents is also a concern. The survey instruments were initially in English and were translated into isiXhosa for this study. Problems may have arisen in the translation process in that certain terms may not have been culturally appropriate for the setting of the study. This point of comprehension of surveys “is inherent” in the survey process (Harrington et al., 2009, p. 861). If persons did not understand questions they may have not responded accurately.

Seventh, the fact that our study was cross-sectional in nature does not allow determinations of cause and effect – in other words, whether disability preceded problems with access to or receipt of health care (Horner-Johnson et al., 2014).

Lastly, this study focused on one rural area within South Africa. This specific context makes it potentially problematical to generalise the findings. However, understanding the context in which people with disabilities face barriers to access health care is fundamental in that societies create their own health care systems and how they are “shaped, in their structure, process and expected outcomes, entirely depends on what each society defines as relevant, meaningful, approachable and sustainable” (Cabieses & Bird, 2014, p. 856). You can only develop relevant and contextually appropriate interventions if you take into consideration the local conditions and make optimal use of local resources (Braathen et al., 2013). As Neille and Penn (2015) concur, understanding both the context and culture is fundamental to the development of appropriate interventions that address the needs of people living with disabilities in rural communities.

### **Recommendations and the Way Forward**

The relationship between disability and poverty must be emphasised and incorporated with health policy and strategies (Grut et al., 2012). Persons with disabilities in Madwaleni experience prejudice and discrimination when it comes to daily living in general and access to health care in particular. They also seem to have more health issues – both physically and psychologically. While there is evidence in South Africa that suggests that policies are good, implementation may be failing people with disabilities on these issues (Graham et al., 2014; Maart et al., 2007). Maart et al. (2007) go on to say that disability in South Africa is framed within a medical and welfare framework which results in the exclusion of people with

disabilities and their exposure to barriers. According to them, government strategies should be focussed on universal access for people with disabilities and placing disability within a human rights framework.

In terms of access to health care for persons with disabilities in Madwaleni we need to find recommendations and solutions to their access issues. As Casey (2015, p. 179) states, accessing health care is a “multi-level process”. Interventions beyond health care access are required to meet the health care needs of rural residents with disabilities (Iezzoni et al., 2006). It was absolutely clear from our findings that the experiences related to health care were linked to other experiences of exclusion. Undoing the standard practice requires a comprehensive approach to universal health coverage which considers the “breadth”, “depth” and “height” of access, rather than financing reform alone (WHO, 2010). According to Harris et al. (2011), a financing centred approach to National Health Insurance in South Africa may reduce some of the affordability barriers, but will not deal with all other access barriers such as geography, attitudes, transport barriers, etc.

With negative attitudes and lack of knowledge on the part of health care providers, there is a need to ensure better training and education about disability (Shakespeare & Kleine, 2013). This is a legal obligation for countries that have ratified the Convention on the Rights of Persons with Disabilities (UN, 2006 cited in Shakespeare & Kleine, 2013). Article 25 (d) states that the States Parties shall:

require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity,

autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

(UN, 2006 cited in Shakespeare & Kleine, 2013)

According to Kirschner and Curry (2009, p. 1334), the following competencies could be proposed:

1. Framing disability within the context of human diversity across the lifespan and within social and cultural environments.
2. Skills training for assessment of disability and functional consequences of health conditions, considering implications for treatment and management.
3. Training in general principles concerning etiquette for interactions with persons with disabilities.
4. Learning about roles of other health care professionals forming integrated teams to care for persons with disabilities.
5. Understanding the legal framework of national anti-discrimination legislation, the Convention on the Rights of Persons with Disabilities, relevant ethical standards, and the principles of reasonable accommodation and universal design.
6. Competency in patient-centred care approaches, including patients perception of quality of life.

How do we address these barriers? According to Morrison et al. (2008, p. 645) it was recommended to reduce barriers through the education about disabilities to professionals, to improve provider-patient communication, enhance physical access (e.g., high-low examination tables, wide automatic doors and wheelchair scales) and increase appointment times. This sentiment of educating the health professionals is supported by Tracy and

McDonald (2015). Tracy and McDonald (2015, p. 29) go on to say that this education has to be delivered by persons with disabilities themselves so that the education is more appropriate, relevant and influential.

Participants in a study by Kroll et al (2006, p. 289) suggested a range of strategies to address these barriers, including:

1. disability-specific continuing education for providers;
2. the development of accessible prevention-focused information portals for people with physical disabilities; and
3. consumer self-education, and assertiveness in requesting recommended services.

However according to Tomlinson et al. (2009, p. 1857) there is insufficient information available about effective interventions that work to improve the lives of people with disabilities. These findings call for “urgent attention to the issue of access to appropriate health care for people with disabilities especially in low income and middle income countries”.

As Yee and Breslin (2010) state, the removal of barriers would only be “a critical first step” toward achieving the broad public policy change needed for sustainable and equal health care for people with disabilities. Long term benefit according to them

will not accrue from these changes until every part of the health care system acknowledges that it does a poor job of maintaining health and wellness for those who do not fit into a physical or mental “norm” and accepts ongoing responsibility for altering the status quo. (Yee & Breslin, 2010, p. 256)

Peters and Cotton (2015, p. 570) mention that education and training of health care professionals in relation to knowledge, attitudes, behaviours and communication is required. This education needs to “encompass a new paradigm that includes sharing of power and expertise between user and provider, rather than perpetuate the top down, clinical, powerful expert-dependent, powerless user perspective”.

It is however broader than this. Poverty alleviation and sustainable economic development can be seen as “critical elements in the prevention of impairment” (Parnes et al., 2009, p. 1172). It is not only about micro management of the barriers such as transport, attitudes and communication, but also the macro elements such as poverty and the economy.

Poverty, disability and health are all related and are impacted by forms of discrimination or stigma (Parnes et al., 2009). Hence one approach to improving the lives of persons with disabilities is to change negative attitudes and eradicate all forms of discriminations and stigma associated with disability and poverty.

There is currently little quantitative data looking at disability and aspects of being included in society (Danquah et al., 2015). The data from this study will help make well-informed decisions on planning to encourage inclusion of people with disabilities in domains such as health and livelihoods (Danquah et al., 2015). Large scale cross sectional studies on health care access would provide more data on the prevalence of discrimination and other barriers preventing health care access, and could be used to plan local health services (Ali et al., 2013). It is hoped therefore that this current study will be a catalyst for further work in this

area so that meaningful positive changes can take place for persons with disabilities in terms of access to health care in particular and daily living in general.

### **Practical Interventions that have Already Taken Place**

A start in terms of interventions around this dissertation has already happened on a local, national as well as international level. Locally, feedback sessions about issues of disability and access to health care have already been presented in Madwaleni as part of the larger international study. These feedback sessions were given to community members, health care providers and key informants (e.g., Traditional Chiefs) in the area. Nationally, I have been involved in the Rural Doctors Association of South Africa (RUDASA) and Rural Rehabilitation of South Africa (RURESA) networks which focus on rural health and rehabilitation issues in South Africa. They have annual conferences which I have attended regularly and where I have presented some preliminary findings looking at disability and access to health care in Madwaleni – the only presentation to date at these conferences looking at rural access issues and disability. Internationally, there have been a number of reports and publications in international journals stemming from this larger study looking at disability and access to health care. These activities have, if anything, raised awareness and stimulated a consciousness about disability issues in the Madwaleni, South Africa and the world. These interventions can be used as catalysts for further work in this area.

### **Proposed Future Interventions**

On a local level, it is proposed to go back to Madwaleni and present the specific findings of this research study to key stakeholders so that future interventions can be discussed and implemented in the area. It is envisaged that part of this process will involve focus group discussions. It is imperative that at least one of these focus groups include chiefs and leaders

of the community as without their support little can be achieved at the community level. This methodology will help create a path forward where the most effective implement strategies can be addressed.

One strategy to be considered is to run a Randomised Control Trial (RCT) in Madwaleni where an intervention strategy can be implemented and compared to a controlled situation. Intervention strategies can, for example, include implementing mobile health centres that can tackle the transport issues that persons with disabilities face, and training health care providers in more effective disability management practices to help manage the attitudinal and communication barriers that persons with disabilities potentially face. Interventions must be planned realistically and with the collaboration of the local Department of Health.

Disability Awareness Workshops in Madwaleni could also be seen as a possible intervention strategy in the future. These will help bring awareness and educate the relevant stakeholders including the community, health care providers and key informants. As stated earlier, this first has to be negotiated and supported by the relevant chiefs in the community for it to get buy-in from the stakeholders. The workshops can be held at any one of the eight health care centres or hospital where community members congregate and have time while waiting for their appointments. Workshops can also then involve health care providers. Workshops can also be held at pension or disability grant pay out venues that occur on a month-to-month basis. Waiting times there provide a wonderful opportunity to bring about awareness and education concerning disability issues in the community.

On a national and international level, it is also proposed that comparisons between data from this study and other sites in the international study be made so that a more comprehensive and

detailed understanding of disability and access to health care in different contexts can be made. It is hoped that further publications will result from this activity.

Although policies at times fail the most vulnerable (including persons with disabilities) in society in South Africa, it must be acknowledged that the responsibility to redress these issues cannot be placed on one body but rather on relationship between government institutions, health care providers, communities and individuals (Neille & Penn, 2015). Neille and Penn (2015) go on to say that the South African government needs to review the ways in which policies and models of care are applied and that context and the needs of individuals need to be considered – a one-size-fits-all policy for persons with disabilities is unlikely to be adequate.

It is proposed that the amount and coordination of disability research needs to be increased and should routinely include people with disabilities in general health research to help close the knowledge gap on effective interventions (Krahn et al., 2015).

As Mji et al. (2009) mention, there is a danger that the research community may simply accumulate evidence without developing practical solutions to address the ways in which society can become more responsive to, and more inclusive of, persons with disability. The challenge according to them is that research must be translated into policy and practice. The findings of this current study will hopefully be translated into practical intervention strategies that will ultimately benefit persons with disability in terms of access to health care in particular and daily living in general.

