Enabling Universal and Equitable Access to Healthcare for Vulnerable People in Resource Poor Settings in Africa

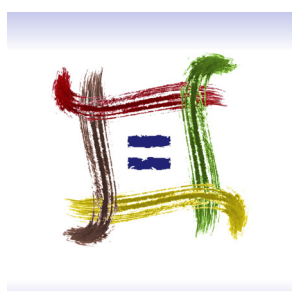## Consolidated Report for Work Package 3 (Phase 1): Intensive qualitative studies

EquitAble:

Enabling universal and equitable access

to healthcare for vulnerable people

in resource poor settings in Africa

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1 Introduction

Healthcare can be neither universal nor equitable if it is less accessible to some sections of society than it is to others. The "Health for All" concept asserts that attaining health for all as part of overall development starts with primary health care based on "acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford" ("Declaration of Alma-Ata," 1978). While the importance of addressing the health needs of vulnerable groups in low-income countries is increasingly being recognised, there are many challenges in how this should be done for different categories of vulnerable people. Vulnerable groups are defined as "social groups who experience limited resources and consequent high relative risk for morbidity and premature mortality" (Flaskerud & Winslow, 1998), and this may include women, children, elderly people, ethnic minorities, displaced people, people suffering from some illnesses and people with various types of disabilities. While some challenges are similar across different groups of vulnerable people, others are specific to a particular vulnerable group. People with disabilities are a vulnerable and marginalised group. They are often excluded from mainstream social, economic and health services and lacking in educational opportunities to meet their full potential (A.H. Eide & Loeb, 2006; A. H. Eide, Nhiwatiwa, Muderedzi, & Loeb, 2003; A. H. Eide, van Rooy, & Loeb, 2003; Groce, 2004; M. Loeb & Eide, 2004; M Loeb, Eide, Jelsma, Ka'Toni, & Maart, 2008; UN, 2006).

The EquitAble project[1] focuses on the challenges that disabled people face in achieving universal and equitable access to healthcare in resource poor settings. The overall project is organised into the following Work Packages (WP):

- *Work Package 1*: Project Management
- *Work Package 2*: Review and Analyses of International and National Health Policies
- *Work Package 3*: Intensive Qualitative Studies of Activity Limitations and Access to Healthcare
- *Work Package 4:* Extensive Quantitative Studies of Activity Limitations and Access to Healthcare
- W*ork Package 5:* Influencing Policy and Practice and Dissemination.

WP1 and WP5 are ongoing throughout the project and are not reported on specifically. WP4 will be reported in a future report as will an additional report on Phase 2 of WP3. This report is for WP3 Phase 1.

1.1 Synopsis of WP2

Policy analysis constituted Work Package 2 of the project, the primary objective of which was to conduct an assessment of existing international, African Union and African country-level policies on universal and equitable access to health care with particular reference to people with disabilities. Policies examined included those from the AU, WHO, World Bank and other UN and multilateral organizations; NGO policies, donor governments' policies and 'in-country' government policies. Our goal was to identify, at the policy level, the extent to which relevant health policies protect and promote universal and equitable access to health care.

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[1] The full title of the project is Enabling Universal and Equitable Access to Healthcare for Vulnerable People in Resource Poor Settings in Africa

A new framework for policy analysis, EquiFrame (Mannan, Amin, Maclachlan, & EquitAble, 2011) was developed by the Work Package Leaders, in consultation with the other three African country partners, the project management team and other project partners. This framework examines the degree to which Core Concepts (CCs) of Human Rights were incorporated in policy documents and the extent of coverage of Vulnerable Groups (VGs) who might benefit from such policies.

Thus, health policies, policy documents operationalising health policies and programme evaluations of health care were collated and analysed to examine whether issues related to universal and equitable access to health care were addressed. A particular focus was to assess the degree to which people with disabilities (one of the Vulnerable Groups covered) were incorporated into the policy documents. The assumption underlying this analysis was that good coverage in policy documents is one component of a strategy to ensure equitable access to health care for marginalised and vulnerable groups.

The WP2 analysis concluded that, while some health policies did have good coverage of vulnerable groups in relation to the core concepts, there remain large gaps in coverage. The coverage was limited particularly for people with disabilities. Many policies make reference to the importance of taking the needs of vulnerable groups into consideration in policy implementation, but little is provided in these documents on how to achieve this effectively.

While Work Package 2 (WP2) focused on analysis of policy documents, Work Package 3 (WP3) collected data from four sites in each of the four countries on the experiences of people in accessing health care services and health care professionals in providing health care services. This allowed for a link to be developed between the policies on paper and the implementation of these policies on the ground.

1.2   Structure of report on WP3

WP3 aimed to investigate the experience of health service users, health service non-users and health service providers in accessing health care. This was undertaken within a qualitative methodology to develop, as its first aim, a detailed and nuanced understanding of these experiences and the factors that shape them. The second aim of WP3 was to provide information for developing the survey tools for WP4.

WP3 was divided into two phases. Phase 1 focused mainly on users and providers, while Phase 2 (to be conducted after WP4) will focus primarily on health service non-users. This report presents the findings from Phase 1 of WP3.

The structure of the report starts with the theoretical model used in the conceptualisation of the EquitAble project followed by the integrated findings from the four African countries: Malawi, Namibia, South Africa and Sudan. The report concludes with suggestions on how the findings fit the model, and how it can be improved or revised to reflect these findings. This process will be revisited, in a later report, once the results of WP3 Phase 2 and the WP4 quantitative study are analysed. Further information on individual countries can be obtained from the individual country reports.

2 Conceptual and contextual frameworks for WP3

2.1 Theoretical model for EquitAble

The model presented in Figure 1 describes the theoretical basis for the EquitAble study, illustrating how the variables of activity limitations, context and systems variables, and personal and community variables interact in informing universal and equitable access to health care:
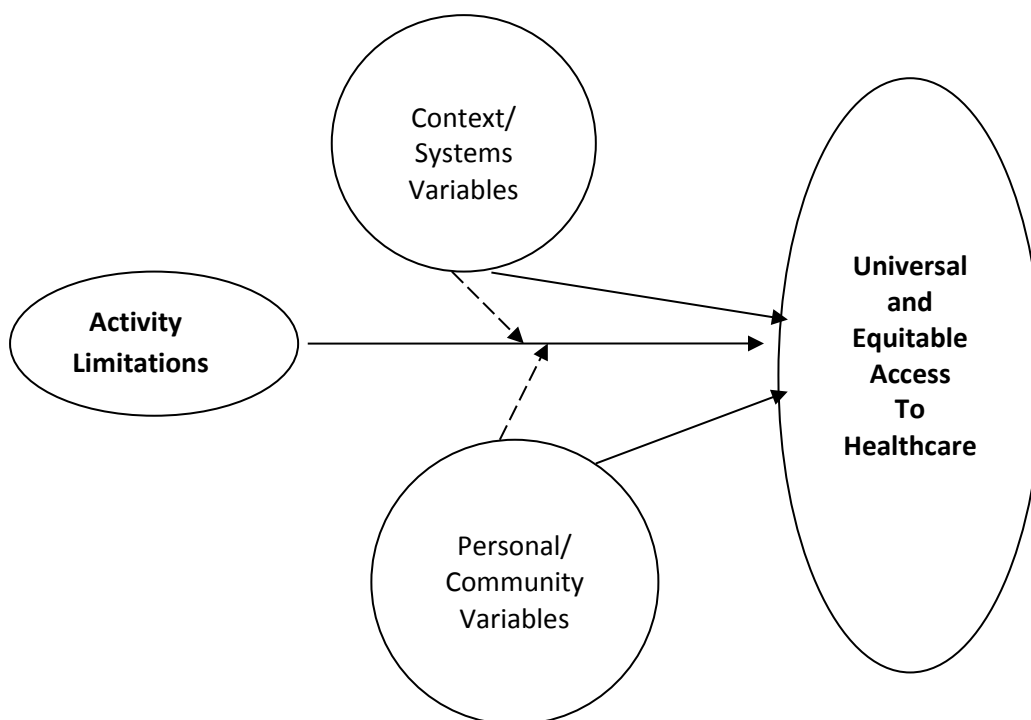
Figure 1: Theoretical model depicting the relationships between activity limitations, context and systems variables, and personal and community variables interact in universal and equitable access to health care

The activity limitations-access relationship is influenced by a number of 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). 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).

Equitable health care services are those that meet the needs of all people and are measured using the following indicators: Accessibility, availability, acceptability and quality.

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 refers to 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 refers to characteristics of the health care services that relate to respect, cultural appropriateness, gender sensitive, acknowledging the life cycle requirements, and designed to respect confidentiality and improve the health status of those concerned.

Quality refers the importance of providing services that are scientifically and medically appropriate and that address all health care needs.

2.2   Health systems in the four African countries

This section presents a brief description of health systems in each of the four countries: Malawi, Namibia, South Africa and Sudan.

2.2.1   Malawi

The delivery of public health services in Malawi has been decentralized and the Ministry of Local Government and Rural Development is responsible for delivering health services at district and lower levels. This follows the 1997 Decentralisation Policy of the Government of Malawi. The Ministry of Health headquarters mainly deals with policy formulation and enforcement and the setting of various standards. It also provides technical support and supervision, including monitoring and evaluation, to local governments. The Ministry of Health has also established zonal health support offices which provide technical support to the districts. The zonal offices are part of the Ministry of Health Headquarters. The private sector is also involved in the delivery of health services.

The Ministry of Health works with the private sector mainly through the Christian Health Association in Malawi (CHAM). Public health services are free but CHAM charges user fees. In order to increase access to health services in particular maternal and child health, service level agreements (SLAs) have been signed between district health offices (DHO) and CHAM facilities. Under these agreements, CHAM facilities provide free services to the population in their catchment area the DHOs pay for these services. This ensures that vulnerable segments of the population, especially mothers and children, are able to access services (see Euro Health Group, 2010). The NGOs also play an important role in terms of implementing promotive and preventive health interventions. The majority of health facilities in Malawi belong to the Ministry of Health followed by the private sector and then CHAM (see Centre for Social Research, 2008).

There are three levels of health care in Malawi: primary, secondary and tertiary levels. Health posts, dispensaries, maternities, health centres and community and rural hospitals constitute the primary level. At community level, health surveillance assistants (HSAs), community-based distribution agents and village health committees (VHCs) are involved in health services delivery. HSAs mainly deliver promotive and preventive health services such as health education, delivery of HIV testing and counselling (HTC) services and provision of immunization services. Community and rural hospitals provide primary care but they also have limited admission facilities (see Ministry of Health 2004).

District hospitals constitute the secondary level of health care and are referral centres for health centres. They provide both inpatient and outpatient services. Each district should, but not all do,

have a district hospital. CHAM also has hospitals that provide secondary level of health care. The provision of health services at primary and secondary levels is the responsibility of the Ministry of Local Government and Rural Development. The district or CHAM hospitals provide general services, PHC services and technical supervision to lower units in the district (see Ministry of Health, 2004). Health services at district level are managed by the District Health Management Team (DHMT) headed by the District Health Officer (DHO) who in turn reports to the District Commissioner at district level.

Specialist health services are provided by Central Hospitals. Currently there are four central hospitals; viz. Mzuzu, Lilongwe, Zomba and Queen Elizabeth Central Hospitals and the Zomba Mental Hospital. A district expenditures study conducted in 2009/2010 found that while central hospitals are supposed to provide specialist services, they predominantly provide essential health package (EHP) services which should be the responsibility of primary and secondary level of care.

2.2.2   Namibia

At independence in 1990 Namibia inherited a racially segregated health systems based on the apartheid doctrine. Thus the Ministry's task was to address these inequalities. In its policy statement entitled *"Towards Achieving Health for all Namibians"* it called for provision of health care based on the principles of primary health care that is guided by, equity, community involvement, sustainability, inter-sectoral collaboration and quality care (MRC, 2009). Furthermore, to strengthen its policy of providing healthcare, it adopted the decentralisation policy to improve service provision and management by devolving authority to 13 Ministry of Health and Social Services (MoHSS) regional directorates. At the national level, re-organisation has been undertaken to enable the national level to support service provision and management development for the whole health sector. The 13 regional directorates oversee service delivery in a total of 34 health districts (Government of the Republic of Namibia, 2005).

Public health services are offered by the MoHSS and faith based services by the Lutheran and Roman Catholic, while private services are provided by medium sized hospitals, pharmacies, doctors, to name but a few. Even though the MoHSS is geared towards providing health services for the public it is also tasked to set norms and standards for health operations in the country. The Ministry provides health and social services based on the tenets of the Primary Health Care (PHC) approach, which remains the benchmark for health and social service delivery as the approach is responsive to rational, evidence–based and anticipatory health needs and social expectations.

2.2.3   South Africa

It is not possible to understand the current context of health within South Africa without reference to the enormous changes which the country has seen since the advent of democracy in 1994. The ushering in of democracy led to a new constitution and far-reaching changes in health issues. Access, which is a core issue for the EquitAble project is therefore not just a policy concern for health provision in South Africa but a constitutional requirement.

The health system in South Africa comprises the public and private health sectors. The public sector consists of primary health provided free of charge, secondary or district hospitals, tertiary or provincial hospitals, and with a few national level hospitals such as Groote Schuur and Tygerberg hospitals in the Western Cape, Charlotte Maxeke and Chris Hani Baragwanath hospitals in Gauteng, and Nkosi Albert Luthuli Hospital in KwaZuluNatal.

The health system in South Africa was described as "dysfunctional" by the former Minister of Health, Dr Barbara Hogan, in October 2008, with vacancies of 46 000 nurses and almost 10 000 doctors. [2] Coovadia et al (2009) also describe the health system in South Africa as "dysfunctional". They note that the national health system has been transformed into an integrated service, but they argue that "failures in leadership and stewardship and weak management have led to inadequate implementation of what are often good policies" (Coovadia et al., 2009, p. 1).

Harrison (2010)[3], in his overview of health and health care in South Africa highlights "ten strategies that have led to significant progress include five instruments of legislation and gazetted policy, and five achieved through good health systems management" (p13). These implemented since 1994 include:

a) *Legislation and gazetted policies*
1. Free primary health care
2. Essential drugs programme
3. Choice on termination of pregnancy
4. Anti-tobacco legislation
5. Community service for graduating health professionals

b) *Better health systems management*
6. Greater parity in district expenditure
7. Clinic expansion and improvement
8. Hospital revitalization programme
9. Improved immunization programme
10. Improved malaria control

Harrison contrasts this with "ten of the biggest challenges facing the health sector [,which] relate to the prevention and control of epidemics, the allocation of resources for health care, and five intractable problems related to health management." (p18). These include:

a) *Prevention and control of epidemics*
1. Prevention and treatment of HIV/AIDS
2. Prevention of new epidemics (esp. MDR-TB)
3. Prevention of alcohol abuse

b) *Allocation of resources*
4. Distribution of financing and spending
5. Availability of health personnel in the public sector

c) *Health systems management*
6. Quality of care
7. Operational efficiency
8. Devolution of authority

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[2] source: http:/ /www. healthe.org.za/news/article.php?uid=20032099.

[3] D Harrison, (2010) An Overview of Health and Health care in South Africa 1994 – 2010: Priorities, Progress and Prospects for New Gains. *A Discussion Document Commissioned by the Henry J. Kaiser Family Foundation* *to Help Inform the National Health Leaders' Retreat Muldersdrift, January 24-26 2010. Accessed 12 Aug 2011 at http://www.doh.gov.za/docs/reports/2010/overview1994-2010.pdf*

9. Health worker morale
10. Leadership & innovation

The results from the South African sites can be assessed in relation to these strategies and challenges, with particular reference to quality of care including both medical and non-medical aspects of health care.

2.2.4 Northern Sudan

The health system in Northern Sudan is a three-tier system. The federal level is concerned with policy making, planning, supervision, co-ordination, international relations and partnership. The state governments are empowered for planning, policy making and implementation at state level while the localities are concerned mostly with policy implementation and service delivery including health, education, and development. Currently there are 25 states, (10 of which constitute the Southern Sudan which as of July 4th 2011 becomes an independent state). Each state is administered by a Wali (Governor) with a cabinet of 5-7 ministries and 5-12 localities. The Localities are administered by a Commissioner.

The decentralized system requires large human and material resources. These are insufficient in most of the localities and states at the present time. There is an inherent problem with regard to resources distribution between the three levels of governance which renders the local level weak in service delivery. The frequent amendments and changes in the function and structure of the locality level is a further factor affecting the development of a clear system of governance and organization. Many partners are involved in health care provision. In the absence of a comprehensive strategic framework there is marked inefficiency, fragmentation of the health system and poor coordination between partners.

Primary Health Care was adopted as the key strategy for health care provision in Sudan in 1978 and re-emphasized in the National Comprehensive Strategy for Health in 1992-2002 and in the 25-Year Strategic Health Plan 2003-2027. The Interim Constitution of the Republic of the Sudan, in its guiding principles chapter, commits the Government to provide universal and free of charge basic health services.

The recent 2009 Federal Ministry of Health (FMOH) policy indicates that the minimum package for PHC services should include; Vaccination of children (EPI), Integrated Management of Child Illnesses (IMCI), Reproductive Health (RH), essential drugs, nutrition, health education and treatment of common illnesses. The Health Management Information System (HMIS) performance is weak, unreliable and fragmented. This was a result of poor administrations of the systems, under funding and a lack of harmony between different players in the health arena. Recognizing these facts, the FMOH has developed a plan to strengthen the HMIS which will be financed through Health Metric Network (HMN).