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## **APPENDICES**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

12 January 2011

**MAILED**

Prof L Swartz  
Dep Of Psychology  
Stellenbosch University  
Main Campus  
Stellenbosch

Dear Prof Swartz

"Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa (EquitAble)."

**ETHICS REFERENCE NO: N10/10/349**

**RE : APPROVAL**

At a meeting of the Health Research Ethics Committee that was held on 17 December 2010, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 11 January 2011 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit. Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Hélène Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

26 January 2011 08:25

Page 1 of 2



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



Verbind tot Optimale Gesondheid · Committed to Optimal Health  
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support  
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa  
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

## APPENDIX A: Ethical Approval



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

12 January 2011

**MAILED**

Prof L Swartz  
Dep Of Psychology  
Stellenbosch University  
Main Campus  
Stellenbosch

Dear Prof Swartz

"Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa (EquitAble)."

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Please quote the above-mentioned project number in ALL future correspondence.

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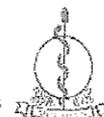
Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Hélène Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

26 January 2011 08:25

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UNIVERSITEIT-SELLENBOSCH-UNIVERSITY  
jou kennisvenoot • your knowledge partner

Approval Date: 11 January 2011

□□ Expiry Date: 11 January 2012

Yours faithfully

**MS CARLI SAGER**

**RESEARCH DEVELOPMENT AND SUPPORT**

Tel: +27 21 938 9140 / E-mail: [carlis@sun.ac.za](mailto:carlis@sun.ac.za)

Fax: +27 21 931 3352

26 January 2011 08:25

Page 2 of 2



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Tel.: +27 21 938 9075 • Faks/Fax: +27 21 931 3352

From:

To: 0218083584

10/05/2010 08:50

#771 P.001/001



**Eastern Cape Department of Health**

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 10<sup>th</sup> May 2010

Fax No: 043 642 1409

e-mail address: [zonwabele.merile@impilo.ecprov.gov.za](mailto:zonwabele.merile@impilo.ecprov.gov.za)

---

Dear Prof Leslie Swartz

**Re: Enabling universal and equitable access to health care for vulnerable people in resource poor setting in South Africa**

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

**DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT**



*Ikama eliqambileyo!*

## **APPENDIX B**

### **Informed Consent Adults**

#### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** Access to Health Care for Persons with Disabilities in rural Madwaleni, Eastern Cape, South Africa

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Prof L Swartz

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 082 459 3559

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way

whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

This study is the second phase of a larger project which is looking at **issues of access to health care**. The research is taking place in four African countries: Malawi, Namibia, South Africa and Sudan. In the first phase of the study we interviewed users and non-users of health services in your area, and we also talked to people who work in **health facilities**. We observed various aspects of how the facilities operate such as patient flow and waiting times. For this second phase of the study we will be conducting a survey questionnaire among users and non-users of health services in your area.

### **Why have you been invited to participate?**

You have been invited to participate in this study because you live in the catchment area of one of the chosen health facilities for this survey.

### **What will your responsibilities be?**

You will be asked some questions on a one to one basis, in a single session of an hour. In circumstances where your home language differs from that of the interviewer an interpreter will be used; we ask that you answer these questions as honestly as you can. The interviewer

will use a survey questionnaire. As a participant you can halt the interview at any point for further clarification and you also have the right not to respond to a particular question.

**Will you benefit from taking part in this research?**

There will be no direct benefit to you from taking part in the research however the researchers will make sure that workshops are organised to provide feedback of the research findings. During these feedback workshops any new information coming from the study will be disseminated. We hope that in the longer term the research will help us create better access to health care for all people.

**Are there any risks involved in your taking part in this research?**

There are no risks to you for taking part in the research. Everything you say to us will be kept confidential. Your responses will be recorded in writing but no names will be used in capturing of the data thereby ensuring confidentiality. Support will be provided/ available when needed during or after the interviews. This research project is based at Stellenbosch University and is sponsored by the European Union. Both the University and the European Union have external and internal auditors that will be inspecting the financial information pertaining to the project.

**If you do not agree to take part, what alternatives do you have?**

You are under no obligation to take part in the study. This will not affect your treatment at the health facility.

**Who will have access to your medical records?**

We will not access your medical records for this study.

**Who will have access to the information we collect about you?**

All information we obtain will be kept confidential and will be dealt with in a professional manner. No participant names will be on record during data capturing and the information will be stored in a safe location. The research team, all of whom are bound by scientific ethics requirements, will have access to the information. If auditors or the funders of the project need to inspect our records, this will be under conditions of strict confidentiality and all names and identifying data will be deleted. In the event that auditors need to check with participants about whether they have been interviewed for the study, this information will be provided separately from any data collected from you, so it will not be possible for them to link any information back to you personally.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study, but out-of-pocket expenses will be covered for each study visit if relevant.

**Is there any thing else that you should know or do?**

- You can contact Prof Leslie Swartz, at telephone: 082 459 3559 if you have any further queries or encounter any problems.
- You can contact the University of Stellenbosch Health Research Ethics Committee at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

## Declaration by participant

By signing below, I ..... agree to take part in a research study entitled  
Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2010.

.....

Signature of participant

.....

Signature of witness

## Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2010.

.....

Signature of investigator

.....

Signature of witness

### **Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.

- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....

Signature of interpreter

.....

Signature of witness

## APPENDIX C

### Informed consent children (parents/ guardians)

#### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR USE BY PARENTS/LEGAL GUARDIANS

**TITLE OF THE RESEARCH PROJECT:** Access to Health Care for Persons with Disabilities in rural Madwaleni, Eastern Cape, South Africa

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Prof L Swartz

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 082 459 3559

Your child (*or ward, if applicable*) is being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how your child could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you or your child negatively in any way whatsoever. You are also free to

withdraw him/her from the study at any point, even if you do initially agree to let him/her take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

This study is the second phase of a larger project which is looking at issues of access to health care. The research is taking place in four African countries: Malawi, Namibia, South Africa and Sudan.

In the first phase of the study we interviewed users and non-users of health services in your area, and we also talked to people who work in health facilities. We observed various aspects of how the facilities operate such as patient flow and waiting times.

For this second phase of the study we will be conducting a survey questionnaire among users and non-users of health services in your area.

### **Why has your child been invited to participate?**

Your child has been invited to participate in this study because s/he lives in the catchment area of one of the chosen health facilities for this survey.

### **What will your responsibilities be?**

You will be asked some questions about your child on a one to one basis, in a single session of an hour. In circumstances where your home language differs from that of the interviewer an interpreter will be used; we ask that you answer these questions as honestly as you can. The interviewer will use a survey questionnaire. As a participant you can halt the interview at any point for further clarification and you also have the right not to respond to a particular question.

**Will your child benefit from taking part in this research?**

There will be no direct benefit to your child from taking part in the research however the researchers will make sure that workshops are organised to provide feedback of the research findings. During these feedback workshops any new information coming from the study will be disseminated. We hope that in the longer term the research will help us create better access to health care for all people.

**Are there any risks involved in your child taking part in this research?**

There are no risks to your child for taking part in the research. Everything you say to us will be kept confidential. Your responses will be recorded in writing but no names will be used in capturing of the data thereby ensuring confidentiality. Support will be provided/available when needed during or after the interviews.

This research project is based at Stellenbosch University and is sponsored by the European Union. Both the University and the European Union have external and internal auditors that will be inspecting the financial information pertaining to the project.

**If you do not agree to allow your child to take part, what alternatives does your child have?**

You/ your child is under no obligation to take part in the study. This will not affect your/ your child's treatment at the health facility

**Who will have access to your child's medical records?**

We will not access your child's medical records for this study

**Will you or your child be paid to take part in this study and are there any costs involved?**

You or your child will not be paid to take part in the study, but out-of-pocket expenses will be covered for each study visit if relevant. There will be no costs involved for you if your child does take part.

**Is there any thing else that you should know or do?**

- You can contact Prof Leslie Swartz, at telephone: 082 459 3559 if you have any further queries or encounter any problems.
- You can contact the **University of Stellenbosch Health Research Ethics Committee** at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

### Declaration by parent/legal guardian

By signing below, I (*name of parent/legal guardian*) .....  
agree to allow my child (name of child) ..... who is .....  
years old, to take part in a research study entitled (*insert title of study*)

### I declare that:

- I have read or had read to me this information and consent form and that it is written in a language with which I am fluent and comfortable.
- If my child is older than 7 years, he/she must agree to take part in the study and his/her ASSENT must be recorded on this form.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to let my child take part.
- I may choose to withdraw my child from the study at any time and my child will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished if the study doctor or researcher feels it is in my child's best interests, or if my child do not follow the study plan as agreed to.

Signed at (*place*) ..... on (*date*) .....

.....

Signature of parent/legal guardian      Signature of witness

### **Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understand all aspects of the research, as discussed above
- I did/did not use a interpreter (*if an interpreter is used, then the interpreter must sign the declaration below*).

Signed at (*place*) ..... on (*date*) ..... 2005.

.....

Signature of investigator

Signature of witness

**Declaration by interpreter (Only complete if applicable)**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of parent/legal guardian*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the parent/legal guardian fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....

Signature of interpreter

.....

Signature of witness

## APPENDIX D

### Assent form for children 15-17

#### PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM



**TITLE OF THE RESEARCH PROJECT:** Access to Health Care for Persons with Disabilities in rural Madwaleni, Eastern Cape, South Africa

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Prof L Swartz

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 082 459 3559

#### **What is RESEARCH?**

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping, or treating children who are sick.

### **What is this research project all about?**

This study is part of a larger project which is looking at **access to health care**. The research is taking place in four African countries: Malawi, Namibia, South Africa and Sudan. We have already interviewed people who use and people who don't use health services in your area, and we also talked to people who work in health facilities (clinics/ hospitals). We have seen how things work in the health services. Now we would like to conduct a survey questionnaire among users and non-users of health services in your area.