The government policy of liberalization and free market declared in 1999, led to great privatization of the health sector, and a concomitant reduction in the subsidisation of free or partially-subsidised public health, education, water and electricity services resulting in users having to pay for all these services at full or almost full cost.

3 Methodology

3.1 Aims and objectives of WP3

The aims and objectives of WP3 were to:

- provide an in-depth description of what happens when people with disabilities are using the health care services (users),
- explain why some people with disabilities do not use health care services (non-users) – reported in a future report.
- determine how health care providers understand their and the health system's role in providing equitable and universally accessible health care including to people with disabilities.
- describe people's understanding of what they see as the important factors that determine access to health care.

3.2 Data collection methods

WP3 used qualitative research methods. The aim of WP3 was to investigate the perceptions and experience of health service users, health service non-users and health service providers, and hence in-depth, qualitative research methods were deemed suitable.

WP3 data collection was planned in two phases: phase 1 occurred prior to and in preparation for WP4 (quantitative survey of households in each site) and phase 2 is planned to occur after the completion of WP4 and will focus on non-users and completing those aspects of Phase 1 not yet completed. Thus this report presents the findings of WP3 phase 1.

The following data collection techniques were used:

1. *In-depth interviews* with users, non-users and service providers using an interview guide to ensure that similar topics were covered but also allowing for open descriptions by the interviewees. The analysis was conducted in form of a thematic analysis using the interview topics as a starting point and also allowing the data to provide further themes not covered in the interview guide. The interviews were conducted in the preferred language of the participant by a fieldworker that was trained in the data collection techniques. Trained interpreters were also used in the instances where the interviewee's preferred language was not the same as that of the participant. Interviews took place in either in the healthcare facility or in the participant's home, and in a few cases in both. The Atlas-ti software programme was used for the analysis of the interviews.

2. *Facility reviews* where a series of checklists were developed, and a full description of the facility undertaken. This included the number and level of staff, size and level of health care provision at the facility, referral networks, financing of the facility, the number and type of consultations (e.g. children, adults, specialist clinics), provision of assistive technology (e.g. wheelchairs, eye glasses, hearing aids, walking frames), as well as individual interviews and/or focus group discussions with providers in the facility. The data collected was reported in the format of a detailed report on the

facility using prescribed headings for the different components. These data were analysed in terms of trends across the different types of facilities.[4]

3.3   Sites

Four sites were selected in Malawi, South Africa and Sudan, and Namibia selected five sites. A synopsis is provided of the selection and description of the four sites in each country. More detail is available in the individual country reports.

While all four countries selected sites that reflected the diversity of the country, the actual selection approach was quite different. Malawi selected four districts and two health facilities within each of these districts. The sites were the catchment area of these health facilities. Namibia selected five districts to obtain a better representation of the country's diversity. Within each district they selected 3 sites. South Africa chose four local sites and one health facility within each of these four sites. Sudan selected Localities in each province and within these selected a number of health facilities ranging from the primary entry level through to referral hospitals.

3.3.1   Malawi

This study was conducted in four districts in Malawi namely Rumphi in the northern region, Ntchisi in the southern region and Blantyre and Phalombe in the southern region. The choice of districts was done in such a way as to capture the cultural diversity prevailing in Malawi. Blantyre was chosen because there was a need to have an urban area as problems in terms of accessing health care in urban areas are different from rural areas. Our point of entry in each district was the District Health Officer: the purpose of the study was explained to him and he was requested to help the research team identify 2 health facilities with at least one being CHAM facility. Therefore eight health facilities were selected with the help of the District Health Officers as follows: Nthenje and Lura Health Centres in Rumphi, Mkhuzi and Khuwi Health Centres in Ntchisi, Chitekesa and Mwanga Health Centre in Phalombe and the Chileka SDA Hospital and Chimembe Health Centre in Blantyre. Data was collected in the catchment areas of these health facilities.

3.3.2   Namibia

Data was collected in 5 regions of the country:

1. *Caprivi*: Caprivi is a rural area in the north east of the country. It has a high number of visually impaired persons, is prone to seasonal flooding that enhances vulnerability, and has a high HIV prevalence rate (31.7%). Three sub-sites were selected within Caprivi: Kabbe, (prone to seasonal flooding); Chetto (home to the San which is a recognised ethnic minority group in the country) and Sibbinda (home to a number persons with disabilities).
2. *Hardap*: The Hardap Region has two main towns namely Mariental and Rehoboth. Mariental hosts the Regional offices of all the government line Ministries. The landscape is mainly made up of the Kalahari Desert in the east, the Namib Desert in the west and the Savannah Highlands in the Centre. Mariental is well known for its floods especially when Namibia receives high rainfall. This region mostly represents a rural-urban divide in the country. It is in the south of the country and the population is highly dispersed with 0.6% per square kilometers. The following sites were selected in Hardap: Gibeon; Stampriet; and Aranos. The sites are mostly surrounded by

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[4] This component will be primarily completed in phase 2 of WP3.

commercial farms on the one hand but also give a geographical spread of the region on the other hand.

3. *Khomas*: The Directorate Khomas Region hosts the capital city of Namibia, Windhoek, with a square kilometer area of 37,590. Informal settlements of shacks have developed to the north and west of Katutura. The size of the population living in these settlements is estimated at 41, 386. A pragmatic policy has been adopted towards informal settlers in an attempt to control the density of settlement and ensure access to basic amenities. In general, squatting is becoming a serious problem, not only in the informal settlement areas but also in other areas such as backyards, garages, under bridges, riverbeds etc. It represents the central parts of the country as well as the urban settings. There is abundance of health facilities for health seekers to choose from and has a diverse language groups representing all parts of the country. The following sites were selected in Khomas: Okuryangava clinic (Close to the disability resource centre); Katutura Health centre (serve as a referral for Okuryangava clinic); and Dordabis clinic (situated in a remote area)

4. *Kunene:* This region is also known as *Kaokoland* and is home to the Himba minority ethnic group. Compared to the rest of Namibia, it is relatively underdeveloped. This may be due to its mountainous inaccessible geography and the dryness that significantly hinders agriculture. The largest town and capital is Opuwo. It is mostly a rural area representing the north western part of the country. A high number of ethnic minorities are representative of the region. The following sites were selected in Kunene: Opuwo clinic (Opuwo is regarded as the main town which serves the surrounding areas); Etanga (very remote area in the mountain of the region); and Okangwati (mostly you find the Vembas as ethnic minorities).

5. *Omusati:* Omusati is in the north-western part of the country. The region is divided into 12 constituencies namely: Outapi, Anamulenge, Oshikuku, Etayi, Okalongo, Ogongo, Elim, Okahao, Otamanzi, Tsandi, Onesi and Ruacana. Its borders are: Angola to the north, Kunene region to the northwest, Oshana region to the east and Oshikoto region to the south. It is urban and represents the north central region of the country. There is a high number of people with physical disabilities and it is dominated by one ethnic group which is part of the whole north-central region. The following sites were selected in Omusati: Anamulenge (under the auspices of the Catholic Church with support from government); Omagalanga (prone to seasonal flooding); and Tsandi (rural town area).

3.3.3 South Africa

Within each of the four sites, one primary health care facility from the formal health care system was selected. The primary health care facility was a health clinic, centre or secondary hospital, governed by the Department of Health, which is the first point of entry into the formal healthcare system.

In South Africa, the sites were chosen from three provinces: Northern Cape, Eastern Cape, and Western Cape. The sites and areas were selected to depict the high levels of inequality that is found in South Africa. The following sites were selected:

1. Fraserburg (Northern Cape): This is a predominately Afrikaans rural farm setting comprising of a small town and, surrounding the town, a number of large sheep farms. Afrikaans is the major language spoken by all residents White and Coloured. There are very few Black people in Fraserburg. Alcohol, violence and the related disabilities, and unemployment (e.g. Fetal alcohol

syndrome) are the major problems in this area. Fraserburg has a clinic as the formal health care system of which a doctor is available every two weeks (functioning as GP and district surgeon). There is limited transport with not even a taxi service from the farms to town or within the town.

2. Madwaleni (Eastern Cape): This is a deeply rural area with many inequities, water and sanitation problems, poverty, and tape worm infestations. Almost every household has someone with animpairment as a result of the tape worm infestation. There are high levels of mental illness (psychosis), combined with many people suffering from seizures. The 200 bed secondary hospital, Madwaleni Hospital, is embedded within the system of approximately 30 villages. There are eight satellite clinics around Madwaleni hospital. The main language spoken is a rural pure form of Xhosa.

3. Worcester (Western Cape): This is classified as a rural area within the demographics of the Western Cape, but it consists of a town whose inhabitants range from high to low socio-economic status and cut across all the main population groups of South Africa. The surrounding townships consist of one predominantly Coloured township whose inhabitants are largely coloured and poor, and a Black township whose inhabitants are predominantly Black and poor. In addition, there are a number of surrounding farms which are owned predominantly by White farmers employing coloured and Black labourers. The catchment area for the local clinic is wide and users have to travel vast distances to access health care. The major health problems in the area are related to occupational injuries (e.g. farmworkers) and a high prevalence of foetal alcohol syndrome (the legacy of the 'dop system'[5] which is still being practiced).

4. Guguletu (Western Cape): This is a large predominantly Black township outside of Cape Town. It was selected as it is an area not over researched compared to some other Cape Town township areas. Guguletu is an old established area with high rates of crime and TB. There are a number of clinics in the area.

3.3.4 Sudan

Selection of the states was done to guarantee a representation of all parts of Northern Sudan. Four states were selected namely, Khartoum State, to represent the northern/central areas; White Nile State to represent the southern part of North Sudan, North Kordofan State to represent the western part and Kassala State to represent the eastern part. In each state one Locality was selected.

The selection of sites within these states was done based on the following criteria: including rural and urban districts and populations; a socially, ethnically and economically diverse population; the presence of multi-levels of health services (i.e. from hospitals (secondary/tertiary) to dressing units (basic primary health care)); and including vulnerable populations. A total of 26 health facilities were selected.

In North Kordofan, the Locality of Sheikan represents the diversity of ethnic groups mainly of West African and Arab descent and with more than 95% Moslems. Severe drought has led to significant numbers of displaced people. Kassala and Wad Sharfi localities in East Sudan represent those from non-Arabic, non-Black East African ethnic groups, non-Arabic mother tongue and many displaced due to floods or refugees from Eritrea and Ethiopia living in the localities. Umbadda locality in

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[5] The 'dop' system is one where farmworkers and other casual labourers are paid partly in cash and partly with alcohol.

Khartoum State represents the diversity of the Sudanese population whereby many displaced and other non-displaced residents come from all parts of Sudan with a substantial number of Christians, Southerners, groups from Western Sudan and others living mainly in poor residential areas as well as having a large number of displaced camps, including one of the largest in Sudan.

3.4   Selection of respondents

Users were defined as people or households who use health care services within the study sites; non-users are either those who are not in need of the health care services, have stopped trying to use these because of significant barriers, or who simply do not use the selected health care facility. Disabled users and users with other vulnerable factors were purposively sampled to ensure case studies on people with a range of activity limitations or who had other vulnerability factors (e.g. women headed households, living far from the health facility) in this exploratory part of the larger EquitAble project. Non-users will be identified and selected from the responses on the quantitative survey (Work package 4) and from those indicating a willingness to take part in a further interview. Because WP3 is an exploratory study, inclusion and exclusion criteria are very wide and selection is based on a purposive sampling approach.

The health service providers were people providing health services at the different levels of health care system (primary, secondary and tertiary care) and including both lay-health workers and traditional health workers. In each of the sites, at least one primary health care facility (formal health care) was selected and investigated through observation of their users' and providers' behaviour, and through their self-reported experiences. Providers include all levels of staff working in the health care facility to provide health care and do not only include the professional clinical personnel, but also, for example, clerks who do the initial administrative processing of users of the services.

3.5   Data collection tools

The South African team, as the lead country for WP3, provided a set of data collection instruments. These listed the topics to be covered in the in-depth interviews, focus groups and health facility checklists. However, the complexities of working across four countries with different levels of skill in doing qualitative work, led to many of the interviews being more semi-structure in nature than in-depth. This issue is covered in more detail in the accompanying EquitAble paper on the methodological challenges faced in doing WP3 across four countries. This led to different number of interviews being completed in each country. The interview guides have been revised for Phase 2 of WP3 to encourage more in-depth interviews. Appendix A provides the data collection instruments for Phase 1 of WP3.

3.6   Number of interviews completed in each country

Health care providers were people involved in some way or another in providing health care. This category includes traditional healers and private health care providers.

Key informants were people who understand or are involved in the community but are not providers of health care. These respondents included people like local councillors, chiefs and headmen, religious leaders and community workers.

Table 1: Total number of interviews completed in WP3 Phase 1

Country	User interviews	Health Care provider interviews	Non-user interviews	Key informants	Comments
Malawi	244	46	(included in user interviews)	Not specified	27 focus groups; 52 of 244 interviews done with people with disabilities
Namibia	323	78	None	Not specified	Providers were more likely to be female
South Africa	53	57	4	22	Key informant interviews were important
Sudan	50	26	None	Not specified	Health care providers were mostly male but included a few females

3.7   Analysis using the code book

As the EquitAble project comprised four African countries, a standard analysis was developed to allow for comparison across the four countries. This standardisation was achieved through an iterative process and coordination of feedback from all four country teams. The initial codes emanated from the themes identified in the model presented at the start of this report. This was then augmented with codes that arose from the thematic analysis of the interviews. Each country provided additional codes or sub-codes for the code book. The final code book was drawn from the range of codes provided by each country team.

The code book included themes which included a range of codes, and which in turn comprised a number of sub-codes. The four themes were: 1) meanings and understandings; 2) social context; c) access to health care; and 4) quality of health care. The full set of codes from the code book is presented in Appendix B.

The codes were seen as the major focus of coding in the analysis of interviews and were common across the four countries. The sub-codes were those that allowed for more specific country level analysis and provide means of showing the specific features of each country or each site within a country. There were few codes provided by one country that were not relevant for all countries.

The country reports were structured according to these major themes. This integrated report goes back to the model presented in the introduction and reviews the findings in relation to these different factors that affect the equitable access to health care for people with disabilities and members of other vulnerable groups in the four study countries.

3.8   Ethical considerations

Each country team applied for ethical clearance from their respective ethics committees.

3.8.1   Malawi

The application for ethical clearance was submitted to the National Health Sciences Research Committee for ethical approval. The implementation of the study only started after getting approval. Most of the respondents in this study were aged 18 years and above and where children are involved parents or guardians were interviewed instead in order to elicit their experiences about seeking care for their disabled children. For people with intellectual disability, a relative or parent in case of children were available during interviews. Participation in this study was voluntary: they

were told about the purpose of the study and that while their participation was important they were free to withdraw at any time.

3.8.2 Namibia

The Namibian team submitted their ethical application to the Ministry of Health and Social Services who granted permission for the study to be conducted in their health facilities.

3.8.3 South Africa

Overall ethical clearance for the project was obtained from the Health research Ethics Committee, Health Sciences Faculty of Stellenbosch University. Ethical clearance was obtained from the relevant provincial department of health authorities. This was done through the Northern Cape Department of Health for Fraserburg, Western Cape Department of Health for Gugulethu and Worcester, and Eastern Cape Department of Health for Madwaleni.

3.8.4 Sudan

The ethical review committees of Ahfad University for Women and the Federal Ministry of Health endorsed the Equitable qualitative and quantitative studies i.g. WP3 and WP4 and clearance certificates were obtained. Verbal informed consents to participate in the study were obtained from the participants after being informed about the purpose and benefits of the study. They were assured of the confidentiality of information obtained. We did not encounter problems or individuals who did not want to participate in the study.

4   Results

The results are presented according to major themes, integrating findings from the four countries for each theme. The major themes are: 1) meanings and understandings; 2) the social context; 3) access; 4) quality of care; 5) availability of care; and 6) acceptability of care. The conclusion of this report (see Section 5: Conclusions) brings these findings together in relation to the model presented in the introduction.

4.1   Meanings and understandings

This theme refers to knowledge, perceptions, attitudes and understandings that people have of concepts such as equitable health care, health, disability and vulnerability. These meanings or understandings are assumed, on the one hand, to shape the way people see the formal health care system and influence their health seeking behaviours. On the other hand they influence how others see the health care seeker and, hence, how these understandings shape the way they assist household members to seek health care or health care providers provide services. The meanings and understandings held by an individual that determine their own access to health care are subsumed under the personal factors in Figure 1. The meanings and understandings of others that determine how an individual accesses care is subsumed under the community or social context variables.

Some of the codes and sub-codes included in this theme are prejudice and stigma, cause or origin of disability or illness and how these views influence the way people use or do not use the formal health care services and other forms of health care.

4.1.1 Equitable Health care

Equitable health care services are those that meet the needs of all people and are measured using the following indicators: Accessibility, availability, acceptability and quality. The health care providers were the main group of participants asked to define the notion of equitable health care. In Sudan users were also asked to define this term.