### **Why have I been invited to take part in this research project?**

You have been invited to participate in this study because you live in one of the project's study areas.

### **Who is doing the research?**

The research is done by Stellenbosch University.

### **What will happen to me in this study?**

You will be asked some questions on a one to one basis, in a single session of an hour. If your language differs from that of the interviewer an interpreter will be used, with your permission. We ask that you answer these questions as honestly as you can. The interviewer will use a survey questionnaire. As a participant you can stop the interview at any point if you have any questions, and you can refuse to answer any questions in the questionnaire.

### **Can anything bad happen to me?**

There are no risks to you for taking part in the research. Everything you say to us will be kept confidential. Your responses will be recorded in writing but your name will not be recorded.

This research project is based at Stellenbosch University and is sponsored by the European Union. Both the University and the European Union have systems in place to make sure that the project is done ethically.

**Can anything good happen to me?**

There will be no direct benefit to you from taking part in the research however the researchers will make sure that workshops are organised to provide feedback of the research findings. During these feedback workshops any new information coming from the study will be disseminated. We hope that in the longer term the research will help us create better access to health care for all people.

**Will anyone know I am in the study?**

Everything you say to us will be kept confidential. Your responses will be recorded in writing but your name will not be recorded.

**Who can I talk to about the study?**

You can contact Prof Leslie Swartz, at telephone: 082 459 3559 if you have any further queries or encounter any problems.

You can contact the University of Stellenbosch Health Research Ethics Committee at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

**What if I do not want to do this?**

You do not have to participate in this study if you do not want to. Even if your parents have agreed to your participation, you can still refuse. This will not affect your treatment in the

health facility in any way. Even if you agree to participate, you can stop being in the study at any time without getting in trouble.

**Do you understand this research study and are you willing to take part in it?**

 YES NO

**Has the researcher answered all your questions?**

 YES NO

**Do you understand that you can pull out of the study at any time?**

 YES NO

\_\_\_\_\_

## APPENDIX E: HOUSEHOLD SURVEY

HOUSEHOLD  
CONFIDENTIAL

EquitAble WP4 –Version 10

IDENTIFICATION OF HOUSEHOLD	CODE
NAME AND CODE OF REGION* _____	<input type="text"/> <input type="text"/>
NAME AND CODE OF CONSTITUENCY* _____	<input type="text"/> <input type="text"/>
NAME AND CODE OF LOCALITY* _____	<input type="text"/> <input type="text"/>
ENUMERATION AREA NUMBER .....	<input type="text"/>
LOCATION 1 = urban 2 = rural .....	<input type="text"/> <input type="text"/>
HOUSEHOLD NUMBER/ID .....	
NAME OF HOUSEHOLD HEAD _____	
TOTAL NUMBER OF PERSONS IN HOUSEHOLD (the same as last Line Number filled in Section A)	<input type="text"/> <input type="text"/>
TOTAL NUMBER OF ELIGIBLE PERSONS FOR INDIVIDUAL INTERVIEW	<input type="text"/> <input type="text"/>
LINE NO. OF PRIMARY RESPONDENT	<input type="text"/> <input type="text"/>

TO BE COMPLETED BY THE INTERVIEWER	DATE OF INTERVIEW
Time interview starts <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Time completed <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Day <input type="text"/> <input type="text"/>
Name of interviewer: _____	Month <input type="text"/> <input type="text"/>
Comments:	Year <input type="text"/>
Signature _____	

SUPERVISOR	INTERVIEW STATUS	Enumerator has to return to the household	CHECKED by the Supervisor
Name : _____	Comple <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Signature _____	te <input type="checkbox"/>	No <input type="checkbox"/>	

### GPS INFORMATION

Accuracy	<input type="text"/> <input type="text"/>	feet						
Latitude	<input type="text"/>	N/S	Degrees	<input type="text"/> <input type="text"/>	<sup>0</sup>	Minutes	<input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> <input type="text"/>	'
Longitude	<input type="text"/>	E/W	Degrees	<input type="text"/> <input type="text"/>	<sup>0</sup>	Minutes	<input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> <input type="text"/>	'

**\*Codes for REGION, CONSTITUENCY AND LOCALITY see separate sheet**

**SECTION A: HOUSEHOLD COMPOSITION: FOR ALL PERSONS**

LINE NO.	WHO ARE PERMANENT MEMBERS OF THIS HOUSEHOLD?	RELATIONSHIP TO HEAD OF HOUSEHOLD	SEX	AGE	MARITAL STATUS	ILLNESS/INJURY
	List the first names and first letter of the surname of all persons in this household, starting with the head of the household	What is the relationship of (NAME) to the head of the household? *	Is (NAME) male or female?  1=Male 2=Female	How old was (NAME) at his/her last birthday?  Enter age in completed years 98=Don't know	What is (NAME'S) marital status? **  Only 12 yrs and above	Has (NAME) been seriously ill or injured during the past 6 months?  If YES, what was the main illness or injury? ***  Enter "00" if NO
(1)	(2)	(3)	(4)	(5)	(6)	(7)
			M F	IN YEARS		
01		<input type="text" value="0"/> <input type="text" value="1"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
02		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
03		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
04		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
05		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
06		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
07		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
08		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
09		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>
10		<input type="text"/> <input type="text"/>	1 2	<input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/> <input type="text"/>

*CODES FOR Q.3 RELATIONSHIP TO HOUSEHOLD HEAD	**CODES FOR Q.6 MARITAL STATUS	***CODES FOR Q.7 MAIN ILLNESS or injury
01 = Head 02 = Spouse/living in partner 03 = Son/Daughter (also step-) 04 = Son/Daughter-in-law 05 = Grandchild of head/spouse 06 = Parent/Parent-in-law 07 = Brother/Sister of head/spouse 08 = Co-wife 09 = Other relatives 10 = Domestic worker/	1 = Never married (and not cohabiting) 2 = Currently married 3 = Consensual union/Cohabiting 4 = Divorced/separated 5 = Widowed 8 = Don't know/refuse	01 = Cancer 02 = Malaria 03 = TB 04 = Bronchitis 05 = Cholera 06 = Severe diarrhoea 07 = Measles 08 = Pneumonia 09 = Heart disease 10 = High blood 13 = Malnutrition 14 = Mental illness 15 = High fever/meningitis 16 = Epilepsy 17 = Physical injury 18 = Asthma 19 = Other disease or injury (specify :) 98 = Don't know

11 = Other non-relatives 98 = Don't know	pressure 11 = Diabetes 12 = HIV/AIDS
---	--

**SECTION A: HOUSEHOLD COMPOSITION: FOR ALL PERSONS – cont. for household member 11 -20**

LINE NO.	WHO ARE PERMANENT MEMBERS OF THIS HOUSEHOLD?	RELATIONSHIP TO HEAD OF HOUSEHOLD	SEX		AGE	MARITAL STATUS	ILLNESS/ INJURY
	List the first names and first letter of the surname of all persons in this household, starting with the head of the household.	What is the relationship of (NAME) to the head of the household? *	Is (NAME) male or female?  1=Male 2=Female		How old was (NAME) at his/her last birthday?  Enter age in completed years 98=Don't know	What is (NAME'S) marital status? **  Only 12 yrs and above	Has (NAME) been seriously ill or injured during the past 6 months?  If YES, what was the main illness or injury? ***  Enter "00" if NO
(1)	(2)	(3)	(4)	(5)	(6)	(7)	
			M	F	IN YEARS		
11		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
12		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
13		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
14		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
15		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
16		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
17		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
18		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
19		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>
20		<input type="text"/>	1	2	<input type="text"/>	<input type="text"/>	<input type="text"/>

IF THERE ARE MORE THAN 20 PERSONS IN THE HOUSEHOLD, PLEASE USE A CONTINUATION SHEET AND TICK THE FOLLOWING BOX

**SECTION B: DISABILITY SCREENING: FOR ALL PERSONS**

LINE NO.	Because of a HEALTH PROBLEM...									Mark X person w. an activity	Is (NAME) 5 yrs old or above?	
	Does (NAME) have difficulty seeing, even if wearing glasses?	Does (NAME) have difficulty hearing, even if using a hearing aid?	Does (NAME) have difficulty walking or climbing steps?	Does (NAME) have any difficulty remembering or concentrating?	Does (NAME) have difficulty with self-care such as washing all over or dressing?	Using the usual language, does (NAME) have difficulty communicating for example understanding or being understood?	Does (NAME) have a problem with nerves, sadness of depression?	Does (NAME) have problem performing tasks that are expected of people of their age?				YES → Q.15
	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE			
	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16A)	(16B)		
										YES	NO	
01	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
02	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
03	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
04	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
05	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
06	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
07	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
08	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
09	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			

10											1	2
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**SECTION B: DISABILITY SCREENING: FOR ALL PERSONS – cont. for household member 11 -20**

LINE NO.	Because of a HEALTH PROBLEM...									Mark <b>X</b> person w. an activity	Is (NAME) <b>5 yrs old</b> or above?	
	Does (NAME) have difficulty seeing, even if wearing glasses?	Does (NAME) have difficulty hearing, even if using a hearing aid?	Does (NAME) have difficulty walking or climbing steps?	Does (NAME) have any difficulty remembering or concentrating?	Does (NAME) have difficulty with self-care such as washing all over or dressing?	Using the usual language, does (NAME) have difficulty communicating for example understanding or being understood?	Does (NAME) have a problem with nerves, sadness of depression?	Does (NAME) have problem performing tasks that are expected of people of their age?				YES → Q.15
	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE	1: NO 2: SOME 3: A LOT 4: UNABLE			
	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16A)	(16B)		
										YES	NO	
11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
12	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
14	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
15	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
16	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
17	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
19	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			