Generally this term was not well understood by participants and was only explored to a limited extent as it was seen as quite an abstract concept.

The major feature of equitable health care was expressed as accessibility. Linked to this were the notions of rights to access the same quality of service at the same cost for all. The lack of discrimination as a basis for equitable health care was embodied in the description of the term as being about providing health care for all without discrimination based on area of residence, gender, disability, age, socio-economic status, ethnicity, religion or political affiliation or geographical location, or as expressed by a clinical officer in Malawi, *"receiving health care and accessing health services at any health facility without problems and without looking at ethnic group, tribe, religion, political affiliation or gender, etc."*

In Sudan, the issue of equitable health care was understood differently by providers and users. Most users interpreted the concept as equality and availability of service while medical personnel associated it with the availability of primary health care service for everyone.

4.1.2 Health

There seems to be many different understandings of what the term 'health' means at grassroots levels. The WHO defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. The discussions focused more on the factors that make up or influence whether a person is healthy or not, than actual definitions of health. Most respondents focussed on one domain of health ranging from aspects related to physical health through to financial aspects. Some respondents were able to integrate more than one domain into their understanding of health. The domains of health noted by participants included physical, social, emotional, spiritual and financial wellbeing. These are all recognised as important features of wellbeing in the literature on quality of life and wellbeing (Manderson, 2005). Thus while most participants referred to the more physical aspects of health, there was consensus across all four countries on the broader notion of health embodied in the WHO definition of health.

The physical aspect of health was seen as most significant across the four countries with the mental and social aspects only really covered in South Africa.

a) Physical wellbeing: Some of the participants considered health merely in terms of disease or infirmity- "*to be the absence of disease, or bad health to be the presence of illness*" (SA) or "*when one is not sick*" (Namibia), or "*It was also considered to be the opposite to being sick*" *(Sudan).*

But physical wellbeing is not the sole component of health as clearly expressed by a Sudanese respondent: *"physical wellbeing counts for only 85% of health"*.

Diet was seen as a main prerequisite for health and was extensively mentioned in all countries. Many comments described what a person should do to remain healthy:

"You can keep your body healthy by eating the right and necessary foods like fruit, vegetables, salads - see to it that you work out a decent diet for yourself and that you keep your weight under control." (South Africa)

"I need to eat a healthy balanced diet. Generally, just to eat health food and get vitamins to keep the body healthy." (Namibia)

"Health for me is the clean water, good nutrition, cleanliness of the body." (Sudan)

"Malnutrition and bad eating lead to illness and poor health.¨ (Sudan)

While diet was seen as important, comments did indicate that it comes at a cost:

"If you have enough money to buy good food, you will not get sick." (Sudan)

Environment was also considered important in Namibia and Malawi:

"In order to live a healthy life a person must make sure he/she lives in a clean environment. The place should be clean and there is no long grass because that is where mosquitoes breed that cause Malaria. So in order to live a healthy life style we have to keep everything in and around us clean and tidy" (Namibia).

"The household should be kept clean all the time by sweeping it, having clean toilets and bathrooms, rubbish pits for proper disposal of rubbish, and also having a good and safe source of drinking water" (Malawi).

Exercise, lifestyle and adherence to prescribed treatment were seen as important factors contributing towards health:

"You must also exercise regularly" (South Africa).

"To be healthy you need to take the medicine as you are told by the nurse within the given time. If they said take the medicine before or after the meal, you do what they said" (Namibia).

"Health is to keep your body fit and healthy by exercising" (Namibia).

How one behaves and one's lifestyle also contribute to health, such as smoking and drinking, taking medications when needed and visiting the doctor on a regular basis.

"Health is a whole lot of behavioural issues around the body and how the person behaves around the body but how the person behaves around life in general. It is a whole lot of things. The way the person behaves is a yardstick if he is well. Health is very important and integral in one's life. When someone is vulnerable and weak that person cannot do much for oneself" (South Africa).

"If you're not a smoker stay a non-smoker, that's the best. (...) Gosh, of course I believe that laughter is very healthy for you. I think laughter is your best medicine" (South Africa).

b) <u>Mental wellbeing</u>: Comments such as those presented below suggest that mental was considered by some to be rep wellbeing is also considered an important component of health:

"Mood must be right" (South Africa).

"Unless psychologically well one cannot be 100% fit" (Sudan).

Thoughts and attitudes were also considered important in maintaining health:

"If you're right and you have a positive attitude, then health will follow" (South Africa).

"My sister tells me not to worry so much about things and then I feel better" (South Africa).

c) <u>Spiritual wellbeing</u>: Health was seen in terms of religious or spiritual wellbeing, and faith considered as a means to overcoming health conditions:

"You must be spiritually in tune" (South Africa).

"Health is when you keep your spirit healthy. You only have one body, you must keep your spirit as healthy as possible. If your spirit is healthy, it houses a healthy body. Therefore you must do everything in your power to firstly keep your spirit healthy. You must build your house on the Lord, your religion must be in control, and then according to that you must build further. And then you must always have a positive attitude in life and then automatically you can try to look after your body, because your body belongs to the Lord" (South Africa).

d) <u>Social well-being</u>: This includes a person's relationship with his/her family and other members of the community, *"to have friends"*, being surrounded by positive people, friendliness, supportive loving families, being of service and useful to others (South Africa). Social wellbeing was not mentioned as an important aspect to health in other countries.

e) <u>Financial wellbeing</u>: This was only mentioned in South Africa but with the proviso that *"It's not only the financial security that facilitates health"* (South Africa).

f) <u>Health as multiple domains</u>: Some participants made reference to multiple domains that make up health, as highlighted in these South African comments:

"In the first place your mood must be right. You must be spiritually in tune. You must set a life quality for yourself. If you're right and you have a positive attitude, then health will follow. If the spirit is right the physical body will automatically follow."

"If you want to live healthy, you must remember that hygiene goes with that. It's not only the financial security that facilitates health. I must foster and nurture health in my immediate environment. I think it starts with the parents. Health must be taught to a child from a young age."

"Personally I would say it's spiritual and physical security. The fact that I'm healthy is for me of the utmost importance. It gives me a better outlook on the future. It makes me feel

positive and through my health I can be constructive in a positive way. Being healthy also means that I should be grateful to my God who created it for me".

"You can keep your body healthy by eating the right and necessary foods like fruit, vegetables, salads - see to it that you work out a decent diet for yourself and that you keep your weight under control. (...)You must also exercise regularly and you must drink a lot of water. You must like yourself. You must see to it that you like yourself".

4.1.3 Vulnerability

Vulnerable groups are "social groups who experience limited resources and consequent high relative risk for morbidity and premature mortality" (Flaskerud & Winslow, 1998) and this may include women, children, elderly people, ethnic minorities, displaced people, people suffering from some illnesses and people with disabilities. While different groups of vulnerable people present some similar challenges for their equitable access to healthcare, there are also distinctive challenges presented by different groups.

Vulnerability in South Africa covered many groups:

- **Disabled people**: *"For him, people who are disabled … like he mentioned one gentleman who is even more severely disabled than him … and he sees him as vulnerable. He sees himself as vulnerable because of his disablement. And she feels that people with mental illness are actually far more vulnerable than other people."*

  "People with physical and mental problems. A lot of people look at you and see you as crazy. It isn't that you are crazy. They just see it in a different view."

- **AIDS orphans:** *"The children. It's always the children because they are [orphaned] because of the HIV virus."*

- **Mental illness:** *"And she feels that people with mental illness are actually far more vulnerable than other people."*

- **Low education: "***But the biggest one, I think, is the lack of education, because that makes them the most vulnerable."*

  "The education…People do not realize the seriousness of a [health] condition or when to be worried."

  "OK, I mean people's education is one of the big things for a number of reasons, one of them being the language barrier. So if your, you know, your education's very low and you can't speak English and you're going to an English speaking health centre - that's going to be a problem. Just education about sort of knowing, in health education - knowing when to go and to seek help, what are warning signs. Patients typically don't come if it's not painful so they'll have a fumigating breast mass, but say it wasn't painful so they don't bother to go to the hospital. So like health education is lacking."

- **Children:** *"Then obviously the children, because they can be overpowered quite easily in terms of physical vulnerability."*

  "they have no exposure…they argue, why do I have to study if I will not find a job anyway? Biggest social decay amongst boys…there are no real father figures...no role models for boys."

  " Ja, I would say children are vulnerable because with our communities, if you look at young people when it comes to relationships, in most instances they don't take informed decisions because they are not capacitated - they are not assertive..."

- *"They are more prone to everything. They don't know anything. They still need to be taught. The older people know better. Those in wheelchairs can't walk but they can still understand. But a kid is different. He still can't read".*

- **Elderly people:** *"And also the geriatrics because they can also easily be overpowered."*

  "Perhaps the elderly - old people who … from the old age home will get easy access, but those who live at their homes with their families and who do not have transport. You see, the ambulance don't come out for things like that. So if they have to come for medication or something like that and they don't have transport, it can be a problem for them to get here."

  "Some elderly people may struggle to access this facilities, ...I find out they cannot walk the long distance as the younger [people] can do that walk from point A to B if they do not have transport money. "

- **Young people:** Young people are vulnerable because of HIV AIDS and the challenge of disclosure. They become infected and do not disclose.

- **Stroke patients:** patients who had a stroke and are now discharged.

- **People living with HIV:** Chronic diseases and disabilities making people living with HIV vulnerable.

- **Women:** *"Ja, because we have that paternal system, and a lot of men are still dominant in relationships. And you will find that a lot of people are using substances, for instance, alcohol and drugs, so they end up abusing women. And also, even those people who are using those substances, are vulnerable."*

  "Some of them, those that are working, the working mother, the single parents that are working – most of them are charring or doing labour work, so it is difficult for them to be off at work because of the bosses who will not be impressed with them staying out of work to bring the kids. So they end up bringing the kid after some days, but they were scared to take off work to bring the child."

- **Poor people:**

"Our biggest economic sector is agriculture, but agriculture cannot create many jobs."

"that night I asked myself why I had to be so poor, because if I weren't so poor, I could have used private [health care]....I mean, I could have helped myself."

- **Farm workers:** They struggle to access health care due to geographical distances

- **Migrants**: *"You can say the Zimbabweans in De Doorns [farming community in the Western Cape] are a vulnerable group."*

For Namibia and Sudan, living far from services and poverty stood out as the most prominent vulnerability factors. Across all study sites in Namibia vulnerability was seen in the context of lack of money and transport:

"Alcohol abuse you drink everything you have and even sell livestock and drink all the money"; "Vulnerability factors: Distance, money, transport, violence by men";
"Money is a big problem because if you don't have money you will experience lot of problems."; "I earn an income but it is not always that I have money for transport and the clinic. It affects my health as I am not free to access health care when I need it."

Vulnerability was also discussed in the context of distance from the nearest health facility, unemployment and poverty: *"Distance is the main problem because many people stay far from the clinic and have to walk a very long distance to get to the clinic."; "Due to my unemployment status I cannot afford to pay the clinic because it is only my mom who is receiving money from old age pension. That money is only for food, water and electricity needs."; "some people are so poor that they cannot pay the fee that is charged at the clinic."*

In Sudan, like with Namibia, poor people were seen as vulnerable group. Most respondents stated that if you are poor and do not have money to eat well, then you are always vulnerable. Some of the elderly users say: *"if you do not have working sons to support you then you are vulnerable.¨*

In Namibia the elderly were especially seen as vulnerable; *"age also makes it difficult for a person to access health care. When a person gets too old, then you will not be able to walk. Like myself, I am very old, I am 88 years and it takes me a lot of time to get to the clinic",* while in Sudan women were also seen as vulnerable. Malawi did not cover vulnerability in their report.

4.1.4   Disability

The International Classification of Functioning, Disability and Health (WHO, 2001) offers a useful framework for studying disablement and health-related consequences of disease based on the following three concepts: impairments, activity limitations and participation restrictions. Impairments are understood to be problems with physiological functioning or anatomical (e.g., organs, limbs) structure of the body. Activity limitations are defined as difficulties in executing a task or action. Finally, participation restrictions are problems relating to involvement in life situations

In South Africa all three concepts were included at different levels while in Namibia it was only activity limitations that were observed and in Malawi and Sudan it was both impairments and activity limitations.

In South Africa disability is generally defined in its narrow term of being a physical impairment resulting in activity limitations, but some participants also considered other impairments such as intellectual and emotional disabilities:

> "*Disabled [people] can be the blind or the physical body disabled. Naturally it depends on the degrees of disability. The person might walk skew or he might need a wheelchair. Maybe talks with difficulty. That is the definition*".

> "*I want to say organ ... but part of his body is not functioning as it is expected.*"

> "*A progressive type of malice and weakness ……..can't be functional and can't do things for themselves.*"

> "*They physical bodily functions are hindered. Strokes make them paralyzed. It means when your bodily movements are obstructed. A disabled child can't do anything. He/she must be carried everywhere. Amputated patients don't have the use of their limbs. Paraplegics also have paralysed legs.*"

> "*I think disability is not just ... if one thinks about a disabled person, then you think about physical problems. But it can be spiritual, emotional, it's not just physical - an arm or a leg that is unable to walk or a mouth that can't speak, it can also be intellectual.*"

> "*Well, I think disability is multi-faceted: I think it's not only physical disability, but it's mental disability.*"

> "*there are three phases of disability: there's a physical disability, but then there's when your soul is disabled and your mind is disabled.*"

> "*disability- any part of the body that does not function properly -body or mind.*"

> "*I think if you have limitations because of some physical defects and mental defects that interfere with the normal function of that particular organ, whether it's an organ or the intellect. Ja, that is who I think is disabled.*"

> "*But we very easily say that deafness is the worst disability you can have because it destroys the human thing about communication between people - it constrains it. But some others would say that the psychiatric domain of autism and schizophrenia, or whatever, is worse. It also destroys your humanity.*"

Few referred to the process of marginalization of disabled people:

> "*Now, again I must lay this concept of social exclusion and social inclusion. The disabled are excluded socially by their disability, to whatever extent, depending on the severity. " but in the normal population, they are diluted and easily marginalized.*"

One respondent did not see disability as anything different:

> "*I see disabled people as normal. In their way they are normal. So basically they can do everything that we do. In their way. So they get along well. Sometimes they don't even want*

to be helped by us. She hates it when we write something down for her. She reads your lips so you just have to face her. I don't see them as abnormal at all."

The above quote is about a Deaf woman, and this comment is reflected in how Deaf participants themselves referred to Deaf Culture or issues around disability/non disability. The key informants reiterated the sentiment that Deaf individuals prefer to be considered a linguistic minority as opposed to being considered disabled, in the sense that they do not suffer from an ailment that needs to be cured;

> *"We're a linguistic and cultural minority, why do you want to change us. Leave us. Respect us. Don't try to heal or cure us with cochlea implants."*

When it comes to the disability grant[6] there seems to be more confusion as to what is disability. People were receiving the disability grant for other reasons and not just disability;

> *"But many people with chronic disease will get on a disability grant, but they are not disabled as defined."*

One provider was exact in his definition by incorporating all three aspects of disability;
> *"Impairment is the specific lack of function that they have globally. So one patient or person will have a similar impairment to another, but then you need to place that level of impairment in the context of their situation; their lifestyle situation; their expectations and their work. And that will then define your level of disability as to whether it has been affected or not."*

A good summary was put succinctly by one respondent in South Africa- *"disability is one of the most challenging to delineate and define."*

In Namibia the primary understanding of disability was activity limitation:
> *"I am so ashamed of myself that I cannot do anything for myself; it is very difficult if you cannot perform anything by yourself. But luckily I have family members that are nearby to help me. Life is so difficult and one needs to survive on your own at times."*

For others disability has also to do with aetiology:

> *"Hi, yes my disability is something very funny, if I could put it that way. I fell from a horse and injured my back, but I was still walking around and could do things for myself. All of a sudden with the age of almost 29, I could not walk the one morning, when I woke up. I went to the doctor, from Mariental to Windhoek, but nothing helped me. We are a poor family and could not afford the amount that should have saved my life. Now I'm wheelchair bound."*

O*thers related disability to* discrimination, how they are treated and vulnerability, as expressed by a physically disabled female user in Namibia:

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[6] The disability grant is a social assistance grant in South Africa for people who are disabled and unable to work or maintain themselves.

"And again staff also discriminates against disabled people. If you are, for example pregnant, they ask you how you became pregnant; meaning they do not see you as a person but as a disability and they do not consider you. "

"Disabled people did not apply to be in the state they are in. It's something one is born with, people like me need love and to be treated in a good manner. There are those who are still in denial, especially if their disability was caused by an accident. These people need counselling to accept their condition. Some need wheelchairs to help them walk around if their caregivers are not around. Disabilities come in different forms so their needs are also different."

In Sudan the concept of disability for most is the loss of one of the main senses, loss of an organ or a function of it and hence focuses on impairment, but, in as much as it stops the person from doing his/her daily chores and duties, disability is also about activity limitations. This view of activity limitations was supported by many providers as to them it means inability to move and function normally.

A very dominant concept in Sudan is that disability is one's fate that must be accepted. Disability is a blessing, a test of faith, not a curse.

The concept of mental disability in Sudan is not recognised by either users or even providers of health service, as part of what they define as disability. Although both saw mental illness as a matter of concern that has to somewhat be dealt with, users view some types of disability as a curse or a blessing, *ibtilaa* (God testing of the strength of believers), loss of memory, *kharaf* (an aging condition) is not categorized as a disability, while providers see it as a sickness but not disability.

In Malawi disability was generally seen in terms of failure by a person to fully perform his or her duties properly because some parts of his body are not *normal* and they were able to give examples such as visually impaired people, people with deformed legs, deaf people or those who have mental illness. The health workers were also asked the same question and they also defined disability in the same manner.

4.2 Social context

This section aims to contextualize the study by highlighting the social factors that influence health and health seeking behaviour. The section will focus on the social context at individual, household, community, national and institutional level.

4.2.1 Individual

4.2.1.1 Self-help

Most of the health users (and some non-users) interviewed across all countries and sites understood the basic elements to live healthily, but many were unable to afford the elements that constitute healthy living. These included balanced meals, hygienic habits, taking multivitamins and exercise. A particular problem in Gugulethu (South Africa), a crime ridden society, is the opportunity to exercise safely; for example, a blind participant described being dependent on other people to get any exercise. In rural contexts in all four countries, daily exercise, for most informants, is linked to household chores, drawing water, walking and a tough life, often characterized by poverty.

There were several examples across countries and sites of people using herbs and other traditional over-the-counter remedies to self-medicate. Some health personnel expressed concern at patient's self diagnoses, as they felt that patients are not educated enough to know the signs and symptoms of diseases, diseases they feel should be addressed by medical staff. A key informant from South Africa (Worcester) spoke of the potential negative consequences of self-medication;

> "Oh yes, so now it's gastro season, and I heard the other day a child arrived, and the mother explained that the granny, she had been working on the farm for three days, and the granny had been looking after the little girl, and the little girl was a dry sack of bones by the time she arrived because the granny had heard somewhere or read or done it for her children, that to kill the gastro bug, the actual germ, she had to give the child vinegar mixed with water. I mean poor child! So there's that; having to fight these myths. You know all the wives-tales; and you can't fight it, you can say 'vinegar is great for washing the child's hands in, you know, or wrapping around an ankle. But please don't give it to your children when they have got gastro - bring them to the clinic, and bring them immediately!" (South Africa)

In Sudan general knowledge on the use of vitamins and exercise are characteristic of the upper middle class, who live mostly in Khartoum.

4.2.1.2 Religion/ spirituality

Across all the countries and all the sites, religious beliefs are closely linked to health and health seeking behaviour, regardless of which religion. Health, illness and disability are often seen as gifts, punishment or tests from God. Religion also works as a guide to a healthy and moral lifestyle for many.

> "If one look at Biblical principles and apply them many of the diseases will not happen. God's word is very clearly against it… alcohol abuse…knife attack…, the AIDS figure will decrease… If one has faith in Christ you realize your responsibility towards your children, your body, which is a temple of God, to take better care of it. That will take a lot of pressure off the health care services." (South Africa)

> "The church where I go for prayers when I am sick really helps." (Namibia)

An interesting observation from the Sudanese data was the link between disability or ill health and the prospect of a better afterlife. Many believe that disability or long term disease is God's way of singling out a person with a disability to give her/him credit in the afterlife. Or if the disabled person is a child, God may offer the supporting family members credit in the afterlife by sending them to paradise.

Other beliefs that came out of the data from South Africa, Namibia and Malawi were linked to the role of witchcraft and ancestors in preventing, creating and curing ill health and disability.

> "I have spoken to very qualified nursing sisters, and they still also…you know, there's an element of culture within them that say 'no, I don't do that, we've got to slaughter a cow, or whatever, have a party, be fixed'. So there's an element of that that we can't fight, but try and work with. My favourite story is my nanny. She was at the time fine financially, but obviously not where you want to be. She was told that her child kept getting worms because she wasn't married to the man who made the baby, and that his family; ancestors, are upset.

And that she needs to buy a sheep and have it slaughtered, and then the elders must sit around the child and pray for the whole night, I don't know what the sheep had to do with it, I suppose they must eat, and then the child will be accepted by the ancestors (…). And so the child would no longer get worms. (...) And I said to her 'I am not borrowing you the money for the cow, (...)what you must do is you must sweep around the house, and you must wash your hands, and you must make sure she drinks her de-worming pills, and YOU must drink YOUR de-worming pills, and you won't get worms anymore.' So I said to her sister that was working with me, highly qualified, very highly qualified that lady, I said to her 'blablabla, the whole story', and she said to me 'but of course she must do that of course, it will work of course'. And then I said to her, 'but how can you even say that? Because you KNOW the child needs to be de-wormed!', and she said 'yes, but that's the way it works, it's the ancestors that are making him do all these things that make the worms'. So that's a barrier" (She suspects that they do this instead of de-worming) (South Africa).

Similar beliefs also came out of the Sudanese data, but linked more specifically to supernatural powers or evil eye, believed to cause misfortune, such as ill health or disability.

Religious and spiritual beliefs can act as psychological coping mechanisms for people, providing explanations and support to people in difficult situations. On the other hand, they may influence people to not seek health care, because some people believe that ill health is a fate, rather than a medical condition that may require medical attention. Furthermore, beliefs linked to punishment or credit in afterlife, as came out of the Sudanese data, may encourage people to help and support people who are ill or disabled.

Among members of the Zion church in Malawi, the use of modern health services is strictly prohibited, because they believe that they are protected by the Holy Spirit through their prayers, and disease and death is God's plan, and should therefore not be avoided.

The kinds of beliefs talked about above are rarely addressed by modern/ professional health care, and hence many informants choose to seek alternative forms of health care (traditional healers/ herbalists/ etc.) that take these beliefs into account in their practice.

4.2.1.3   Substance use

Alcohol use and even alcoholism seems to be widespread in the four South African sites, constituting a big problem for communities, families and individuals. Problems related to alcohol use were also mentioned in one of the Namibian sites, but it is not a prominent issue arising from the Namibian data. In Sudan alcoholism and drug abuse were not reported as threats to the communities, except in Umbada locality where alcoholism and crime were reported. Health risks associated with the latter were not reported. Most informants in Sudan said that they could not afford cigarettes, but some men used snuff, which may have negative health consequences.

In South Africa, alcohol use is not only a problem among adults, but also found with underage children. In Madwaleni alcohol and drug use is mainly a men's activity, but it is used by both men and women in the other sites. It is used frequently in daily life, but even more so during ceremonies in Madwaleni. According to participants alcohol abuse leads to vulnerability, as well as the misuse of social support and other money that should go towards food and basic necessities. Problems caused by alcohol abuse according to participants are neglect of children, teen age and other pregnancies,

sexual risk behaviour, assault, rape, leaving school early, Fetal Alcohol Syndrome and breakdown of families. In all the South African sites, particularly in Gugulethu, crime, assault, motor vehicle accidents and abuse is associated with alcohol.

> *"90% of the people that have come in have been hit by a car, or hit by their friend or stabbed or whatever, they were drunk or their friend was drunk or both of them were drunk, that's a lot of what fuels the violence"* (South Africa).

Alcohol and drug use also negatively affects patient responsiveness, responsibility as well as the outcome of many medical treatments. In South Africa, Namibia and Malawi, TB and HIV are common diseases, and alcohol and drug use can be detrimental to their treatment.

Participants mentioned that other drugs than alcohol were available and in use, but the use of these drugs and its consequences was not nearly as serious as that of alcohol.

4.2.1.4   Lack of opportunity
Low levels of education and lack of employment are major problems in all the four countries. Many of the informants have casual employment as their major source of income, and time off work means loss of income or, even worse, losing their jobs.

4.2.2   Household

4.2.2.1   Poverty
Poverty is one of the major factors affecting access to health services in the four countries. The majority of the informants are poor. Often an entire family, even sometimes an extended family, lives off the (often unstable) income of one member of the family. Low levels of education and unemployment is associated with poverty and poor access to social and health services, and hence undernourishment and poor health. In all the study sites and all the countries specific poverty related problems include low access to safe drinking water and running water, lack of decent toilet and sanitation, lack of electricity, small or inadequate housing, lack of food and poor access to health prevention and care. While social and health services are often more expensive in urban areas, they are generally more accessible in these areas compared to access in remote rural areas.

Most of the informants were self-employed (including farmers) or had casual employment as their major source of income. Time off work to have a medical condition attended to or to have assistive devices maintained, repaired or replaced have an impact on lower income and unskilled labour groups where employment legislation is often not followed. Those who are employed in casual labour will often not attend healthcare until too late for fear of losing a job or not getting paid when not reporting for duty.

> *"People who work at the farms the boss may not permit you to go to the clinic and it becomes a problem"* (Namibia).

In South Africa and Namibia, poverty and unemployment motivates some users to try to qualify for a social or disability grant. In Gugulethu, this results for many in repeated visits to the health facility in an attempt to build a disability profile. This behaviour again overloads already stretched resources:

"And sometimes you will find that most of the patients they come in maybe with the same problem every time because they've got that thing if you come to the hospital every time with the same problem you will get a bigger folder. So if you get a bigger folder then you qualify for the grant. Because of the unemployment. So they keep on coming in maybe saying they've got this problem, I can't work…and they'll be coming in, in, in, in…and after that they say, you know what the main thing that I want is the grant. I want to see the doctor so that I can get the grant" (South Africa).

In Sudan, almost all the households in the rural sites and displaced communities have livestock, such as a donkey for transport, goats for milk, chicken or lamb. Animals are kept as a source of security sold or mortgaged to pay for health services and medication. It was reported several times that household members wait till they sell a lamb or some chickens at the weekly open market to have enough cash to be able to pay for the cost of transport to an urban centre or hospital, and pay for the needed medical services and medication. Some are so poor that they do not have livestock as they are expensive for them to keep. Few people in urban areas have livestock.

4.2.2.2 *Family support*

Informants spoke of both negative and positive aspects of family support or lack of family support. People with disabilities are often dependent on family support to carry out activities of daily life, and also to access health services. Many deaf informants need help from family members in interpretation into sign language or other communication strategies developed, because most health personnel do not speak sign language, or do not know how to communicate with a deaf person. As for blind and visually impaired informants, many need assistance in navigating their way around; getting to and from health services and getting around inside the health service. Similarly, people with physical impairments often need assistance getting around, and this assistance is often provided by family members. Moreover, most of the informants in all the four countries were poor, and needed financial assistance for transport, health care, medication, and so on.

Although the household economy in all four countries and all the sites is generally very poor, the family ties are strong and is characterized both in rural and urban settings by family members and neighbours supporting sick people in various ways by visiting, keeping company, accompanying them to health facilities, nursing at home, monetary support, doing household chores, physical support in movement, etc. The social protection network depends greatly on relatives in general and household members in particular. With the almost complete absence of social protection, a culture that puts a high value on strong kinship and family relations is crucial to ensure support for the sick, people with disabilities and other vulnerable groups.

The ability to pay for health care is, hence, largely influenced by household income. The support a person gets from his or her household also plays a major role in access to health care, the resources available and type of housing they live in. This was well recognised by participants in this research:

"The other problem is also when the old person is sick, then he/she needs to be taken to the clinic by someone and this someone is his/her child who is looking after his/her livestock. This will make the pensioner not to come to the clinic because he will not want the livestock to be left alone as they need to be looked after on a daily basis" (Namibia).

"As you can see that I am disabled due to this accident, I cannot afford to pay the taxi fare. My sister is the only person helping me to pay the taxi. I pay fifteen Namibian dollars every day to come for dressing. The pain that I am experiencing does not allow me to come while walking by myself to the clinic." (Namibia).

Medical staff In South Africa spoke of the positive aspects in terms of family support for disabled persons:

"A *lot of the patients have a good support system because of the family.*"

"We've had kids in here whose parents are so involved and ... they improve a lot if they have that love and care - that support system."

On the other hand, there were also negative aspects in terms of family support for people with activity limitations. Relatives do not always seem to understand what physical disability is about and believe that physical disability also implies mental disability. The negative aspects of family support came out particularly strong from the South African data:

"...to relatives sometimes, when you are disabled, it appears ... that even though you are physically disabled and there is nothing wrong with your mind ... it always appears as if there is something wrong with your mind. Because the environment was that of undermining my abilities and my mentality, I also had the tendency of feeling just sorry for myself. (...) They didn't expect anything from me, the fact that I'm in a wheelchair and everything. (...) It was again me who had to assist them to actually change that attitude." (South Africa).

Furthermore, lack of understanding and acceptance from the family members was a problem for some in addition to neglect;

"I think the old people their thing is that they are neglected especially on some days because they come in because they couldn't take their medication, there was no-one to supervise them and they'll come in with low sugar and those things. Also they'll come in and you'll see that this one is very dirty, she has been neglected and then they will stay here for days without having anyone to come. The only time we'll see the relative is the time they bring in the mother or the father then after that we will never see them. Then you will end up referring the patient to GF Jooste because there is no other person that is coming to visit the patient. This is a day hospital the patient is not supposed to stay more than (the day)..." (South Africa).

4.2.3   Community
There are some community factors that hinder or allow people to access health care. Examples of these are crime, community support, alternative forms of health care, availability of roads and transport in the community, education and issues of power plays in communities.

4.2.3.1   Community support
Similar to the aspect of family support, informants spoke of both positive and negative aspects of community support. As mentioned above, the family and community ties are generally strong in all the four countries, characterized both in rural and urban settings by family members and neighbours supporting sick people in various ways by visiting, keeping company, accompanying to health facility,

nursing at home, monetary support, doing household chores, physical support in movement, etc. With the almost complete absence of social protection, a culture that puts a high value on strong kinship and family relations is crucial to ensure support for sick people, people with disabilities and other vulnerable groups.

In Madwaleni, South Africa, in particularly, the role of community leaders, the families of people with disabilities and people with disabilities themselves was highlighted in their abilities to influence the attitudes and practices of the larger community. An example was given from a community which was very supportive of people with disabilities. Health providers felt that this particular community was so supportive because the community leaders and the families of the disabled people were so supportive, and this influenced the attitudes and behaviours of the overall community towards people with disabilities.

> "So to have a role model (a leader) who actually acts in a certain way, can also help to take away attitudes and change attitudes. (...) If the family cares then the village is supportive. (...) It's because of ... like I'm saying, because of our headman loves the disabled ones. So there is no one who discriminate against those in the community" (South Africa).

> "There was a time when he saw as being disabled as actually an advantage to him. Because even when he enters a hall that is full and others are struggling to find seats, he's going to be the first one to be given a seat. When he enters a bank or wherever, in terms of queues, he is going to be put right in front of other people. So for him, … he sees the fact that he is disabled as an advantage because he always gets these extra perks. First treatment is actually given to him. (...) But I also must mention that there are times with transport, it's an advantage to be disabled. They usually open the front seat for you" (South Africa).

Similarly, people living in Worcester, South Africa, seem to be more sensitized, accepting and knowledgeable about disability issues. This is highlighted both by members of the community, key informants and health personnel. This is linked to the presence of large numbers of people with disabilities who have attended or are still attending the many disability organisations and institutions for disabled people in Worcester. Worcester town is very disability friendly, with ramps for wheelchairs, streetlights with sound, and so on.

> "I think, as a small town, with having those two institutions for the deaf and the blind for over a hundred years, people are much more aware" (South Africa).

On the negative side of community support, negative attitudes, stigma, lack of support, distance, poor support of elderly, slowness in dealing with applications for social grants and lack of assistance to parents were mentioned.

4.2.3.2   Cultural factors
Several cultural factors were mentioned, which may influence people's view and actions towards health and disability. In Sudan, the culture around complaining is one such factor. Health providers (as well as other service providers) are considered to be offering a valuable service to help others and should be credited for that regardless of the quality of the provision of the service. Complaining is viewed as non-ethical, and as gossip and is, therefore, immoral. This has implication on demand

for quality, accountability or a sense of rights for provision of service. This view is less strong amongst educated urban people.

In South Africa participants referred to moral decay in the community:

> "*People's moral values are so decayed that they do not even care for themselves anymore. They know they have TB, but still smoke and drinks. They do not take their medication*" (South Africa).

This is linked by participants to teenage pregnancies which are apparently "*soaring*" in numbers (South Africa). The issue of parents condoning statutory rape for the money that it might bring in was mentioned:

> "*Statutory rape… since the boyfriend provides an income…they [parents] refuse to lay the charge*" (South Africa).

Some participants did feel that teenagers and other women were getting pregnant in order to access the child support grant. In South Africa, some informants also pointed out that too much charity may rob people of their dignity and spirit: "*Our people receive too much…One should work and show your appreciation*" (Fraserburg).

4.2.3.3   *Crime*

Issues of crime came out strongly from the South African data, but not so much from the other countries. Problems of crime were talked about in several of the South African sites, but it was much more prominent in Gugulethu than in the other three sites. Gugulethu is a violent community with crime and violence being an everyday part of life. Crime and violence play a significant role in the health care seeking behaviour of vulnerable groups. Most people are unable to afford public transport and, therefore, walk to the clinics. Walking in the predawn makes them an easy target to criminals operating in the early morning hours. Being targeted by criminals and fearing for their life is the most important factor cited as limiting access to primary health care. The following experience was described by an 80 year old grandmother and non-user on her way to the clinic in Gugulethu:

> "*No, I stopped (going to the clinic). I almost got killed. When you go to the Nyanga clinic you have to wake up at 4 am for you to see a doctor. It's been years since I have stopped using it. I was walking just after 4am and there was this crowd of young men, about ten behind me. They asked if I wasn't scared walking alone at that time and I told them the only person I'm scared of is God. Fortunately there was one who recognized me and told the others to let me go and accompany me and I said I was fine to walk on my own and by then I had already wet myself because one of them had a gun against me*" (South Africa).