..... 8 = Don't know	07 = Unemployed (health reasons) 08 = Unemployed (disability reason) 09 = Unemployed (other reasons) 10 = Others 98 = Don't know/Refuse
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**SECTION C: LEVEL OF EDUCATION AND EMPLOYMENT – AGED 5 YEARS OR ABOVE – cont. 11 to 20**

LINE NO.	HIGHEST GRADE COMPLETED*	LITERACY	WORK STATUS**
Transfer the LINE NO. of persons as listed in Sect. A who are 5 yrs old or above	What is the highest standard form or level of education [NAME] completed?*	Can (NAME) read and write in any language?  1 = YES 2 = NO 8 = DON'T KNOW	What is the work status of (NAME)?**
	(15)	(16)	(17)
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

<p><b>*CODES FOR Q.15 HIGHEST GRADE COMPLETED</b></p>	<p><b>*CODE FOR Q.17 WORK STATUS</b></p>
<p>0 = No formal education 1 = Less than primary school 2 = Primary school 3 = Secondary school/ High school (or equivalent) 4 = Tertiary level education 5 = Other 8 = Don't know</p>	<p>01 = Paid work 02 = Self employed, such as own business or farming 03 = Non-paid work such as volunteer or charity 04 = Student/learner 05 = Keeping house/homemaker (unpaid) 06 = Retired 07 = Unemployed (health reasons) 08 = Unemployed (disability reason) 09 = Unemployed (other reasons) 10 = Others 98 = Don't know/Refuse</p>

**NOTE:** The following questions should be completed by the PRIMARY RESPONDENT/HEAD OF HOUSEHOLD

**SECTION D: INCOME AND EXPENSES**

**Question (18):**

What is the PRIMARY source and SECONDARY source (if any) of income in your household?

<b>Income Category</b>	<b>Primary source [Circle <i>one</i> only]</b>	<b>Secondary source [Circle <i>one</i> only]</b>
a. Wage/Salary work	01	01
b. Remittances received	02	02
c. Cash cropping	03	03
d. Livestock sales	04	04
e. Subsistence farming/fishing	05	05
f. Social cash transfer	06	06
i) Poverty cash transfer	07	07
ii) Disability grant	08	08
iii) Child support grant	09	09
iv) Old age pension	10	10
v) Foster care grant	11	11
vi) Other (specify)	12	12
g. Formal business (registered)	13	13
h. Informal business (non-registered - see below*)	14	14
i. Private insurance/pension	15	15
j. Workman's Compensation	16	16
k. Rent	17	17
l. Other (specify)	18	18
m. No income from any source	19	
n. Not stated/Refused	20	

\*This includes payments received for handicrafts, knitting, sewing, repairing shoes, repairing punctures, for providing services (e.g. making thatch roofs for huts, cutting reeds etc.). Also includes income from selling e.g. charcoal, local gin, local beer etc.

**Question (19):**

Are the primary sources of income stable and regular?

Yes	No	Once of two sources is stable but not other	Don't know
1	2	3	4

**SECTION E: OWNERSHIP**

**Question (20):**

Do you or anyone in your household own any of the following (in working condition)?

	Yes	No
a. Radio	1	2
b. Hi-fi/music stereo	1	2
c. Internet access in the home	1	2
d. DVD/VHS player	1	2
e. Cell phone/mobile	1	2
f. Telephone in the house	1	2
g. Iron	1	2
h. Fan	1	2
i. Heater	1	2
j. Air conditioner	1	2
k. Stove with gas/electric	1	2
l. Stove with paraffin	1	2
m. Sofa	1	2
n. Television	1	2

	Yes	No
o. Refrigerator	1	2
p. Microwave	1	2
q. Electricity	1	2
r. Solar energy system	1	2
s. Electrical generator	1	2
t. Personal computer	1	2
u. Bicycle	1	2
v. Motorcycle/quad bike	1	2
w. Dishwasher	1	2
x. Bed(s)	1	2
y. Livestock (cattle etc.)	1	2
z. Washing machine	1	2
aa. Satellite dish	1	2
bb. Car	1	2

**SECTION F: POPULATION DISPLACEMENT**

**Question (21):**

Have you and your family ever been forced or obliged to leave your home or place of habitual residence?

Yes	No
1	2

→ If the answer is NO, skip to Question 23

**Question (22):**

Could you tell me the main reason that you have moved from your home? [Circle **one** only]

Main reason	Code
Armed conflict	1
General violence	2
Violations of human rights (political persecution)	3
Natural or human-made disasters	4
Economic reasons (unemployment, services, education, health care, etc.)	5
Farm eviction	6

Other, specify_____	7
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**Question (23):**

What language do you speak most often at home? [Circle **one** only]

Language group	Code
Afrikaans	1
English	2
Xhosa	3
Zulu	4
Northern Sotho	5
Sotho (southern)	6
Tsonga/shangaan	7
Venda	8
Swati	9
Tswana	10
Ndebele	
South African Sign language	
Other, specify_____	

**Question (24):**

Do you feel that your language group is a minority?

Yes	No
1	2

**SECTION G: USE OF HEALTH FACILITY**

**Question (25):**

Do members of your household generally use the .....(NAME OF FACILITY):

Frequency	Code
Yes, always	1
Yes, sometimes	2
Use both health care facility plus others	3
No, but use other health care facilities	4
Never use any health care facilities	5

→ If the answer is 'YES, always', end the interview.

**Question (26):**

What are the main reasons why you *never* use this facility, or only use it *sometimes*, or why you use *other* facilities?

Main reasons	Code	Main reasons	Code
a. Cost	01	l. There are no services	12
b. No transport	02	m. Language barrier	13
c. Discrimination by health providers	03	n. Distance from home to clinic	14
d. Attitudes of health care providers	04	o. Physical accessibility of the facility	15
e. Had a bad incident and so don't go anymore	05	p. Not satisfied with outcomes of previous experience	16
f. The gender of health care provider	06	q. Opening times are not suitable	17
g. The type (professional category) of health care provider	07	r. Not sick enough or not sick (do not need)	18
h. Old age	08	s. Waiting times too long	19
i. Disability	09	t. Religious belief	20
j. Crime, danger	10	u. No knowledge about the health facility	21
k. Lack of time due to domestic or other responsibilities	11	v. Other, specify .....	22

**THANK YOU VERY MUCH FOR YOUR TIME!**

## APPENDIX F: INDIVIDUAL SURVEY

INDIVIDUAL

CONFIDENTIAL

### EquitAble WP4 – Version 010

IDENTIFICATION OF INDIVIDUAL	CODE
NAME AND CODE OF REGION* _____ NAME OF CONSTITUENCY* _____ NAME OF LOCALITY* _____ ENUMERATION AREA NUMBER ..... LOCATION      1 = urban    2 = rural HOUSEHOLD NUMBER/ID ..... NAME OF HOUSEHOLD HEAD _____	<div style="display: flex; flex-direction: column; align-items: center;"> <div style="border: 1px solid black; width: 20px; height: 20px; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-bottom: 5px;"></div> <div style="display: flex; justify-content: space-around; width: 100%; margin-bottom: 5px;"> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> <div style="border: 1px solid black; width: 15px; height: 15px;"></div> </div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px;"></div> </div>
<b>DETAIL OF INDIVIDUAL</b>	
NAME _____ AGE <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> LINE NUMBER IN HOUSEHOLD LISTING <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<b>DISABILITY</b> <div style="display: flex; justify-content: center; gap: 10px;"> <span style="border: 1px solid black; padding: 2px 5px;">Y</span> <span style="border: 1px solid black; padding: 2px 5px;">N</span> </div>
<b>IS THIS A FACE-TO-FACE INTERVIEW WITH THE PERSON?</b> [Do not read out. Code by observation]  1 = YES (i.e. interview directly with the person) 2 = NO (i.e. someone else is reporting on behalf of the person) 3 = BOTH (i.e. someone else is reporting or interpreting together with the person)  If NO or BOTH, who is the person reporting?  Line number of person as proxy	<div style="border: 1px solid black; width: 20px; height: 20px; margin-bottom: 20px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px;"></div>
<b>TO BE COMPLETED BY THE INTERVIEWER</b>  Time interview starts <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> Time completed <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<b>Date of interview</b> Day <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> Month <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> Year <input style="width: 20px; height: 20px;" type="text"/>
Name of interviewer: _____ Comments:  Signature _____	
<b>SUPERVISOR</b> _____	Enumerator has to _____

Name : _____ Signature _____	INTERVIEW STATUS		return to the household		CHECKED by the Supervisor <input type="checkbox"/>
	Comp <input type="checkbox"/>	Incomp <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	

**\*Codes for REGION, CONSTITUENCY AND LOCALITY see separate sheet**

**SECTION A: DIFFICULTIES AS A RESULT OF RESULT OF A HEALTH PROBLEM OR IMPAIRMENT**

**Question (1):**

The next questions ask about difficulties you may have doing certain activities BECAUSE OF A HEALTH PROBLEM OR IMPAIRMENT: [Circle only **one** per row]

	No	Some	A lot	Unable
a) Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b) Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
c) Do you have difficulty walking or climbing steps?	1	2	3	4
d) Do you have difficulty remembering or concentrating?	1	2	3	4
e) Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f) Using your usual (customary) language, do you have difficulty communicating for example understanding or being understood?	1	2	3	4
g) Do you have a problem with nerves, sadness or depression?	1	2	3	4
h) Do you have a problem performing tasks that are expected of people of your age?	1	2	3	4

**Question (2):**

In the last 30 days, how much difficulty did you have doing the following activities BECAUSE OF A HEALTH PROBLEM OR IMPAIRMENT? [Circle only **one** per row]

	None	Mild	Moderate	Severe	Extreme or cannot do
a) Standing for long periods such as 30 minutes?	1	2	3	4	5
b) Taking care of your household responsibilities?	1	2	3	4	5
c) Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
d) Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5