4.2.3.4   *Alternative forms of health care*

Alternative forms of health care were utilised in all the four countries and almost all the study sites. Types of alternative health care mentioned by informants included herbalist, diviners (witchcraft), religious/ faith healers/ healing, homeopathy, reflexology and home remedies. Most of the informants use modern health care as their primary source of health care, either in addition to or instead of alternative forms of health care. There were, however, some informants that only use alternative forms of health care.

"I use modern health care although there are times that the elders force me to use traditional medicines. Therefore I would say I use both modern and traditional but I would rather use modern as I trust it and it is much cheaper than traditional." (Namibia).

Most traditional healers indicated that they encouraged their clients to disclose the fact that they use traditional medicine when attending clinics for appointments. Although traditional healers promote communication with the formal health care sector, this does not seem to be reciprocated by the staff of health facilities. Most traditional healers felt that there was a lack of acknowledgement of their role in health care and spiritual support. The main complaint of all traditional healers was the lack of acknowledgement of their role as an important link in the continuum of care. Most expressed the wish to be able to work together with the formal health care sector.

In general health providers agreed that users often used traditional medicine as well as professional medicine, but was reluctant to admit it for a number of reasons. The providers see this as a barrier to the success of health care management. It is important that the missing link between the two types of treatment be found to optimise health care management for this group of users.

"You see it is difficult to balance the two (western and traditional medicine)…our people are very traditional and are very staunch to their traditional norms, customs and beliefs …I don't think our patients are quite honest…I don't think there is such a dialogue between them and the doctor and they will definitely want to hide that they're using the traditional medicine, because they would not think that it would be accepted by the doctors" (South Africa).

Modern health professionals sometimes warn people not to use alternative forms of health care:

"…I raised my children with it…They [service providers] say you must not use the bossies since it is not healthy, but it works…it is healthy" (South Africa).

A story told in Malawi highlights the role of traditional healers:

This traditional healer had a cellphone-like thing which helped him to identify witches. The gadget flashed whenever one with "nyanga" was around. When he arrived in the village, the traditional healer told everybody who knew that he/she had or keeps nyanga (witchcraft substances) to surrender those to him but nobody went forward. Then he started using his cell-phone like thing to identify anyone with nyanga. A number of witches were identified and the traditional healer together with the members of the village went to the houses of the witches to get the witchcraft substances. All those who were accused of witchcraft accepted that they were witches. All the witchcraft substances that the traditional healer took were burnt in the presence of villagers. Incisions were made on the skins of the witches onto which traditional medicine was rubbed. The witches were advised that they would die if they practiced witchcraft again. They were also fined to pay money ranging from MK10,000.00 to MK50,000.00 depending on the strength of the witchcraft substances. The amount was also higher for those who refused being witches and later they were found with the witchcraft substances. This money was taken by the traditional healer himself. After the cleansing by the traditional healer the village headman said that sudden deaths, fire at the graveyard, the

> *flying coffins and the teaching of witchcraft to children stopped. However, he added that death is from God and everyone will die one day but in the way God wants us to die.*

The reasons why people choose to use alternative forms of health care instead of, or in addition to, modern health care are varied. The following reasons were highlighted by our informants: Cost, availability, beliefs, tradition/culture, and health worker attitudes.

a) Cost:

Cost is a factor for people in determining which health service to utilize. While health care is supposed to be free of charge in all the countries, in reality there are a number of 'hidden' cost related to the use of health care. These hidden costs can be loss of income (because one may need to take time off work to see a health provider), travel cost, cost of medication, and so on.

Selective use of modern health service on the basis of when one feels they need them and can afford to pay for them is widespread in rural Sudan, and many respondents stated that they use non-modern medicine because it is cheaper and accessible in their areas.

Also in Namibia lack of money to pay at the clinic swayed some towards faith healers;

> *"If I do not have money to go pay the consultation fees at the clinic, then I rather go to the pastors for them to pray for me, so that I can be healed / helped through their prayers. This is because we are not paying anything and it is the help that is coming from my creator (God)"* (Namibia).

Some users of modern health care in Malawi said that services by traditional healers in Malawi are more costly compared to modern health care. This argument is, however, premised on the fact that modern health services are provided free of charge, and that the user has no additional expenses or financial losses connected to health care utilisation.

b) Availability (distance):

Although modern health services have been decentralised in all four countries, distance to health services is still a major barrier to accessing them for our informants. Alternative health services, particularly traditional healers and spiritual healers are present in large numbers in practically all villages, towns and cities in all four countries and health users, therefore, experience these services as more accessible and available to them.

Some Malawian informants said that they use traditional healers not because they want to, but because modern health facilities are situated very far away, and they are unable to walk to the facilities because of disability or old age.

c) Belief:

Traditional healing, as described by informants, is not just managing illness with herbs and medicine from the field, but also often incorporates a spiritual component:

> *"Another thing – the Xhosa people they ask for the Xhosa medicine because it is there in their minds – they know that it is going to help. They prefer that rather than Western medicine.*

Second point – they also believe that the cause of that (the sickness) is caused by the traditional causes. That's why they also believe that they can be healed by that Xhosa medication" (South Africa).

In Sudan and Malawi, many stated that not all kinds of sicknesses require one to see a medical professional. Some believe that traditional medicine is more effective and has no side effects.

"Some diseases can be treated by the sheikh, others by the faki (religious healer) and others just go away with time and hence require a degree of patience" (Sudan).

Members of the Zion church in Malawi never use modern health care, but believe that God can save any problem that man fails to solve *'because with God anything is possible'* (Malawi). Prayer is seen as the best prevention and cure against illness, but sometimes a priest may also be able to assist with holy water. Zion church members do not believe in treating drinking water with chlorine and/ or other chemicals, and while they use mosquito nets, they do not use insecticide treated nets.

d) Tradition/ Culture:

The use of alternative forms of health care is for many closely linked to culture and traditions, passed on from one generation to another.

e) Health worker attitudes:

In Namibia some prefer traditional doctors (herbalists) to avoid rudeness by health workers

"In situation whereby every time you visit the clinic the nurses are rude and insult patients, you would stop coming at the health centre and rather use traditional health care to avoid insults from nurses" (Namibia).

4.2.3.5 Migration

Service providers reported that at times when they contact users to give test results or for follow up procedures, it is found that the user has moved out of the area. Apart from preventing effective treatment, the migrant nature of a population can also make it difficult to contain diseases.

4.2.4 National

4.2.4.1 Government support

People with disabilities and families of children and adults with disabilities are often dependent on support on many levels to function well and cope with everyday life. The importance of government support is emphasised by the informants, but this is not always available.

People talk about the importance of the government in influencing people's perceptions:

"...the government has made a huge impact in society in changing the perception of society towards disabled people as government started considering them and putting them in certain positions. And that on its own made the community to change its attitude. She says that also the fact that the government has managed that, even when you are injured and you recover, then still the government will integrate you into the job situation. That also has assisted" (South Africa).

a) <u>Legislation:</u>

In South Africa the government and the constitution is important in supporting people with disabilities, and informants feel that the new constitution and the post-apartheid government has been crucial in recognizing the needs and rights of people with disabilities.

> *"First, there's the whole thing of the constitution, and that has assisted a lot. Because in the constitution they had to build in certain guidelines, laws and all that, that are underpinned by the constitution. (...) And out of those rights there is an emphasis around the disabled person himself actually respecting himself; respecting his dignity so that other people can also respect him"* (Madwaleni).

b) <u>Preference given to people with disabilities:</u>

In South Africa and Namibia two aspects of preference given to people with disabilities was highlighted; namely, payment exemption and preference given in the queue at health facilities.

A policy declaring free services for people with disabilities and other vulnerable groups was highlighted as an important government support tool. The aim of this policy is to increase access to health care for vulnerable groups, being disabled, old, orphans and vulnerable children and pensioners.

> *"The other access thing that you must write up there, is the policy thing about (...) free services for people with disabilities, which was declared by minister Mantho. They started off with the free … first, it was Madiba with free service for pregnant mothers and children under five. The next one was primary health-care free service for the state sector"* (South Africa)".

> *"I don't know about the costs, I don't pay. I used to pay two dollar for my medicine but now I understand that we don't pay any cent no more, oh, that's good!"* (Namibia).

There were, however, some difficulties reported in relation to the implementation of this policy. Although most people were happy with the exemption, some facilities were not implementing the policy and disabled people were made to pay at health facilities. This was the case in some facilities in the Caprivi region of Namibia:

> *"I have heard of new policies that exempt disabled people from paying. I don't think it has been implemented here though"* (Namibia)

> *" (...) but I don't think it is being implemented in the right way. (…)But they struggle with the definition. If they can issue a card to a person with a disability … an OT [occupational therapist] can certify and issue a certificate to say that this is a disabled person according to our criteria, and that person must get free services. But it's not implemented like that. At the moment, they say people with disability grants. But many people with chronic disease will get on a disability grant, but they are not disabled as defined. If the intention is to give something to the people with disability, it's not being implemented correctly. So in terms of the access question, to me as a provider, that is something that is not right yet. They are being charged"* (South Africa).

Furthermore, people also talked about a policy giving preference to people with disabilities in accessing health care. The policy states that people with disabilities should be given preference at the clinic, get treated first, and be fast-tracked through the health system.

c) Grants:

Grants from the government were also mentioned by the South African informants;

> *"They say that to them the only assistance they have is a disability grant."* (South Africa)

4.2.4.2 Human rights

Human rights issues were in a number of interviews, including people's knowledge and understanding of their human rights, as well as their attempt and responsibility to have their rights realised. People talked about their rights as human beings, as people with disabilities, their rights as patients and as workers (health personnel). While some people are actively fighting for their rights, others know of their rights, but are more passive. Others again are not even aware of their rights, and hence do not know to fight for them.

Going hand in hand with demanding your rights, is the insight and knowledge that the users themselves also have responsibilities. This example from South Africa clearly illustrates the user's insight into his responsibility to be on time for appointments:

> *"Most of the time I am always punctual so that if they don't help me at right time I can complain better"* (South Africa).

This is in strong contrast with some users who do not understand their responsibilities in demanding their rights and blame the staff for unfair behaviour:

> *"The behaviour of the staff is unacceptable especially when you forget your date of appointment - they don't compromise"* (Gugulethu).

Others are not empowered to fight for their rights at all and just give up trying to seek health care:

> *"If I'm seeking for help to the clinic and I don't get it I usually give up because I don't have money for private doctor all the time"* (Gugulethu).

The Sudanese data indicate that the country's low human development indicators could be linked to not only a context of conflict and economic underdevelopment, but also to the concept of citizen's rights to basic services of education, health, safe water, electricity, security, residence, connectivity by roads, transport and communication. For the majority of the Sudanese population, these rights are not realised. This has led to citizens developing strategies to cope with their lives almost independently from the government. The lack of governance principles and practices and a traditional culture that nurtures acceptance and satisfaction with the minimum limits understanding of citizens' rights for quality of services to be offered by government. There is a spirit of fatalism that God's destiny is behind their situation whether it is one of poverty or wealth, a situation of health or sickness.

4.2.4.3 *Civil Society/ NGO*

While the government is responsible for the provision of modern health care in all four countries, civil society/ NGOs also play a significant role in both Malawi and in Sudan, where there are NGO-run hospitals and clinics. In South Africa there are a large number of private health centres, but these are only available for people with health insurance, or people who can afford to pay large amounts of money for health care.

In Sudan there are common characteristics in all studied sites. One is that all towns have a main government-run hospital that acts as a teaching hospital for the school of medicine in the town. There can be another hospital run by NGO and private sector or built by donors or United Nations High Commission for Refugees (UNHCR). Health centres focused in urban and rural settings are of two types: public or private. The same health providers (doctors, medical assistants, nurses) work in both types of centres in different shifts (morning at the public facility, afternoon or evening at the private one). The private health centres have advantage over the public in terms of quality and type of services offered (e.g. availability of a laboratory and pharmacy) or in terms of more careful attention by medical doctors or assistants.

There are few civil societies working with disabled people in the localities, with only two NGOs in two localities identified for deaf people and HIV/AIDS patients).

In Malawi, there are a number of clinics spread around the country run by the Christian Health Association (CHAM), and various NGOs operating in Malawi, providing community-based care. CHAM charges user fees, but they collaborate with the government, and an agreement has been made that CHAM should provide free services to the population in their catchment area, and the district health office pays for the services.

4.2.5 Institutional

Institutional support was not mentioned in Sudan, Namibia or Malawi, nor was it mentioned in the South African sites of Madwaleni, Gugulethu or Fraserburg, but it was an important aspect for many of the informants in Worcester, South Africa. Many of the informants in Worcester were living and/or working and/or studying in institutions for deaf people and blind people, and received a lot of support through these institutions in relation to seeking health care. In some institutions health care was available for the residents inside the institution, while other institutions provide support to residents who need to seek health care. The support can be transport, translation (sign language interpreter), personal assistance, and so on. Many of the residents of the institutions get free assistive devices through their institution.

> *"You know, the blind and deaf people who are associated with Pioneer School and the deaf school, they always bring someone along. They always have someone with them"* (South Africa, Worcester).

4.3 Access to health care

Access to health as a theme was coded into different components including transport and geographical location of the facility, physical accessibility of the facility, access to information, safety, cultural aspects, attitudes at the facility and cost. These are discussed individually.

4.3.1 Transport

Transport is a major barrier to those living in rural areas compared to those living in urban areas, where transport is readily available and reasonably accessible. However, in South Africa participants reported that private and public transport services are often not on schedule resulting in missed appointments at hospitals and clinics. Also in South Africa taxi drivers will often refuse service to individuals with mobility impairments, such as wheelchair users, or overcharge them. According to the participants, taxi drivers feel it is too cumbersome and time consuming to help individuals such as wheelchair users into the taxi.

In rural areas the lack of transport makes it very difficult to manage vast distances to health care facilities, difficult terrain and scarce to no ambulance services. In rural areas have limited public transport services and if private transport is available it is costly. One of the South African sites, Fraserburg, is notable in its lack of any form of transport including minibus taxis. While, people in the town of Fraserburg can walk to the health facility, those living in the nearby farms are reliant on their employers for transport. The lack of transport is particularly burdensome to people with mobility impairments such as elderly people, blind people, wheelchair users, etc. In rural, areas roads mostly consist of dirt roads or small pathways which are difficult to manage by people in wheelchairs or using crutches. The same problem applies to people having to cross difficult terrain such as rivers, hills and mountains.

Reports from South Africa, Malawi and Sudan noted the use of donkey carts and ox carts as an alternative to walking. South African and Malawi reports also mentioned the use of bicycles. In Malawi health care facilities make use of what is referred to as bicycle and motorbike ambulance services, as well as the use of wheelbarrows and stretchers. Despite the availability of these various forms of transport, they are not always suitable for transporting seriously ill or injured patients. Data from Malawi and Sudan suggests that participants living in rural areas close to main roads often make use of hitch-hiking as a method to get a lift to the nearest health care facility. In Malawi motorists will only provide hitch-hikers with a lift if they are willing to pay a certain amount.

Once again most of the participants in rural areas reported that ambulance services are scare and costly. Although ambulance services are less costly than private transport participants still find it difficult to afford ambulance services. Ambulance services are only dispatched when it is a severe medical emergency and takes time to arrive on the scene. In South Africa a case was reported where the individual died of her wounds whilst waiting for the ambulance. Ambulance services are also over-utilized. Reports from Namibia and South Africa indicate that ambulance services are often used to transport patients from one health care facility to another. This results in the ambulance not being available for medical emergencies.

4.3.2 Physical access

All of the countries reported that most health care facilities were physically accessible. However South Africa, Malawi and Namibia reported that a few facilities had problems in terms of physical access. In Namibia participants complained that there were no porters at the entrance of the facility to assist them in entering the clinic. In Malawi some clinics were situated on hilly terrain which made physical access difficult for people with mobility impairments. In South Africa issues were raised in regard to wheelchair ramps. Although most health care facilities have a ramp it is not always adequate, often being too steep or without railings. The reception counters at facilities are often not

the adequate height for a person in a wheelchair. At certain facilities there were no accessible toilets or, when present, were used as storage space.

4.3.3   Communication and information

All countries reported communication barriers for people who are deaf or hearing impaired. No resources exist in health care facilities to accommodate persons with a hearing impairment. This results in patients having to provide their own interpreters, which raises issues of confidentiality. Because of these barriers, persons with a hearing impairment find it difficult to explain symptoms which often result in misdiagnoses and incorrect prescriptions. In the South African report it was noted that persons who rely on lip reading also find it difficult to communicate. Health professionals often look down at reading material when speaking or simply speak to fast, which makes it impossible for someone to lip read. Due to the difficulty in communicating with someone who is hearing impaired, health professionals often become frustrated. The Malawian report provides an example of a woman who is deaf and unable to speak and who is ignored by health professionals because of her difficulty in communicating. This results in her having to return home without having received medical care.