***If all of Questions 2a – 2d scored “1” (none) skip Question 3 and go straight to Section B***

**Question (3):**

In the last 30 days, how much difficulty did you have doing the following activities BECAUSE OF A HEALTH PROBLEM OR IMPAIRMENT? [Circle only **one** per row]

	None	Mild	Moderate	Severe	Extreme or cannot do
a) Concentrating on doing something for ten minutes?	1	2	3	4	5
b) Walking a long distance such as a kilometer [or equivalent]?	1	2	3	4	5
c) Washing your body?	1	2	3	4	5
d) Getting dressed?	1	2	3	4	5
e) Dealing with people you do not know?	1	2	3	4	5
f) Maintaining a friendship?	1	2	3	4	5
g) Your day to day work?	1	2	3	4	5
h) Concentrating on doing something for ten minutes?	1	2	3	4	5

**SECTION B: PAIN**

**Question (4):** Do you have frequent pain?

Yes	1
No	2

**Question (5):**

In the past 3 months how often did you have pain? [Circle **one** only]

Never	1
Sometimes	2
Most days	3
Every day	4

Skip → Go to Q: 7

**Question (6):**

Thinking about the last time you had pain, how much pain did you have? [Circle **one** only]

A little	1
A lot	2
Somewhere in between a little and a lot	3

**SECTION C: QUESTIONS FOR INDIVIDUALS WITH LIMB AMPUTATIONS ONLY**

**Question (7):**

Do you have a limb amputation? [IF NO GO TO QUESTION 18]

No	1	Skip → Go to Q: 18
Yes	2	

**Question (8):**

Do you experience **residual limb (stump) pain** (pain in the remaining part of your amputated limb)?

No	1	Skip → Go to Q:
Yes	2	

**Question (9):**

During the last week, how many times have you experienced stump pain?

**Question (10):**

How long, on average, did each episode of pain last?

**Question (11):**

Please indicate the level of stump pain experienced during the last week on the scale below: [Circle **one** only]

Excruciating	1
Horrible	2
Distressing	3
Discomforting	4
Mild	5

**Question (12):**

How much did stump pain interfere with your normal lifestyle (e.g. work, social and family activities) during the last week? [Circle **one** only]

A lot	1
Quite a bit	2
Moderately	3
A little bit	4
Not at all	5

**Question (13):**

Do you experience **phantom limb pain** (pain in the part of the limb which was amputated)?

No	1
Yes	2

Skip → Go to Q: 18

**Question (14):**

During the last week, how many times have you experienced phantom limb pain?

[If zero, go to Q 18]

**Question (15):**

How long, on average, did each episode of pain last?

(minutes)

**Question (16):**

Please indicate the level of phantom limb pain experienced during the last week on the scale below:  
[Circle **one** only]

Excruciating	1
Horrible	2
Distressing	3
Discomforting	4
Mild	5

**Question (17):**

How much did phantom limb pain interfere with your normal lifestyle (e.g. work, social and family activities) during the last week? [Circle **one** only]

A lot	1
Quite a bit	2
Moderately	3
A little bit	4
Not at all	5

**SECTION D: FATIGUE**

**Question (18):**

In the past 3 months, how often did you feel very tired or exhausted? [Circle **one** only]

Never	1
Some days	2
Most days	3
Every day	4

Skip → Go to Q: 21

**Question (19):**

Thinking about the last time you felt tired or exhausted, how long did it last? [Circle **one** only]

Some hours	1
Some days	2
Most days	3
Every day	4

**Question (20):**

Thinking about the last time you felt very tired or exhausted, how would you describe the level of tiredness?

A little	1
A lot	2
Somewhere in between a little and a lot	3

**SECTION E: HEALTH CONDITIONS**

**Question (21):**

Tell me the health conditions that you have.

**[LIST ALL THE HEALTH CONDITIONS MENTIONED BY RESPONDENTS] *In case of other illnesses, write at "Other"*.**

*[Circle one for each row]*

Condition/impairment	Yes	No
a) Heart problems	1	2
b) Lung problems	1	2
c) Mental health problems	1	2
d) Joint problems	1	2
e) Malaria	1	2
f) Diabetes / Sugar disease	1	2
g) Blood pressure	1	2
h) Cancer	1	2
i) Albinism or disfigurement	1	2
j) Intellectual disability	1	2
k) Epilepsy / Fits / Seizures	1	2
l) HIV / AIDS	1	2
m) Measles	1	2
n) Diarrhoea / cholera	1	2

Condition/impairment	Yes	No
o) Foetal alcohol syndrome	1	2
p) Drug related problems	1	2
q) Alcoholism, drug abuse	1	2
r) Malnutrition	1	2
s) Stroke	1	2
t) Pregnancy problems	1	2
u) Birth problems	1	2
v) None	1	2
w) Other 1 _____	1	2
x) Other 2 _____	1	2
y) Other 3 _____	1	2
z) Other 4 _____	1	2

**SECTION F: PARTICIPATION RESTRICTION**

For the following questions, think about the environment in which you live, including the use of assistive devices or personal support:

**Question (22):**

Do you have any difficulty doing the following? *[Read out the options and code using the codes below]*

Participation restriction items	Score
a) shopping (getting goods and services)	
b) preparing meals (cooking)	
c) doing housework (washing/cleaning)	
d) taking care of personal objects (mending/ repairing)	
e) taking care of others	
f) making friends and maintaining friendships	
g) interacting with persons in authority (officials, village chiefs)	
h) interacting with strangers	
i) creating and maintaining family relationships	

Participation restriction items	Score
j) making and maintaining intimate relationships	
k) going to school and studying (education)	
l) getting and keeping a job (work & employment)	
m) handling income and payments (economic life)	
n) taking part in clubs/organisations (community life)	
o) taking part in recreation/leisure (sports/play/crafts/hobbies/arts/culture)	
p) taking part in religious/spiritual activities	
q) taking part in political life and citizenship	

Coding
0 = No problem
1 = Mild problem
2 = Moderate problem
3 = Severe problem
4 = Complete problem (unable to perform)
8 = Not specified/not applicable

**SECTION G: ASSISTIVE DEVICES**

*Ask either direct or proxy respondents: please remember the information must be about the person with disability.*

**Question (23):**

Do you use an assistive device? [For examples, see 23 below]

Yes	1	Go to Q: 24
No	2	Go to Q: 34

**Question (24):**

Please specify which assistive devices you usually use [Read out; circle **one** answer for each row].

Device	Device category	Examples:	Yes	No	Not applicable (don't need it)
1	Information	• Hearing aids	1	2	3
		• Visual aid	1	2	3
2	Information	Eye glasses, magnifying glass, telescopic lenses/glasses, enlarge print, Braille	1	2	3
3	Communication	Sign language interpreter, fax, portable writer, computer, picture boards, cards	1	2	3
4	Personal mobility	• Walking	1	2	3
		• Wheeled mobility	1	2	3
		• Orthoses and prostheses	1	2	3
5	Household items	Flashing light on doorbell, amplified telephone, vibrating alarm clock	1	2	3
6	Personal care & protection	Special fasteners, bath & shower seats, toilet seat raiser, commode chairs, safety rails, eating aids	1	2	3
7	For handling products & goods	Gripping tongs, aids for opening containers, tools for gardening	1	2	3
8	Computer assistive technology	Keyboard for the blind, screen reader, synthetic speech	1	2	3
9	Other	Specify:	1	2	3

**Question (25):**

Is the assistive device(s) mentioned above in good working condition/order?

*[If more than one device in one category, choose **most important** device - List device by **name**]*

Name of Device:	Good working condition?
a.	
b.	
c.	

CODING
1 = Yes
2 = No
8 = Don't know

**Question (26):**

Think about how much you used your assistive device over the past two weeks. On an average day, how many hours did you use it? [*Circle one only*]

None	1
Less than 1 hour	2
1-4 hours	3
5-8 hours	4
More than 8 hours	5

**Question (27):**

Does your device help you as intended? [*Circle one only*]

Helped not at all	1
Helped slightly	2
Helped moderately	3
Helped quite a lot	4
Helped very much	5

**Question (28):**

How much difficulty do you still have even if you use the assistive device? [*Circle one only*]

Very much difficulty	1
Quite a lot of difficulty	2
Moderate difficulty	3
Slight difficulty	4
No difficulty	5

**Question (29):**

Has obtaining and using the device been worth the trouble? [*Circle one only*]

Not at all worth it	1
Slightly worth it	2
Moderately worth it	3
Quite a lot worth it	4
Very much worth it	5

**Question (30):**

Considering everything, how much has your use of assistive devices improved your quality of life? [*Circle one only*]

Worse	1
No change	2

Slightly better	3
Quite a lot better	4
Much better	5

**Question (31):**

Where did you get the assistive device(s)? *[Read out; record only **one** answer for each line]*

*[If more than one device in one category, choose **most important** device - List device by **name**]*

Name of Device:	Where did you get the device?*	Can you give an estimate of the cost of the device?
a.		
b.		
c.		

*CODING
1 = Private hospital
2 = Government health service
3 = Other government service (not health)
4 = NGO
5 = Other
8 = Don't know

**Question (32):**

Were you given any information or help on how to use your device(s)? *[Record only **one** answer for each line]*

Name of Device:	Information or help
a.	
b.	
c.	

CODING
1 = Complete/full information
2 = Some information
3 = No information
8 = Don't know/ Can't remember

**Question (33):** Who, if any, maintains or repairs your assistive device(s)? *[Do not read out: record only **one** answer for each line]*

*[If more than one device in one category, choose **most important** device - List device by **name**]*

Name of Device:	Maintenance /Repair
a.	
b.	
c.	

CODING
1 = Self
2 = Government
3 = Family
4 = Employer
5 = NGO
6 = Other (specify)
7 = Not maintained
8 = Cannot afford to maintain or repair it

98 = Don't know

**SECTION H: INVENTORY OF ENVIRONMENTAL FACTORS**

**Question (34):**

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never**.

**[Please CIRCLE only one]**

	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	8. Not applicable	2. Big problem	1. Little problem
<p><b>a)</b> In the past 12 months, how often has the availability/accessibility of transportation been a problem for you?</p>	1	2	3	4	5	8		
	<b>a1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>b)</b> In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?</p>	1	2	3	4	5	8		
	<b>b1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>c)</b> In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?</p>	1	2	3	4	5	8		
	<b>c1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>d)</b> In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?</p>	1	2	3	4	5	8		
	<b>d1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>e)</b> In the past 12 months, how often has the availability of health care services and medical care been a problem for you?</p>	1	2	3	4	5	8		
	<b>e1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>f)</b> In the past 12 months, how often did you need someone else's help in your home and could not get it easily?</p>	1	2	3	4	5	8		
	<b>f1)</b> When this problem occurs has it been a big problem or a little problem?						1	2

	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	8. Not applicable	2. Big problem	1. Little problem
<b>g)</b> In the past 12 months, how often did you need someone else's help at school or work and could not get it easily?	1	2	3	4	5	8		
<b>g1)</b> When this problem occurs has it been a big problem or a little problem?							1	2
<b>h)</b> In the past 12 months, how often have other people's attitudes toward you been a problem at home?	1	2	3	4	5	8		
<b>h1)</b> When this problem occurs has it been a big problem or a little problem?							1	2
<b>i)</b> In the past 12 months, how often have other people's attitudes toward you been a problem at school or work?	1	2	3	4	5	8		
<b>i1)</b> When this problem occurs has it been a big problem or a little problem?							1	2
<b>j)</b> In the past 12 months, how often did you experience prejudice or discrimination?	1	2	3	4	5	8		
<b>j1)</b> When this problem occurs has it been a big problem or a little problem?							1	2

**Question (35):**

To what extent does your usual environment make it easier for you to perform activities of daily living? *[Circle one only]*

**Makes it easier for you:**

Environmental factor	Yes	No	Don't know
<b>a)</b> Positive attitudes towards you of others	1	2	8
<b>b)</b> Support from others when needed	1	2	8
<b>c)</b> Accessibility of buildings	1	2	8
<b>d)</b> Easy terrain (pathways, roads etc.)	1	2	8
<b>e)</b> Good climate and other conditions (heat, cold, rain, noise, pollution, no crowding, etc.)	1	2	8
<b>f)</b> Accessibility of transport	1	2	8
<b>g)</b> Service provision	1	2	8
<b>h)</b> Accessible information	1	2	8
<b>i)</b> Inclusion in society by all	1	2	8

**SECTION I: HEALTH SERVICE AWARENESS**

I am going to ask you about different services:

**Question (36):**

Which services, if any, are you *aware* of and have ever *needed and received*?

[Read out; and enter the appropriate code for each column of each row].

	Aware of service 1=Yes 2=No	Needed service 1=Yes 2=No	Received service 1=Yes 2=No
	(1)	(2)	(3)
<b>a) Medical rehabilitation:</b>			
<b>aa)</b> Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ab)</b> Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ac)</b> Speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ad)</b> Hearing therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ae)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>b) Assistive devices service:</b>			
<b>ba)</b> Sign language interpreter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>bb)</b> Wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>bc)</b> Hearing aids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>bd)</b> Visual aids, Braille etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>be)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>c) Primary health care clinic/centre</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>d) Secondary health care (e.g. hospital)</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>e) Mobile health clinic</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>f) Home based care</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>g) Counselling</b>			
<b>ga)</b> Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>gb)</b> Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>gc)</b> Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>gd)</b> School counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ge)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>h) Health information</b>			
<b>ha)</b> Media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hb)</b> Schools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hc)</b> Clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hd)</b> Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>he)</b> Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hf)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>i) Traditional healer/faith healer</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**SECTION J: HEALTH CARE UTILISATION**

I would like to know about your recent experiences with obtaining health care from health care workers, hospitals, clinics and the health care system. I want to know if you needed health care recently, and if so, why you needed health care and what type of health care provider you received care from.

**Question (37):**

When was the last time that you needed health care?

Years ago	
Months ago	
Weeks ago	
Days ago	
Never	97
Don't know	98

**Question (38):**

The last time you needed health care, did you get health care?

Yes	1
No	2
Don't know/ Don't remember	8

*Skip → Go to Q: 40*

**Question (39):** Which reason(s) best explains why you did not get health care the last time you needed it?

*[Mark all that the respondent indicates, but do not read out items]*

Reasons	Code
<b>a)</b> No one to accompany me	1
<b>b)</b> Cost	2
<b>c)</b> No transport	3
<b>d)</b> Discrimination	4
<b>e)</b> Attitudes of health care providers	5
<b>f)</b> Had a bad incident and so don't go anymore	6
<b>g)</b> The gender of health care provider	7
<b>h)</b> The type (professional category) of health care provider	8
<b>i)</b> Old age	9
<b>j)</b> Disability	10
<b>k)</b> Crime, danger	11
<b>l)</b> Lack of time due to domestic or other responsibilities	12
<b>m)</b> Lack of medication	13

Reasons	Code
<b>n)</b> Did not want family to know I am ill	14
<b>o)</b> There are no services	15
<b>p)</b> Language barrier	16
<b>q)</b> Distance from home to clinic	17
<b>r)</b> Physical accessibility of the facility	18
<b>s)</b> Not satisfied with outcomes of previous experience	19
<b>t)</b> Traditional (culture)	20
<b>u)</b> Opening times are not suitable	21
<b>v)</b> Not sick enough or not sick (do not need)	22
<b>w)</b> Waiting times too long	23
<b>x)</b> Religious belief	24
<b>y)</b> No knowledge about the health facility	25
<b>z)</b> Other, specify	26

**Question (40):**

Thinking about health care you usually need, where do you normally go? *[Circle one only]*

Private doctor's office	01
Private clinic or health care facility	02
Private hospital	03
Public clinic or health care facility	04
Public hospital	05
Charity or church run clinic	06
Charity or church run hospital	07
Traditional healer [ <i>use local term</i> ]	08
Faith healer [ <i>use local term</i> ]	09
Pharmacy or dispensary	10
Have not needed any health care in the last 3 years	11
Other (specify)	12

**Question (41):**

Now, let us think back to the last time you needed health care. What was the reason you needed health care the last time, even if you did not get it?

	<i>Office use</i>

**Question (42):**

The last time you used health care, how did you get there? [*Circle one only*]

Private vehicle (car or motorcycle)	1
Public transportation	2
Taxi/cab	3
Bicycle	4
Walk	5
Other (specified)	6
Never used health care	7
Don't know	8

**Question (43):**

About how long did it take you to get there?

Hours	
Minutes	
Don't know	98

**Question (44):**

Once you got to the health care facility the last time you used health care, how long did you wait?

Hours	
Minutes	
Don't know	98

	Yes	No	Don't know/ Don't remember
<b>Question (45):</b> The last time you went to the health facility, did you go with someone to assist you?	1	2	8
<b>Question (46):</b> Do you usually need someone to come with to assist you whenever you come to the health facility?	1	2	8

**Question (47):**

Considering your own experience, tell me whether the following make it difficult for you to get health care:

*[Read out the alternatives, and show card. Circle only **one** code for **each** row]*

	No problem	Small problem	Moderate problem	Serious problem	Insurmountable problem
a) Lack of transport from home to health facility	1	2	3	4	5
b) No services available	1	2	3	4	5
c) Physical access to facility	1	2	3	4	5
d) Because of faith/belief	1	2	3	4	5
e) Negative attitudes among health workers	1	2	3	4	5
f) There is no accommodation at the health facility	1	2	3	4	5
g) Communication with health workers	1	2	3	4	5
h) Standard of the health facility	1	2	3	4	5
i) The journey to the health care is dangerous	1	2	3	4	5
j) You did not know where to go	1	2	3	4	5
k) Could not afford the cost of the visit	1	2	3	4	5
l) Don't have the necessary document (health card/passport)	1	2	3	4	5
m) You thought you were not sick enough	1	2	3	4	5
n) You tried but were denied health care	1	2	3	4	5
o) The health care provider's drugs or equipment were inadequate	1	2	3	4	5
p) Could not take time off work or had other commitments	1	2	3	4	5
q) You were previously badly treated	1	2	3	4	5
r) Could not afford the cost of transport	1	2	3	4	5

s) Other (specify)	1	2	3	4	5
--------------------	---	---	---	---	---

**Question (48):**

Considering your experience receiving or visiting health care providers, how would you rate the following?

[Circle **one** only code for each row]

	Very good	Good	Moderate	Bad	Very bad
a) The amount of time you waited before being attended to.	1	2	3	4	5
b) Your experience of being treated respectfully.	1	2	3	4	5
c) How clearly health care providers explained things to you.	1	2	3	4	5
d) Your experience of being involved in making decisions for your treatment.	1	2	3	4	5
e) The way the health services ensured that you could talk privately to providers.	1	2	3	4	5
f) The ease with which you could see a health care provider you were happy with.	1	2	3	4	5
g) The cleanliness in the health facility.	1	2	3	4	5

**Question (49):**

Overall, how satisfied are you with the provision of health care in your area? [Circle **one** only]

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5

**Question (50):**

Overall, how satisfied are you with the personnel in your area or those that are accessible to you?

[Circle **one** only]

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5

**Question (51):**

Has a health worker visited you at home during the last 3 years?