South Africa, Malawi and Namibia reported language as a barrier to access to health care. Health care professional often do not speak the same language as the patient which results in miscommunication and misdiagnosis. This experience causes the patient to not return to the specific health care facility. In South Africa staff such as cleaners, porters, nurses from a different unit, etc. are often used as translators. This however, results in these staff not being at their posts and fulfilling their duties.

It was found that in Sudan doctors often do not provide medical advice and information in a non-medical or technical way. Doctors are often not willing to make the effort to explain the information in such a way as to be understandable to a lay person. It was also found that a dominant culture of not distributing information exist among health professionals in Sudan.

In Sudan health care users face a severe lack of information and are met with a multitude of misinformation. This is partly due to the government that doesn't view information provision as a top priority. Health promotion in Sudan focuses on mainly three categories namely: HIV/AIDS, maternal health and children Immunization. No information regarding rights and eligibility are provided. Thus many services, which are often free, remain un-utilized. Information regarding service availability is usually promoted through word of mouth.

The Sudan report identified a lack of information regarding the following topics: cost of service, type of services offered at each facility, criteria for exemption from fees, physical access for disabled persons, sign language experts, health promotion and awareness, options for treatment, use of medical drugs and possible side effects, opening hours and closing days.

4.3.4   Attitudes of staff

All four countries provide evidence of positive as well as negative attitudes of health care providers. It seems that a positive attitude and being treated kindly is highly valued by participants and is a strong indicator that participants will return to the facility if treated kindly and respectfully. These attributes are so highly valued by participants from Sudan that they are often willing to pay to receive health care from health workers that are friendly to them.

However, many participants who have experiencing negative attitudes from health care workers will be reluctant to return to the facility or simply become non-users and refuse to make use of health care facilities. These negative experiences create an impression that health care workers are disrespectful and uncaring, resulting in a lack of trust between them and the patients.

Participants from South Africa report cases of stigmatization and stereotyping due to their disability. Such experiences leave the patient feeling inferior and frustrated. Namibian reported cases of health care workers being rude, favouritism and staff attending to personal matter during office hours whilst patients are waiting. In Malawi as well, participants found health workers to be rude and disrespectful, especially towards elderly people. There were some instances of elderly people being denied active treatment as health workers feel that these resources should be reserved for the youth.

4.3.5   Cost

In South Africa medical services and medication are free of charge or fees are established according to income. In case of the latter medical services are still considered cheap in comparison to private health care. Although public primary health care services are free for persons with a disability, not all services relating to a person's disability are free, for example, the repairing and payment of hearing aids, the repairing or replacement of a prosthetic eye, and the cost of a wheelchair need to be covered by the individual as it is not covered by government. As these assistive devices are expensive, they are not affordable to most people with a disability.

In Namibia cost seems to be a barrier in accessing health care whilst others consider the cost a reasonable fee. For example the cost of a consultation is N$4. This is viewed as fairly cheap by some participants whilst those who are unemployed complained that they simply do not have the money to pay, even if it is this little.

As health services in Sudan are privatized, in can be very costly receiving health care in Sudan. Patients have to pay for everything such as consultations, medication, laboratory tests, x-rays, etc. If a patient is admitted to hospital, in addition to paying for medical services they have to pay for things such as transport and food. This adds up to a considerable amount which can be a huge burden on patients. Although very few in Sudan can afford medical insurance, these insurance schemes eliminates most of the costs. Besides being unaffordable by most it can also be a complicated process to join certain medical insurance schemes.

In Malawi certain health care facilities provide services for free whilst others provide services at a certain cost. Participants noted that they would have liked to make use of facilities that are situated closer to where they live. However to access these facilities one needs to pay certain fees. As the participants are too poor to afford to pay these fees they often have to travel long distances to access health care facilities that are free of charge. Despite the availability of free health care, people have to travel far to access these health care facilities. They often have additional expenses such as food or transportation costs. These costs are often taken from the household expenditure resulting in persons being unable to buy food and basic necessities for the household. One woman was hesitant to make use of health care services as the involved cost would result in her children being without food. Produce such as maize, potatoes and vegetables are often sold to raise money in order to afford medical costs. This becomes problematic as the produce is usually meant for consumption by the household.

4.3.6   Cultural factors

In Namibia there are certain areas where a culture of violence and poverty prevents the access of health care. It seems that male spouses do not want to have their wives or girlfriends accessing health care facilities. If such a transgression has taken place the male spouse would beat his partner which causes the woman to become fearful in accessing health care services again.

> *"For women I think the reason why they find it difficult to come to clinic is because of violence by their husbands and boyfriends. My friend who is in a similar state lost her baby (miscarriage) because her boyfriend beat her every time she goes to clinic. He said that she spreads their HIV status to strangers and she did not get the necessary antenatal care which caused the death of her baby. Maybe it would be better if nurses go to our houses to let our boyfriends understand the need to seek medical help if pregnant. Because some men who are especially uneducated and from rural areas lack information and do not allow girlfriends or wives to seek medical help"* (Namibia).

4.4   Quality of health care services

The quality of health care was analysed with respect to all non-medical aspects of health care. The EquitAble study did not seek to review the quality of medical care, as in the correctness of diagnoses and treatment schedules prescribed for users. The main areas of analysis were in relation to the non-medical health care, availability of health care and acceptability of these services.

It seems as if the quality of care given and the clinical skills varied between individuals in all four countries. Positive comments were made:

> *"…the primary care sisters in the Northern Cape that I worked with are very thorough"* (South Africa).

> *"They always do their best; they deliver what they are supposed to even if they cannot always help us"* (Namibia).

Experiences of users included excellent management in some cases to references made of wrong dosage of medication, rough treatment, and no explanation of procedures. However, the above quote from Namibia implies that the general air of satisfaction might be born out of acceptance of a less than optimal situation. This view is supported by the following quotes: "*they are doing their best and that is fine (Sudan)"*, *"this is better than nothing (Sudan)"* and *"if we do not have this we have nothing" (South Africa).*

This perception is borne out by providers in Sudan who are generally extremely dissatisfied with the quality of the service they provide and the fact they were unable to provide adequate service for many people simply because they cannot afford to pay;

> *"Patients choose what medical drugs they can buy and how much of it on the basis of their affordability and access to cash at the time"* (Sudan).

There is sense of helplessness amongst providers. Daily, they face so many situations about which they can do nothing, such as seeing patients suffering unnecessarily because they are unable to pay

for medicines, using equipment that they knew to be below the acceptable standard and prescribing cheaper drugs that are less effective.

Areas that negatively affected quality of care in all the countries were a lack of clinical skills amongst certain clinicians, short consultation times and less than optimal explanations and counselling, a lack of communication between various levels of service provision, poor fitting assistive devices and long waiting times for assistive devices and rigid protocols. These are discussed individually in more detail.

4.4.1 Clinical skills of professionals

The clinical skills of providers varied between individuals throughout the four countries. Some users perceived a lack of skills:

> *"It seems to me that the nurses here are not having the necessary qualification"* (Namibia).

> *"My wife has become more competent in changing my Caniola. We don't wait for the nurse to finish her chat or whatever, my wife brings the sterilizer from home and change my Caniola"* (Sudan).

> *"…no support on secondary level and quality of medicine practice by outreach specialist poor…they are supposed to be specialists. But for 90% of the time if you sent a patient with such a prescription they will just prescribe the same medicine. Without you know giving a plan or adding something. I have sent patients with bad fractures and I just put them in a back slab and then…my colleague will write me a great letter. Congratulations with a good reduction, because he thinks the alignment of the fracture is good enough now. It is not necessary to do an operation... So that patient is going to go with a crooked arm for the rest of his life"* (South Africa).

On the other hand:

> *"the centre is crowded because the doctor is kind and doesn't shout at you or dismiss you he is very competent; so I do come here"* (Sudan).

Two areas where knowledge seemed to be especially wanting in various countries were in the use of emergency equipment and in providing rehabilitation. Apart from the lack of rehabilitation services at primary level, even the specialised rehabilitation services lack adequate expertise.

4.4.2 Limited contact time with users

Limited time with service providers was a complaint in all four countries. The ratio between numbers of users and numbers of service providers were skewed to such an extent that providers had to rush through consultations:

> *"I spoke to a sister who runs a mobile here the other day, and she saw 120 patients in one day"* (South Africa).

"At the moment it's just the personnel shortage that totally irritate us, because we actually can't provide a patient with the necessary attention they need. We have to rush through everything" (South Africa).

"There is no time to sit with the patient and explain the whole thing to the patient" (South Africa).

This lack of time and having to rush can negatively affect quality of care and user outcomes:

"When they (the nurses) give directions (about taking medication) they talk so fast as a result you get lost when you are at home. You ended up taking a wrong medication because that person never checked your understanding by that time because she is in a hurry" (South Africa).

In addition, there are inadequate staff numbers to provide individual or dedicated small group health care education and promotion. General health care education is done in groups with patients in the waiting rooms and this is fraught with problems:

"(The) health promoter ...She will see patients one-on-one…but she does spend more of her time standing in the club (chronic care section) giving group education and in the OPD giving group education, ...but doing it in a group they don't always listen, if they're all in the club and they all waiting for their name to be called, for their blood pressure to be done..." (South Africa).

4.4.3 Poor communication between various levels of service providers

Lack of feedback and loss of information between levels of service negatively affects quality of care:

"I think just a little example of something that was challenging: we had a patient that had a sarcoma on her leg, and she came here after having this malignancy for quite a while and she didn't know what to do with this tumour any more. And I think the challenge was that she had actually been seen by a provincial and a tertiary hospital, and her information got lost. She is dead now, and she could have been saved if she had the amputation in time. So I think the challenge for the public service is actually to get their information system … and to get information back to patients. Because they do a lot of good work, but it's so difficult to follow up people and in that instance, to get to the patient and say you need an amputation that is life-saving. So I think the whole way we handle information, I think is quite a big challenge. And I think the way the government or the provincial health services do that is also quite a challenge for them. So I think it's not only information on what is available, but it's also how to get personal information back to people. I think that is one of the biggest challenges to grapple with" (South Africa).

4.4.4 Assistive devices

Both waiting times as well as poor fit of assistive devices negatively affected the quality of health care provided in South Africa:

"…there is a waiting list…such a long waiting list [for prostheses]" (South Africa).

"… they take the measurements and send it to Cape Town you know they must go to Cape Town… and then they must, fit again and fit again and fit again and, you know how must the people get there you know, you can, you can understand that the fittings is not right, because you gain weight you, lose weight, there is so many things that can happen in weeks" (South Africa).

"The previous week we finally got a wheelchair and when I went to deliver it to the lady in Brandvlei she had passed away. And with buggies for CP children. If a three year old needs a buggy, but the buggy only comes in two years time then that child is five and the buggy will not fit anymore. It is a waste of money actually when you look at it" (South Africa).

4.4.5   Rigid protocols and lack of choice

In South Africa the rigidity of the state system negatively affects its quality. Clinics and Community Health Centres serve a particular geographic area and users are required to access the closest one and from there follow a rigid referral route to secondary and tertiary services. Dedicated regional and referral systems, although efficient in delivering organised health care to the public, denies patients the basic right of choice. Not being able to choose where to access health care, or which health care provider you want to work with, can be extremely disempowering:

"…I am no longer staying there…I'm no longer qualifying to go back as a patient" (South Africa).

Many persons interviewed voiced the wish to directly access other levels of the public health care system or other secondary and tertiary hospitals, because they felt that it offered better quality of care or could address their needs more appropriately.

In addition service providers in South Africa mentioned the challenges caused by rigid treatment protocols:

"Part of the problem is protocol…according to protocol one has to prove TB of the lung with a sputum culture…The problem is especially with HIV patients the sputum's yield or positive results are very little…even with full blown TB the person might spit empty and we cannot prove TB on a direct culture…The direct culture is the simple easy way and takes only a few days…The other one is more accurate, but takes longer…6 weeks…You might have a patient with all the symptoms… but no sputum result…Then we cannot start treatment…they want proof…I feel more freedom should be allowed for clinical judgment" (South Africa).

In Sudan users were allowed to access services at any point and ask for specific service providers as long as they could pay the fee involved. While this allowed choice it can increase expenditure since users might have accessed the wrong professional and then needed to pay for another consultation. In addition it overburdens some levels of service with complaints that could have been dealt with at a lower level.

4.4.6   Continuation of care and follow up

Continuity facilitates the building of a relationship between patient and provider, facilitating better communication and improved quality of care:

> *"people prefer the Health Centre and not the hospital because in the Health Centre they will see the same doctor each time and they will build a good relationship with him, not like in the hospital"* (Sudan).

Findings in this regard varied between sites and countries. Findings from Worcester, South Africa, mostly pointed to good continuation of care and follow up systems, but challenges were experienced in other sites and countries. The following quotes provide a picture of follow up services in the Worcester area:

> *"…you know the person…It's people who you see again and again and you follow up on them…"* (South Africa).

> *"…in catching preventative problems. So they'll [mobile clinic nurses] be able to see if a child is actually losing weight instead of gaining weight. And then they refer, and that's how the whole thing comes together; you take someone from a tiny farming community which has a farm in the middle of nowhere, the sister will go there once or twice a month. She will see this baby who really is not coping, refer the baby to the clinic in Rawsonville. The sister there might then say; 'you know this is not just a nutrition issue, there is something more involved here', and then refer the baby to the community health centre in Worcester, where she'll see a doctor. And then the doctor might actually say 'this is something beyond my diagnosis, it needs to go to the specialist hospital', which is Worcester hospital, and there the baby will see a paediatrician, and the paediatrician will say 'oh I recognize this, the baby has got pyloric stenosis, or whatever, and then they'll have an operation or whatever"* (South Africa).

> *"We are four doctors here. We have patients for thirty years and walk all the way with them"* (South Africa).

However the picture from other countries was bleaker. Areas where following up and continuation of care suffered was:

a) Provision of medication:
"If his medicine has been out of stock for say 2 or 3 of 4 months and now he is seeing a different sister and she is not checking the previous visits then she is going to continue him on the medicine that he is on now, because she… has not seen that he has been on something else in the past, which was changed because it was out of stock" (South Africa)

b) Management of a serious injury after the acute initial phase.
c) <u>For users with serious impairments</u>: In cases where users where told nothing further can be done, but the disease did not progress as was predicted they cannot access the specialist again for another opinion without paying for it: *"They told me if I want to go to Calvinia again I have to pay"* (South Africa).
In another case the doctor refused to examine the patient in fear of causing damage, but also did not refer her for specialist assessment.

The problem was aggravated by high staff turnover and lack of hand over:

"A big problem is lack of continuity. For example there is no permanent occupational therapist. Every year it is someone new and the previous one have left before the new one arrives, so there is no hand over" (South Africa).

"We actually try to get it so that you always see the same doctor at the moment, let alone anything else, at least the same sister. But it is so difficult in an environment with high staff turnover, and we are also a training ground. So you'll see one doctor now, and come again in six months, and meanwhile that doctor has moved on to specialize at Tygerberg, or … so the poor patient doesn't have sort of the same thing" (South Africa).

4.4.7   Fragmented inter-sectoral care and lack of a multi-dimensional approach

Although many users utilise informal, private and public health care sectors, the private care seems to be reserved for acute incidents, whereas chronic conditions are managed by the public and informal health care sector. By utilising different sectors confusion and conflicting expectations may result. Recommendations of one sector may not necessarily be based on the full understanding of the patient's condition (there may be limited disclosure), the patient's current treatment and responses to treatment. Apart from the need for full disclosure by the patient who consults in various sectors, open consultation between the different parties involved in treating the person is needed.

It would therefore be important to ensure that health care to African communities incorporates a multi-dimensional approach, including both traditional and conventional Western medicine. Most traditional healers felt that there was a lack of acknowledgement of their role in health care and spiritual support. Most expressed the wish to be able to work together with the formal health care sector: *"If we can work together I think that will be the best"* (South Africa). At present, most however felt that: *"The government undermines the traditional healers"* (South Africa).

4.4.8   Poor management and support from district and provincial level

Allegations were made of less than optimum management and support from district level in South Africa and Sudan. Examples include poor support of staff, poor management of budget, sluggishness with appointments, wasting time, money and resources, not showing appreciation for staff and treating staff with disrespect:

"…on Monday I went to Upington for the decentralization of the ARV clinic, but the people from the national department of health did not pitch for their meeting with us. The whole Northern Cape a few doctors and all the head nurses of the clinics. They were all there. They all slept over the Sunday night as well. So just the accommodation must have been between 20 and 30 thousand [rand]" (South Africa).

"…the budget is not managed optimally" (South Africa).

Complaints were also not responded too by either district or provincial authorities:

"I just don't know where to complain. We have sent so many faxes to the health department, to ministers, to national health, but no-one hears us" (South Africa).

4.4.9 Feedback of test results

With regard to feedback of test results, there were conflicting experiences. In some cases, test results were available immediately, whilst in other cases, there was a wait. Users may also not be clear on the delays brought on by test procedures which require longer times to process:

> *"…sometimes you don't get results immediately then you need to come back after a week"* (South Africa).