Yes	1	
No	2	Skip → Go to Q: 53

**Question (52):**If yes, how many times? [Circle **one** only]

Once	1
A few times	2
Many times	3

**Question (53):**Have you ever accessed the following services? [Circle **ALL that apply** or **ONLY 'Not applicable'** (8) if none of the services were accessed]

a) Malaria prevention (bed nets, etc.)	1
b) HIV/AIDS counselling	2
c) HIV/AIDS testing	3
d) Immunisation	4
e) Not applicable	8

**SECTION K: ATTITUDES TOWARDS HEALTH SERVICES****Question (54):**Please tell me how much you agree with the following statements. [Circle only **one** code for each row]

	Strongly Disagree	Slightly Disagree	Slightly Agree	Strongly Agree
a) The health personnel at the <u>local clinic/health center</u> have appropriate competence to help with your health problems	1	2	3	4
b) The health personnel at the <u>hospital</u> have appropriate competence to help with your health problems	1	2	3	4
c) <u>The traditional healer</u> have appropriate competence to help with your health problems	1	2	3	4
d) You trust the treatment provided by health personnel at the hospital	1	2	3	4
e) You trust the treatment provided by health personnel at the clinic/health center	1	2	3	4
f) You trust the treatment provided by the traditional healer to be effective	1	2	3	4
g) People are received in a positive manner in the clinic/health center	1	2	3	4
h) People are received in a positive manner at the hospital	1	2	3	4
i) People are received in a positive manner at the traditional healer	1	2	3	4

**Question (55):**

I would like to ask you how your health has been in general, over the past few weeks. For the past few weeks have you....? [Circle **one per row**]

Health in general	Yes	No
a) Been able to concentrate on what you're doing	1	2
b) Lost much sleep over worry	1	2
c) Felt you were playing a useful part in things	1	2
d) Felt capable of making decisions about things	1	2
e) Felt constantly under strain	1	2
f) Felt you couldn't overcome your difficulties	1	2
g) Been able to enjoy your normal day-to-day activities	1	2
h) Been able to face up to your problems	1	2
i) Been feeling unhappy and depressed	1	2
j) Been losing confidence in yourself	1	2
k) Been thinking of yourself as a worthless person	1	2
l) Been feeling reasonably happy, all things considered	1	2

**Question (56):**

Thinking about your general physical health (things like: sickness, illness, injury, disease etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall physical health today? [Circle **one only**]

Poor	1
Not very good	2
Good	3
Very good	4
Don't know	8

**Question (57)**

Thinking about your general mental health (things like: anxiety, depression, fear, fatigue, tiredness, hopelessness etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall mental health today? [Circle **one only**]

Poor	1
Not very good	2
Good	3
Very good	4
Don't know	8

**Question (58):**

Do you consider yourself to have a disability?

Yes	1
No	2

---

**We may want to follow up with you on these issues, would you be willing to participate in another interview at a later stage?**

**If no – don't record name and phone number**

**If yes, record full name and phone number:**

**Name:** \_\_\_\_\_

**Phone number:** \_\_\_\_\_

---

**Thank you very much for your time!**



Signature _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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**\*Codes for REGION, CONSTITUENCY AND LOCALITY see separate sheet**

**SECTION A: DIFFICULTIES AS A RESULT OF RESULT OF A HEALTH PROBLEM**

**Question (1):**

The next questions ask about difficulties you may have doing certain activities BECAUSE OF A HEALTH PROBLEM: [Circle only **one** per row]

	No	Some	A lot	Unable
a) Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b) Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
c) Do you have difficulty walking or climbing steps?	1	2	3	4
d) Do you have difficulty remembering or concentrating?	1	2	3	4
e) Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f) Using your usual (customary) language, do you have difficulty communicating for example understanding or being understood?	1	2	3	4
g) Do you have a problem with nerves, sadness or depression?	1	2	3	4
h) Do you have a problem performing tasks that are expected of people of your age?	1	2	3	4

**Question (2):**

In the last 30 days, how much difficulty did you have doing the following activities BECAUSE OF A HEALTH PROBLEM? [Circle only **one** per row]

	None	Mild	Moderate	Severe	Extreme or cannot do
a) Standing for long periods such as 30 minutes?	1	2	3	4	5
b) Taking care of your household responsibilities?	1	2	3	4	5
c) Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
d) How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5

***If all of Questions 2a – 2d scored “1” (none) skip Question 3 and go straight to Section C***

**Question (3):**

In the last 30 days, how much difficulty did you have doing the following activities BECAUSE OF A HEALTH PROBLEM? [Circle only **one** per row]

	None	Mild	Moderate	Severe	Extreme or cannot do
a) Concentrating on doing something for ten minutes?	1	2	3	4	5
b) Walking a long distance such as a kilometer [or equivalent]?	1	2	3	4	5
c) Washing your body?	1	2	3	4	5
d) Getting dressed?	1	2	3	4	5
e) Dealing with people you do not know?	1	2	3	4	5
f) Maintaining a friendship?	1	2	3	4	5
g) Your day to day work?	1	2	3	4	5

**SECTION C: FATIGUE**

**Question (17):**

In the past 3 months, how often did you feel very tired or exhausted? [Circle **one** only]

Never	1
Some days	2
Most days	3
Every day	4

Skip → Go to Q: 20

**Question (18):**

Thinking about the last time you felt tired or exhausted, how long did it last? [Circle **one** only]

Some hours	1
Some days	2
Most days	3
Every day	4

**Question (19):**

Thinking about the last time you felt very tired or exhausted, how would you describe the level of tiredness?

A little	1
A lot	2
Somewhere in between a little and a lot	3

**SECTION D: HEALTH CONDITIONS**

**Question (20):**

Tell me the health conditions that you have.

**[Show card, read out if the respondent is not able to read. In case of other illnesses, write at "Other"].**

*[Circle one for each row]*

Condition/impairment	Yes	No
a) Heart problems	1	2
b) Lung problems	1	2
c) Mental health problems	1	2
d) Joint problems	1	2
e) Malaria	1	2
f) Diabetes / Sugar disease	1	2
g) Blood pressure	1	2
h) Cancer	1	2
i) Albinism or disfigurement	1	2
j) Intellectual disability	1	2
k) Epilepsy / Fits / Seizures	1	2
l) HIV / AIDS	1	2
m) Measles	1	2
n) Diarrhoea / cholera	1	2

Condition/impairment	Yes	No
o) Foetal alcohol syndrome	1	2
p) Drug related problems	1	2
q) Alcoholism, drug abuse	1	2
r) Malnutrition	1	2
s) Stroke	1	2
t) Pregnancy problems	1	2
u) Birth problems	1	2
v) None	1	2
	1	2
w) Other 1 _____	1	2
x) Other 2 _____	1	2
y) Other 3 _____	1	2
z) Other 4 _____	1	2

**Question (20b):**

I would like to ask you how your health has been in general.

*[Circle one for each row]*

	Yes	No
a) Able to concentrate?	1	2
b) Have been worried?	1	2
c) Feeling useful?	1	2
d) Able to make decisions?	1	2
e) Felt under strain?	1	2
f) Able to overcome difficulties?	1	2

	Yes	No
g) Enjoy normal activities?	1	2
h) Able to face problems?	1	2
i) Felt unhappy or depressed?	1	2
j) Losing confidence?	1	2
k) Thinking of yourself as a worthless person?	1	2
l) Feeling happy?	1	2

<b>SECTION E: PARTICIPATION RESTRICTION</b>
---

For the following questions, think about the environment in which you live, including the use of assistive devices or personal support:

**Question (21):**

Do you have any difficulty doing the following? *[Read out the options and code using the codes below]*

Participation restriction items	Score
<b>a)</b> shopping (getting goods and services)	
<b>b)</b> preparing meals (cooking)	
<b>c)</b> doing housework (washing/cleaning)	
<b>d)</b> taking care of personal objects (mending/ repairing)	
<b>e)</b> taking care of others	
<b>f)</b> making friends and maintaining friendships	
<b>g)</b> interacting with persons in authority (officials, village chiefs)	
<b>h)</b> interacting with strangers	
<b>i)</b> creating and maintaining family relationships	

Participation restriction items	Score
<b>j)</b> making and maintaining intimate relationships	
<b>k)</b> going to school and studying (education)	
<b>l)</b> getting and keeping a job (work & employment)	
<b>m)</b> handling income and payments (economic life)	
<b>n)</b> taking part in clubs/organisations (community life)	
<b>o)</b> taking part in recreation/leisure (sports/play/crafts/hobbies/arts/culture)	
<b>p)</b> taking part in religious/spiritual activities	
<b>q)</b> taking part in political life and citizenship	

Coding
0 = No problem
1 = Mild problem
2 = Moderate problem
3 = Severe problem
4 = Complete problem (unable to perform)
8 = Not specified/not applicable

**SECTION G: INVENTORY OF ENVIRONMENTAL FACTORS**

**Question (33):**

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never**.