However, sometimes results were lost in the system. Being unable to provide test results in a timeous manner not only affects treatment and management strategies of the patients conditions, but also creates an impression that staff is incompetent:

> *"Last year I went to the clinic to collect the result of my father with a letter that shows to them, but each and everyone send me to another. I found out that they don't know what's written on the letter but it's specified that the result is there. They show the signs of lack of understanding and incompetence. There are situations that need you to be there (at the clinic) but you won't go because you've got a picture in your mind they aren't capable to help. I don't know how did they get into those positions because they don't deserve to be there"* (South Africa).

4.4.10 Lack of accountability

The accountability issue was raised in almost all the interviews in Sudan:

> *"The whole health is based on patriarchal system, where the MOH is the father and the hospital mangers are the children who won't and can't say no or why"* (Sudan).

> *"The cause behind the lack of accountability is the poor resources. I can hold people accountable based on the support I provide. Since I provide nothing I can't order them"* (Sudan).

Users believe that accountability is very poor within the public health facilities because the judge and the defendant is the same:

> *"At the end you complain to the medical director of the facility who will not support you against himself"* (Sudan).

4.5 Availability

Availability of services was an area that showed major challenges in all countries and which negatively affected other aspects such as quality and acceptability of services. The aspects most severely affected were availability of equipment, staff, medication, rehabilitation services and assistive devices. In addition space in facilities and the number of facilities were inadequate in all the countries. In combination these challenges caused, long waiting times, overcrowding and user dissatisfaction.

4.5.1 Quantity

4.5.1.1 Equipment

References to lack of or broken down equipment were made in interviews from South Africa, Malawi and Sudan. In Malawi the problem was so severe that the maternity wing of one facility was closed for a month for this reason. This included clinical and non-clinical equipment as indicated by comments such as: *"…equipment at the clinic aren't up to standard…"*; *"difficult to get resources"*, *"shortage of supplies"* (South Africa).

> *"I only saw the items in your list when I was working outside Sudan or in few private hospitals in Khartoum city, but here in this governmental hospital I work with what is available and given to me, which I know is below what is ideal but what can I do. Sometime I ask the mother to hold the drip as we have only one drip stand, as for the emergency trolley I am sure if you asked my young college they will not know what it is"* (Sudan).

> *"…I had three patients who gave birth simultaneously…I had to lie the one woman down on the ground on a blanket and the other two on beds"* (South Africa).

> *"I receive 50 gloves per day and we are four in the room and we see around 12 patient each, so gloves are a luxury and I do not have enough supplies so I do send patients to buy plasters"* (Sudan).

With regards to non-clinical equipment computers seemed to be in short supply. In Malawi wireless equipment used to contact referral centres were not always in working order. In such instances users must buy airtime for the administrator's cell phone to make the necessary calls. In addition some clinics in Malawi did not have electricity.

4.5.1.2 Personnel

Staff shortages were mentioned in all four countries and the following quotes illustrate the challenge: *"Our health services are hugely overburdened. HUGELY overburdened!... the patients never end…"* (South Africa).

a) Nursing staff:

> *"…nurse staff will always be a problem with too little staff… I have petitioned the minister for more health workers as a result of the capacity of people that visit the Day Hospital and the shortage of staff. The MEC says that there isn't any money"* (South Africa),

> *"I have a lot of respect for our sisters…the amount of hours that they do…three or four of them must cover the entire month…including after hours…it is tough"* (South Africa).

> *"I think one can quite categorically say that we are understaffed… I would suggest that our vacancy rate among the nursing staff is certainly more than 50%"* (South Africa).

> This situation is aggravated by staff being on leave, sick leave and courses:

"We do have a high absenteeism rate, that's part of the problem, so you've got…15 nurses on the staff but there's only 7 of them on duty because 2 of them are on a course, 2 are on leave and 3 are off sick… so actually on paper our staff is enough, but maybe on the floor we don't enough because of absenteeism" (Provider, South Africa).

b) Doctors:

Sudan, Malawi and rural sites in South Africa reported a shortage of doctors:

"I prescribe medications and do investigations like ultrasound which I know are beyond my competence but no doctor will come to this isolated area where there is no cold water, no computer and no air conditioning; so I have to help my people" (Provider, Sudan).

Challenges experienced were there were no doctors on site included:

- Users dying
- The need to transport patients (e.g. person with a serious illness or injury; women with labour complications) over long distances on often poorly kept roads. In this time lapse impairments can worsen and cause permanent impairment or death.
- Loss of time:
  "If you are there on a daily basis or at least three times a week you can address issues… do follow up and manage things within a week…When you come once a week and have to see many patients you cannot address every person's case on a continuous basis and as quickly" (South Africa).
- Sisters might not have the same ability as doctors to determine the severity of signs and symptoms: *"…doctors might be more attuned or have a better judgment with regards to what is serious…we call it urgent elective…something is not life threatening, but you can also not wait two weeks to do it"* (Provider, South Africa).
- Inadequate support to the sisters
- Challenges with regards to sister's scope of practice

c) Therapists

No information on the availability of therapists was received from Sudan, Namibia and Malawi. In South Africa there were therapists (occupational, physiotherapy and speech therapy) based at all the sites except Fraserburg. In Fraserburg community service therapists visited the clinic once in two weeks as a team.

d) Medication

One of the most serious health care problems experienced in Namibia, Sudan, Malawi and rural South Africa was a shortage of medicine:

"…the doctor is kind and good, but he is helpless, he has nothing to offer apart from words; but I don't have a choice I come here as it is near and cheap and I cannot go to the city it will cost me a fortune" (Sudan).

"Nurses are giving one tablet for more than one disease, e.g. eye problem, headache and leg problem" (Namibia).

"…sometimes the medicine is not available. If the medicine is out of stock, then you have to wait until it is available or if the patient's condition worsens, then they will call the ambulance" (Namibia).

"At the moment there is no anti hypertensive in this clinic that I can use to treat a pregnant woman with. None. I am giving them now medicine that I think is the least contra indicated. Of course I must, you know you must weigh it up now" (South Africa).

Other medications which were specifically mentioned included epilepsy medicine, asthma medication, antibiotics, long term pain medication, eye ointment and children's pain and fever syrup. Long term implications of this cannot be ignored:

"…For sometime we had no eye ointment at the clinic. It costs about R10.00… and you can use it for a myriad eye conditions, but there is none in stock. Now you can have a 5year old child that must wait a month for eye ointment and will develop permanent eye damage just because there is no money for eye ointment that costs R10.00, or the ointment was not ordered or mixed or something" (South Africa).

e) Rehabilitation

Data on rehabilitation services were only available for the South African sites. Data from Gugulethu and Fraserburg paints a bleak picture with challenges in rehabilitation services both at primary and referral level, while data from Worcester and Madwaleni were more positive.

In Gugulethu disability specific services were offered by two staff members (viz. an orthopaedic after care professional nurse and a physiotherapist). In Fraserburg, rehabilitation services were offered by outreach therapists. In both sites therapy offered was impairment focused rather than being focused on comprehensive rehabilitation:

"All they said is that I must exercise my arms a lot… My wife helps me onto the bed and to wash and dress" (User, South Africa).

"… I would try and give them an exercise program to follow…sometimes I only get to see a patient every two weeks which is not ideal but that is the best that I can come up with" (provider, South Africa).

"Not rehabilitation, more maintenance" (Provider, South Africa).

In Madwaleni the rehabilitation department was seen as particularly strong:

"… the rehab department, which is essentially the department that works with disabilities in our community, it's actually quite a strong unit and they have done some good work, and we

don't want that to fall off…they have done some excellent work with very few resources"
(South Africa).

In the Worcester area, a mobile team of therapists and the orthopaedic nurse were achieving success: *"… rehabilitation for any disability …"* (Provider, South Africa). Therapists moved away from impairment and maintenance based therapy to more holistic rehabilitation:

> *"…got all the mothers with disabled kids together… those mothers could for the first time share their experiences with each other and with… therapist people…they took some of these mother groups that were established via the therapist's visit to the clinics… to Worcester and they had a day-long function. In the morning they gave them a debriefing kind of session with the emotional kind of stuff, and sharing. Then they gave them a good lunch, with flowers and so on - and little presents. And in the afternoon they gave them the dope, in terms of what can you do with occupational therapy principles with your mentally-handicapped child. And they also took them to some of the institutions, to see what's going to happen to your child eventually when they grow up. So that the mother sitting in Ashton can have information about what they can expect and what's going to happen to my child in the next 20 years and so on"* (South Africa).

These mobile teams covered all aspects from identification and referral. Services to users with disabilities were more integrated into the general spectrum of service delivery:

> *"We give the medicine which the mobile clinics take to the patients like a paraplegic that needs his medication every month. We will prepare it and the sister will take it to where it needs to go"* (South Africa).

f) Mobility Assistive devices

Information on assistive devices was only noted in the South Africa and Malawi interviews. Few assistive devices of any kind were available to users in Malawi. No wheelchairs were available to Malawians in the rural areas. In Worcester and Gugulethu mobility devices such as basic folding frame wheelchairs, walking sticks and crutches were issued at Community Health Centre level. Orthopeadic nurses had their own assistive devices budgets which they manage:

> *"I always have in stock. At the beginning of the financial year they say how much money I'm getting. Like for example, I got about R165,000 for wheelchairs and so and 22,000 for crutches. I ordered the wheelchairs and everything. So I always have stock of everything"* (South Africa).

In instances where users from Worcester and Gugulethu needed more advanced devices (e.g. custom seating systems), they were referred to a specialised seating clinic at the Western Cape Rehabilitation Centre:

> *"…we can only order the basic stuff that our budget allows us to… So someone who needs more than that have to go to the seating clinic, then they can order through them"* (South Africa).

Worcester was the only site where any mention was made on follow up and maintenance of mobility devices:

> "Yes and follow-up. Look, if you received a wheelchair, then you have to come to me twice a year so that I can see whether the wheelchair is still ok or whether you have warn it out. Do you still sit fine in it, or does the wheelchair need a service? And if the brakes of your chair are faulty I try to fix it myself there and then - the basic stuff like fastening the screws and so… we have a tool box… and all the necessary things are there. And if the chair has to go in, we have Abrie who repair wheelchairs at Brewelskloof Hospital. So then I take the broken wheelchair in and I lend a chair to the patient and I ensure that the chair is repaired" (South Africa).

Walking devices were available to users in Fraserburg through the secondary hospital in Calvinia, while users in Madwaleni struggled to access even these basic devices: "have no crutches" (South Africa).

For users in Fraserburg wheelchairs and buggies were ordered from Kimberley and provision was a challenge:

> "…we struggle a lot…I do an assessment and complete a form which we fax to Kimberley…we only get the standard wheelchair" (SA-230610-F-AGb-HP-SV). The wheelchair waitlist dates back to 2006. The impact is severe and varied from user's dying before they received the device to devices being too small when they are finally delivered: "CP Buggies…if a three year old child needs a buggy and the buggy comes in two years time the child is five and the buggy too small…it is a waste of money if you think about it" (South Africa).

g) Orthotic and prosthetic devices

Orthotic and prosthetic devices include artificial limbs, calipers and raised shoes. Only South African interviews raised these services and comments indicated a number of problems in the provision of orthotic and prosthetic services.

> "… we struggle a lot there. There is almost just one person who makes the prostheses with a helper. And the money is not there" (South Africa)

> "…the prostheses are made in Cape Town, so they take the measurements and send it to Cape Town you know they must go to Cape Town, they don't have the money and then they fit again and fit again and fit again…, you can understand that the fittings is not right, because you gain weight you lose weight… there is so many things that can happen in weeks" (South Africa).

Orthotic and prosthetic services to Fraserburg were provided through outreach clinics in Calvinia However, the clinics did not have a fixed schedule and few orthotic or prosthetic (O&P) devices were provided:

"The O&P workshops are supposed to be held on a regular basis, but in the previous four years one was held at the end of last year and another will be held this year…Twice in four years…And they come without devices…People need to go to Kimberley for prostheses…That does not really happen…I do not know of one person who received a prostheses" (South Africa).

h) Facility status

A lack of <u>space</u> was generally experienced in all four countries:

"…it is packed. We have to stand and those nurses in the meantime they will say, we need space to work here. When you try and find an empty space, they say: look you do not stand here we need to work and you decided to wait outside. Someone who knows you will call you when your name is announced, inside they shout at you…" (South Africa).

Facilities were mostly <u>clean</u> and well kept. However in Sudan some facilities were so dirty they constituted a health hazard:

"I stay next to him all day using a hand made fan to kick the flies and I let him sleep on my tob (Sudanese ladies gown) as their sheets are so dirty." (Sudan).

Another issue was the <u>waste disposal</u>, none of the visited facilities have any special methods except burning of waste, the waste bins are full and syringes lie on the floor:

"I know that syringes are dangerous but I receive few boxes per week that wouldn't last me two days, I use my connections with other health centres and ask for them to donate extra boxes; what can I do more - biological waste is a crises in Sudan" (Provider, Sudan).

Complaints of inadequate <u>waiting areas</u> and seating came from South Africa, Sudan and Malawi.

Sudan reported poor quality <u>toilet faculties</u> which, in addition, were not wheelchair accessible. Wheelchair accessibility was also a challenge in some of the South African sites. Namibia reported adequate wheelchair accessibility of toilets. Malawi reported mostly clean toilets, but did not comment on wheelchair accessibility.

Some sites in Sudan and Malawi had no <u>water</u> and at some other the water was of poor quality.

Challenges with regards to <u>operating hours</u> were mentioned in Namibia, South Africa and Malawi. In Namibia some clinics have only one service provider and are closed when this person is not at work. In addition strict closing hours were being observed. In Malawi complaints about services not opening on time or not opening at all were made by users and observed by researchers. In addition users would be sent home when it is closing time regardless of how long they have been waiting. Furthermore, there were no emergency treatment facilities available over weekends or during the night at primary level in Malawi. This was in contradiction to the Malawian Health care policy.

<u>Crowding and long waiting times</u> were experienced in Malawi, Sudan and South Africa: *"You must take off a whole day for these visits"* (South Africa) and *"…you go there at six o'clock in the morning… And at about five o'clock in the afternoon you come home"* (South Africa). In the Gugulethu Community Health Centre, waiting times is the most common complaint dealt with by the community liaison officer.

Where users needed to be <u>referred for specialist services</u> long waiting times occurred in Fraserburg and Worcester, South Africa*:*

> *"I think that [waiting for appointments] is a problem in the whole uh in state medicine, because if I see a lady with a breast lump in my surgery today within 14 days she will be sorted out, but if she went to the clinic I am going to wait a month for the first fine needle biopsy to get back and then she must wait 3 or 4 months for an appointment with a specialist and then he is going to send her back a few times. She would be lucky if she needs a mastectomy if she get it in a year or 18 months, she would be very lucky"*(South Africa).

> *"I was passing urine it was burning. Now I didn't want to go to the government doctor then I'd have to wait six months, so I just went to the private doctor, ja ok it costs you more but it's umm, better and they help you quicker, they give you the right medicine, medication or they give you a prescription or something and you take it to a chemist where you have an account maybe and hand it in there"* (User, South Africa).

<u>Appointments</u> could be made in two South African sites (Worcester and Gugulethu), but not in Sudan, Malawi or the rural South African sites. Although reported to be a positive feature there remain problems. Appointment systems reduced waiting times and improve flow and planning of services. It also allows the user to choose suitable times to access health care services. Problems arose when users were not able to keep appointments. Poverty, lack of transport, lack of family support or delays caused by unreliable transport services caused users to be late and miss their appointments.

A <u>health passport</u> was a prerequisite to receive treatment in Namibia and Malawi. A need to own a document like this in order to receive treatment was not identified in the other two countries. Problems arose when payment was required for this document or when the document was lost.

<u>Preferential treatment</u> issues were reported in South Africa, Sudan and Malawi. Disabled individuals got preference in Sudan and at some institutions in Malawi at the discretion of the employees rather than as a clear policy or a matter of rights. Not only the providers but also the vulnerable users believed that they should be served first:

> *"There is a norm here not to ask the disabled people to pay, and we allow them to skip the queue. It is not by law, it is actually for humanity reasons"* (Sudan).

However, unless the disability is a physical one which is also visible, the user will not be given preferential treatment.

Elderly and disabled users got preference in Madwaleni (South Africa). Health care providers from Fraserburg (South Africa) indicated that seriously ill users will receive treatment immediately. However, users did not always agree that this was the reality:

> "Often I have gone there, because of my chest…I lie there at the hospital. But then there are many people and they cannot help you immediately. So I have often come close to death with my chest" (South Africa).

This might be due to the fact that very ill users are identified through observation by staff at reception and not through a formal triage system. The fast tracking system in Gugulethu experienced similar problems:

> "(If someone is very sick) they will help that person but sometimes is difficult for them to notice a sick person. Let me make an example there was someone passed away in the waiting area. … he was in a queue already for a long time then he died in the process of waiting for help" (South Africa).

Where users with disabilities visited the service designated for them in Worcester their route was streamlined:

> "…I am supposed to give them right of way. A fast lane. I must ensure that every three months that sister [name] has a clinic. The folders will come to me to call out. The D window will be used for them then so they won't have to wait for the whole process. Otherwise the people in the wheelchairs will make the place too full" (South Africa).