**[Please CIRCLE only one]**

	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	8. Not applicable	2. Big problem	1. Little problem
<p><b>a)</b> In the past 12 months, how often has the availability/accessibility of transportation been a problem for you?</p>	1	2	3	4	5	8		
	<b>a1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>b)</b> In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?</p>	1	2	3	4	5	8		
	<b>b1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>c)</b> In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?</p>	1	2	3	4	5	8		
	<b>c1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>d)</b> In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?</p>	1	2	3	4	5	8		
	<b>d1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>e)</b> In the past 12 months, how often has the availability of health care services and medical care been a problem for you?</p>	1	2	3	4	5	8		
	<b>e1)</b> When this problem occurs has it been a big problem or a little problem?						1	2
<p><b>f)</b> In the past 12 months, how often did you need someone else's help in your home and could not get it easily?</p>	1	2	3	4	5	8		
	<b>f1)</b> When this problem occurs has it been a big problem or a little problem?						1	2

	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	8. Not applicable	2. Big problem	1. Little problem
<b>g)</b> In the past 12 months, how often did you need someone else's help at school or work and could not get it easily?	1	2	3	4	5	8		
<b>g1)</b> When this problem occurs has it been a big problem or a little problem?							1	2
<b>h)</b> In the past 12 months, how often have other people's attitudes toward you been a problem at home?	1	2	3	4	5	8		
<b>h1)</b> When this problem occurs has it been a big problem or a little problem?							1	2
<b>i)</b> In the past 12 months, how often have other people's attitudes toward you been a problem at school or work?	1	2	3	4	5	8		
<b>i1)</b> When this problem occurs has it been a big problem or a little problem?							1	2
<b>j)</b> In the past 12 months, how often did you experience prejudice or discrimination?	1	2	3	4	5	8		
<b>j1)</b> When this problem occurs has it been a big problem or a little problem?							1	2

**Question (34):**

To what extent does your usual environment make it easier for you to perform activities of daily living? *[Circle one only]*

**Makes it easier for you:**

Environmental factor	Yes	No	Don't know
<b>a)</b> Positive attitudes towards you of others	1	2	8
<b>b)</b> Support from others when needed	1	2	8
<b>c)</b> Accessibility of buildings	1	2	8
<b>d)</b> Easy terrain (pathways, roads etc.)	1	2	8
<b>e)</b> Good climate and other conditions (heat, cold, rain, noise, pollution, no crowding, etc.)	1	2	8
<b>f)</b> Accessibility of transport	1	2	8
<b>g)</b> Service provision	1	2	8
<b>h)</b> Accessible information	1	2	8
<b>i)</b> Inclusion in society by all	1	2	8

**SECTION H: HEALTH SERVICE AWARENESS**

I am going to ask you about different services:

**Question (35):**

Which services, if any, are you *aware* of and have ever *needed/received*?

[Read out; and enter the appropriate code for each column of each row].

	Aware of service 1=Yes 2=No	Needed service 1=Yes 2=No	Received service 1=Yes 2=No
	(1)	(2)	(3)
<b>a) Medical rehabilitation:</b>			
<b>aa)</b> Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ab)</b> Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ac)</b> Speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ad)</b> Hearing therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ae)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>b) Assistive devices service:</b>			
<b>ba)</b> Sign language interpreter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>bb)</b> Wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>bc)</b> Hearing aids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>bd)</b> Visual aids, Braille etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>be)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>c) Primary health care clinic/centre</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>d) Secondary health care (e.g. hospital)</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>e) Mobile health clinic</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>f) Home based care</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>g) Counselling</b>			
<b>ga)</b> Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>gb)</b> Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>gc)</b> Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>gd)</b> School counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ge)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>h) Health information</b>			
<b>ha)</b> Media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hb)</b> Schools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hc)</b> Clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hd)</b> Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>he)</b> Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>hf)</b> Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>i) Traditional healer/faith healer</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**SECTION I: HEALTH CARE UTILISATION**

I would like to know about your recent experiences with obtaining health care from health care workers, hospitals, clinics and the health care system. I want to know if you needed health care recently, and if so, why you needed health care and what type of health care provider you received care from.

**Question (36):**

When was the last time that you needed health care?

Years ago	
Months ago	
Weeks ago	
Days ago	
Never	97
Don't know	98

**Question (37):**

The last time you needed health care, did you get health care?

Yes	1
No	2
Don't know/ Don't remember	8

*Skip → Go to Q: 39*

**Question (38):** Which reason(s) best explains why you did not get health care the last time you needed it?

*[Mark all that the respondent indicates, but do not read out items]*

Reasons	Code
<b>a)</b> No one to accompany me	1
<b>b)</b> Cost	2
<b>c)</b> No transport	3
<b>d)</b> Discrimination	4
<b>e)</b> Attitudes of health care providers	5
<b>f)</b> Had a bad incident and so don't go anymore	6
<b>g)</b> The gender of health care provider	7
<b>h)</b> The type (professional category) of health care provider	8
<b>i)</b> Old age	9
<b>j)</b> Disability	10
<b>k)</b> Crime, danger	11
<b>l)</b> Lack of time due to domestic or other responsibilities	12
<b>m)</b> Lack of medication	13

Reasons	Code
<b>n)</b> Did not want family to know I am ill	14
<b>o)</b> There are no services	15
<b>p)</b> Language barrier	16
<b>q)</b> Distance from home to clinic	17
<b>r)</b> Physical accessibility of the facility	18
<b>s)</b> Not satisfied with outcomes of previous experience	19
<b>t)</b> Traditional (culture)	20
<b>u)</b> Opening times are not suitable	21
<b>v)</b> Not sick enough or not sick (do not need)	22
<b>w)</b> Waiting times too long	23
<b>x)</b> Religious belief	24
<b>y)</b> No knowledge about the health facility	25
<b>z)</b> Other, specify	26

**Question (39):**

Thinking about health care you usually need, where do you normally go? *[Circle one only]*

Private doctor's office	01
Private clinic or health care facility	02
Private hospital	03
Public clinic or health care facility	04
Public hospital	05
Charity or church run clinic	06
Charity or church run hospital	07
Traditional healer [ <i>use local term</i> ]	08
Faith healer [ <i>use local term</i> ]	09
Pharmacy or dispensary	10
Have not needed any health care in the last 3 years	11
Other (specify)	12

**Question (40):**

Now, let us think back to the last time you needed health care. What was the reason you needed health care the last time, even if you did not get it?

	<i>Office use</i>

**Question (41):**

The last time you used health care, how did you get there? [*Circle one only*]

Private vehicle (car or motorcycle)	1
Public transportation	2
Taxi/cab	3
Bicycle	4
Walk	5
Other (specified)	6
Never used health care	7
Don't know	8

**Question (42):**

About how long did it take you to get there?

Hours	
Minutes	
Don't know	98

**Question (43):**

Once you got to the health care facility the last time you used health care, how long did you wait?

Hours	
Minutes	
Don't know	98

**Question (46):**

Considering your own experience, tell me whether the following make it difficult for you to get health care:

*[Read out the alternatives, and show card. Circle only **one** code for **each** row]*

	No problem	Small problem	Moderate problem	Serious problem	Insurmountable problem
a) Lack of transport from home to health facility	1	2	3	4	5
b) No services available	1	2	3	4	5
c) Physical access to facility	1	2	3	4	5
d) Because of faith/belief	1	2	3	4	5
e) Negative attitudes among health workers	1	2	3	4	5
f) There is no accommodation at the health facility	1	2	3	4	5
g) Communication with health workers	1	2	3	4	5
h) Standard of the health facility	1	2	3	4	5
i) The journey to the health care is dangerous	1	2	3	4	5
j) You did not know where to go	1	2	3	4	5
k) Could not afford the cost of the visit	1	2	3	4	5
l) Don't have the necessary document (health card/passport)	1	2	3	4	5
m) You thought you were not sick enough	1	2	3	4	5
n) You tried but were denied health care	1	2	3	4	5
o) The health care provider's drugs or equipment were inadequate	1	2	3	4	5
p) Could not take time off work or had other commitments	1	2	3	4	5
q) You were previously badly treated	1	2	3	4	5
r) Could not afford the cost of transport	1	2	3	4	5
s) Other (specify)	1	2	3	4	5

**Question (47):**

Considering your experience receiving or visiting health care providers, how would you rate the following?

[Circle **one** only code for each row]

	Very good	Good	Moderate	Bad	Very bad
a ) The amount of time you waited before being attended to.	1	2	3	4	5
b ) Your experience of being treated respectfully.	1	2	3	4	5
c ) How clearly health care providers explained things to you.	1	2	3	4	5
d ) Your experience of being involved in making decisions for your treatment.	1	2	3	4	5
e ) The way the health services ensured that you could talk privately to providers.	1	2	3	4	5
f ) The ease with which you could see a health care provider you were happy with.	1	2	3	4	5
g ) The cleanliness in the health facility.	1	2	3	4	5

**Question (48):**

Overall, how satisfied are you with the provision of health care in your area? [Circle **one** only]

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5

**Question (49):**

Overall, how satisfied are you with the personnel in your area or those that are accessible to you?

[Circle **one** only]

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5

**Question (50):**

Has a health worker visited you at home during the last 3 years?

Yes	1	
No	2	Skip → Go to Q: 52

**Question (51):**

If yes, how many times? [Circle **one** only]

Once	1
A few times	2
Many times	3

**Question (52):**

Have you ever accessed the following services? [Circle **ALL that apply** or **ONLY 'Not applicable'** (8) if none of the services were accessed]

a) Malaria prevention (bed nets, etc.)	1
b) HIV/AIDS counselling	2
c) HIV/AIDS testing	3
d) Immunisation	4
e) Not applicable	8

**SECTION J: ATTITUDES TOWARDS HEALTH SERVICES**

**Question (53):**

Please tell me how much you agree with the following statements. [Circle only **one** code for each row]

	Strongly Disagree	Slightly Disagree	Slightly Agree	Strongly Agree
a) The health personnel at the <u>local clinic/health center</u> have appropriate competence to help with your health problems	1	2	3	4
b) The health personnel at <u>the hospital</u> have appropriate competence to help with your health problems	1	2	3	4
c) <u>The traditional healer</u> have appropriate competence to help with your health problems	1	2	3	4
d) You trust the treatment provided by health personnel at the hospital	1	2	3	4
e) You trust the treatment provided by health personnel at the clinic/health center	1	2	3	4
f) You trust the treatment provided by the traditional healer to be effective	1	2	3	4
g) People are received in a positive manner in the clinic/health center	1	2	3	4
h) People are received in a positive manner at the hospital	1	2	3	4
i) People are received in a positive manner at the traditional healer	1	2	3	4

**Question (54):**

Thinking about your general physical health (things like: sickness, illness, injury, disease etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall physical health today?  
[Circle **one** only]

Poor	1
Not very good	2
Good	3
Very good	4
Don't know	8

**Question (55)**

Thinking about your general mental health (things like: anxiety, depression, fear, fatigue, tiredness, hopelessness etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall mental health today? [Circle **one** only]

Poor	1
Not very good	2
Good	3
Very good	4
Don't know	8

**Thank you very much for your time.**