However if they came for other services it seemed like they had to wait their turn except for blind and deaf users:

> "…but if it were for something else like chronic medication, then I don't think there's a, no there is not a special box for them, where their folders are kept. Perhaps we should consider it but at the moment it's just the deaf and blind.." (South Africa).

Comments on <u>the availability of information and health education</u> came primarily from the South African interviews. Participants emphasised a need for appropriate health care workshops or training on chronic diseases, although this is done to some extent already: *"…they also recruit patients from the waiting rooms through group talks about HIV. So they will motivate the patients to go for HIV testing"* (South Africa).

At the Gugulethu CHC and Malawi, general health care education is done in groups with patients in the waiting rooms – an approach that has a number of shortfalls:

> "...but doing it in a group they don't always listen, if they're all in the club and they all waiting for their name to be called, for their blood pressure to be done..." (South Africa).

Health care education messages were also on murals in waiting rooms, information leaflets, health care promotion and counselling.

"We also give out flyers. Even if you go into the pharmacy's waiting area there is a table with all kinds of flyers. Anyone who'd like to read… there is education verbally in the prep area to make people aware of whatever is going around" (South Africa).

While health promotion is a key component of primary health care, staff struggle to obtain the necessary resources to do training and generally had to make do with personal resources to design training packages and training materials:

"If I want to give a talk but I want to use a visual aid like a simple thing like a poster – where do I find my material? I for one will buy things out of my pocket, but the next health educator is not going to use something out of their pocket. And it is proven – in uneducated people – pictures tells them the best stories" (South Africa).

4.6 Acceptability

The essence of acceptability is summarized by the following statement:

"…the only way that you really make a difference is if you have a solid value system at the base of the way that you see people and treat people. And if your heart is not in the right place - if it's just a job … people will see that, and they will feel that it's not necessarily a heart-felt service that you are rendering to them. So I think it's really about the values that we have when we serve other people…people need to believe in the system, and people will only believe in the system if they can actually see that they are cared for. So there are two sides to it, and the one is that people need to know that this is not just your job - that you care for people. And the other side is that you have to be up to date with what is happening in the medical field, and that the decisions that you make, need to be the correct ones. So you not only need to be professional, but you also need to be a person that can hear people and respect and honour them" (South Africa).

If service providers can achieve the ethos expressed in the above quote then the *"negative stigma connected to government health care"* (South Africa) can be eradicated and the staffing crises addressed:

"One doctor that comes back is a lot more than five doctors from other lands that come to work here. You understand your people. You understand their hearts. To make a difference to your community you need to have a relationship. Further you need doctors in the rural areas that want to live there and be a part of their community" (South Africa).

Themes which relate to service acceptability could be divided into those pertaining to the service and those pertaining to the users. Service related themes included: Ethics, Equality, Privacy, Staff morale, Staff attitudes, communication, user dissatisfaction and complaints management.

4.6.1 Ethics
Comments by participants showed an awareness of ethical issues:

"Translation is different to speaking, and it needs to be done very sensitively. A lady doesn't want a male translator. And the more strict the religion or the culture is, the more difficult it is to communicate" (South Africa).

"A person cannot expect that a patient will trust you immediately. You must be professional and they must be sure that their information is confidential. Anything that we discuss is confidential. You must build up that confidence. It must come from both sides. If we see them regularly, they will realise that we don't judge them" (South Africa).

4.6.2   Equality

Little information was gathered on equality, but users and providers from South Africa felt an equal service was provided:

"Every patient, I try to give them quality time. When I see a patient I respect them. It is perhaps the only place where they receive respect. It is low income people and therefore I give them all the attention I can. We treat all patients equally" (South Africa).

"They treat us equally and they keep your matters confidentially, so far I'm still satisfied about the way they treated me" (User, South Africa).

However, in Namibia some users complained of unequal treatment:

"Not treated equally as everyone else, no respect, even here at the centre" (Namibia).

And in Malawi reports were made that old people are not always treated with dignity. They are told by health workers that available medicines are for young and productive people, and that giving them health care is like *"applying fertilizer to a crop during harvesting time"* which is perceived as a waste of resources. A 71 year old man in Rumphi alleged that when he visited a clinic in his area some three years ago he was given two tablets of aspirin because drugs were *"reserved for his grandchildren"*. He felt humiliated and has since vowed never to go there again. An old woman in Ntchisi also said that in 2009 she went to a health centre to seek treatment. When she got into the consultation office, she was disappointed to hear from the medical assistant that the medicines are for the youth not the old people.

4.6.3   Privacy and confidentiality

Complaints in this regard came from Malawi and South Africa:

"There is no confidentiality because if you are HIV/Aids or diabetic there are different sides for those diseases. I felt that is wrong because if diagnosed with HIV most of the time you are not ready to be known by other people. They embarrass us because they will call loudly saying, those who came for Antiretroviral drugs that side and the result of HIV that side" (User, South Africa).

4.6.4 Staff morale

Findings about staff morale were ambivalent. Staff tried to present an upbeat face: "*I am very happy with my work. I enjoy my work. I am fortunate that I enjoy my work. It is a learning process every day*" (South Africa). However, spirits were flagging due to working conditions:

> "*…people lose heart because all initiative gets taken away from them. It becomes very tedious work, and after years it's actually quite difficult to still sustain your motivation*" (South Africa).

User non-compliance also negatively affected staff morale:

> "*…I have never met a sister or doctor that wants to give bad care. I have met sisters and doctors who are tired and frustrated, because there are patients who are not being responsible about their health care, and they don't even come in to follow up on blood tests or pap smear, etc. All the support is here, but they don't use it. It's very frustrating for staff to treat for example a baby to good health at the hospital, and then six months later it is back just as bad. That's harsh on the public system and on the sisters and doctors. A nurse caring all day, and she goes home to care for her family; she gets cared out! There are high levels of marital problems in nursing households. Nurses are simply cared out by the end of the day; they don't feel like fiddling with difficult husbands*" (South Africa).

In Gugulethu, South Africa, morale was further negatively affected by staff feeling unsafe and vulnerable outside the facility, especially those making use of public transport or walking to work:

> "*You will find that in terms of caring for them (staff) and supporting them and acknowledging the hostile environment that they are working in and the situation and the long hours that we work there isn't much of an appreciation. So the morale is not that high. Sometimes they will complain that when they work overtime it will take 4 to 5 months for their overtime to be paid. So things like that…*" (South Africa).

4.6.5 Staff Attitudes

The overall impressions on staff attitudes in South Africa, Malawi and Sudan were positive. Generally the staff was friendly, hardworking, patient and approachable and treated users with courtesy and respect:

> "*It [staff attitude] is more positive than I have seen at a lot of places. They have a good team spirit. Some of the staff are very organised and committed to serve people*" (User, South Africa).

> "*the doctor is polite and nice*" (Sudan).

Users showed a lot of appreciation for providers working in difficult circumstances:

> "*…I take my hat off to these ladies who have the courage to work there and under those circumstances [clinic]…I don't think it is always very nice…the emotional pressure that you must feel that the community's health is on your shoulders*" (South Africa).

However, some attitudinal issues were raised in all four countries. These included:

a) A lack of efficiency

"I experience problems with the staff that they do not take our sickness serious and they work with their time and do their personal work while us the patients are waiting in the waiting area" (Namibia).

"One can come as early as you can and when it comes to be assisted, you will find out that the nurses are not taking notice of you; at times they might be busy on their phones" (Namibia).

"They (the staff) behave like people who were sitting in the sun and they were just called there to do this nursing work. They are here because of money, including doctors. As long they signed register to show that they are present at work" (South Africa).

"Type of go slow… No urgency to get things done …Does not put people first and serve them with energy …Not time efficient - can cut down on waiting times" (South Africa).

b) Insensitivity

" I saw one woman deliver a baby on the floor at clinic in front of me and the nurse were just walking around her never mind that situation…" (South Africa).

c) Sticking to job descriptions

"…all this rules and regulations regarding overtime, you know you cannot work more than that overtime and this is out of your scope of practice. A cleaner at the hospital is not allowed to wet the garden as well… The health personnel as well….the sister will not do something that the doctor is supposed to do and the doctor vice versa instead of Batho Pele" (South Africa).

"But then the attitude comes in again. They believe that I owe them or the government owes them. They come in and say that this is my job description. This is what I need to do and what I am only going to do" (South Africa).

d) Rudeness

"There are lot of obstacles because when you tell the doctor what you have like headache, swollen feet and thrush, the doctor response will say - do not mention everything you did not come here to do some grocery shopping" (South Africa).

"In a situation whereby every time you visit the clinic the nurses are rude and insult patients, you would stop coming at the health centre and rather use traditional health care to avoid insults from nurses" (Namibia).

"They (the staff) shout at old people and disabled people…" (-Namibia)

"…the person that's there in front at the front desk is very rude, she doesn't have a way of talking to people and she's basically the face of the clinic and if that's the first impression that you get when you go inside you are not gonna feel free to go again because I know these women at the shelter told me that they not going back again and even if they are sick, they are reluctant to go back" (South Africa).

e)   Uncaring

"An 18 year old woman in Rumphi gave an example of what happened to her in-law whom she escorted to one health facility in 2009. Her in-law was pregnant and she escorted her to the facility on the day she was to deliver. When they arrived at the facility and explained to a nurse that she was due for delivery, the nurse examined her and told her to go back home because she was not yet due. The patient insisted that she was not feeling well and that she wanted to deliver but the nurse shouted at her and was sent back. On their way back home, her in-law delivered but unfortunately, she lost the baby because it was very cold on that day and they went back to the hospital for check up. The nurse welcomed her and pretended as if nothing had happened" (Malawi).

"She went to the health centre to receive treatment and unfortunately it was during the 'Eidi ur fitre' (Islamic holiday) and the medical assistant refused to treat her because it was a holiday. When the respondent saw this, he took the injured niece back to the health facility to plead for his niece to be treated. When the medical assistant saw the respondent and the injured person, he ran away and hid in the house. The respondent met the wife of the medical assistant who is also a female medical assistant at this facility but this time she was on maternity leave. The wife told them that the medical assistant had gone away and added, "Don't you know that today is a holiday?" His niece went back home untreated - she was then taken to a CHAM health facility some 15 kilometres away. The medical assistant referred the case to the police and claimed that the 80 year old man allegedly wanted to beat him. Because of this incident the man was called for questioning and was charged with "conduct likely to cause breach of peace." He was locked up for 2 days and released after he was given a bail. He was told to report to the police station twice a week and as at the time of data collection he had been going there for 13 times. This incident has worsened the relationship between the two people. Whenever he or anyone in his family is sick, the medical assistant refuses to treat them. These experiences have forced people to stop using services" (Malawi).

"…nurses here at Sibbinda don't have a caring heart that nurses should have to towards patients. These people are called heartless and people don't always come here because they know that they will be ill-treated and named all the names the nurses could think of" (Namibia).

"I lie here in this hospital bed for two days no doctor come to check on me or tell me my status, my wife has to nag the nurse to come and change my dressing" (Sudan).

"…the doctor did not even look at my child he prescribed the medication after what I said" (Sudan).

f) Disrespect

"… the nurses treat them with no respect" (South Africa)

"…the way they talk to the people there… that's very sad for me… if somebody talks to me like that as if I'm nothing ehm then maybe I shouldn't come back again or I'm to scared to go because I might be humiliated in front of all the other patients" (South Africa).

g) Favouritism

Allegations of family and friends being assisted first were made in Malawi, Namibia and South Africa:

"…receptionist also practices favouritism here. They do not let their family and friends pay which is unfair. I am telling you I have witnessed it. The government should put in strong regulations here" (Namibia).

"…there is favouritism - they treat better their families and friends. When their friends come, they give them folders before us and they finish sooner than those of us who were there from early in the morning" (South Africa).

However, the perceived favouritism may also be the result of strategies by users to try and beat the system:

"In my case, a disability person, I send someone in the morning to stand (in the queue) for me because they take some limited numbers in the clinic. Due to the fact that I am crippled it takes too long for me to reach the clinic early" (South Africa).

h) Apathy

"So I think also staff apathy is a big problem. Often I think our staff are so exhausted, they're not bad at what they are doing, they are exhausted, they are burnt out entirely" (South Africa).

Unprofessional behaviour and negative attitudes of staff was often linked to particular individuals.

"… in any environment you've got good potatoes and rotten ones so the truth is that you'll find those that will really not work well with the patients… Ja, (the complaints are usually) from the same person or the same department. Ja. There are those cases – it is an open secret that we cannot hide" (South Africa).

4.6.6 Attitudes towards persons with disabilities

Negative assumptions and stereotypical views on disability by health care providers excluded people with disabilities from using health care services. These attitudes can lead to sub-optimal treatment and unacceptable behaviour by service providers. These attitudes were reported in South Africa, Malawi and Namibia as the following examples shows:

"…staff also discriminates against disabled people. If you are, for example pregnant, they ask you how you became pregnant; meaning they do not see you as a person but as a disability and they do not consider you" (Namibia).

"Even the HIV/Aids diseases nurse will say - hee- hee, where did you get it? It does not register to them that you are sexual active and you have blood. Even if you …are pregnant they will asked why are you pregnant, how this person make you pregnant….Yes by saying how many children do you have and when you tell them they make a joke of you and the other patients will laugh at you and you became frustrated and angry, all of that" (South Africa)

"…the sister came to me with the admission forms, and then she put the paper in front me, give me the pen, and she said to me write down, my goodness I cannot write, I am blind" (South Africa).

"One 42 year old woman in Blantyre, Malawi who was deaf and intellectually disabled complained that doctors always discriminate against her saying "atichedwetsa awa" (which literary means that this one will delay us) and then they just ignore her. This woman further complained that there is no privacy because if she goes with her sister, she has to interpret hence she is shy to explain the problems she has to the doctor" (Malawi).

4.6.7   User – provider communication

Communication difficulties were reported in all four countries and centred on language barriers (see separate section), a lack of time and inadequate explanations with regards the condition the person suffers from, management strategies and medication:

"The doctor that operated on me did not explain to me why he is going to operate me and what the complications were if any. The worst part was, that when the operation was done, they just told me to come back on the 9th of May (no time was given) for my results. They did not tell me to come or to go to the nearest clinic for dressing the wound or come back to the hospital, because of no information given by the doctor. I just went home and went for my follow up dates that they had given me and that were written in the health passport. The wound started getting bad and I was in pain then I decided to go to the clinic for dressing - now I am getting my dressing here at the clinic. I approached them and they told me that they forgot to inform me on what to do and where to seek further treatment" (Namibia).

"Those doctors talked to you with big words that you do not understand, and you cannot say you don't understand, so when you go home you can ask your son or the person accompanying you to explain to you" (Sudan).

In some instances this omissions were acknowledged as being deliberate:

"People are illiterate - they have so many misconceptions about their illness so I don't waste time to discuss diagnosis or treatment. They should listen to what the doctor says" (Sudan).

However, examples of better communication were also found:

"I am one of them; I know each one by name and they respect me; I help their children with their studies and deliver their babies safely - I am here for them" (Sudan).

4.6.8   User satisfaction/dissatisfaction

The general impression created was one of satisfaction with services. Users were positive about the services they received and felt that the clinics and Community Health Centre was an asset to the various communities and the key to their health:

> *"…I use the clinic because they give my treatment and explain to me the direction to use and if I cheat my medication they also tell me what is going to happen"* (South Africa).

> *"… this clinic is good, they analyse your blood and urine using machines and they give you medications through your veins, that is why I always come here and tell everyone in my family to come here"* (Sudan).

Users also showed understanding for the difficult circumstances state providers work in:

> *"…the work load is heavy in a provincial hospital and so I understand you know they try their best and they did well I can't complain that they didn't treat me well at all because they treat me very well ehm the personnel was great, I can't complain about the service"* (South Africa).

However, the challenges with regards to availability and health worker attitudes did lead to some dissatisfaction especially amongst users from Malawi and South Africa.

4.6.9   Complaints management

In Gugulethu and Worcester (South Africa) specific systems were instigated for users' complaints. No other country reported on complaints management. At Gugulethu CHC a community liaison officer was appointment to liaise with users about their problems. Both Gugulethu and Worcester had health forums where the community and the healthcare management liaise and plan together and facilities had boxes for compliment / complaints slips:

> *"If the patient feel that they want to complain or compliment then there are slips that they can hand in. They can complain to seniors"* (South Africa).

> *"…we have a a ehm, a forum, ehm on which members of the public serve, it's a committee health forum I think it's called… that was established so that complaints can be attended to…"* (South Africa).

This is in contrast with Fraserburg where users felt they received no response to complaints even when these were sent to district or provincial level:

> *"I just don't know where to complain. We have sent so many faxes to the health department, to ministers, to national health, but no-one hears us"* (South Africa).

4.7   User behaviours and attitudes

4.7.1   User behaviour and attitudes

Some users were themselves guilty of poor behaviour and attitudes. This was reported in South Africa and Malawi. Personal attitudes, user expectations not being met, substance abuse or working in a context of a violent society were reasons given for these:

> "So even patients themselves…they can be very bad. Sometimes some of them come drunk…But sometimes you try to understand their problems because this person is hungry, he is coming from poverty his vulnerable and he is sick…They come smoking, drinking and all those problems…. Or they come during gang fights…some of the gangs will be bringing in their friend they will demand that everything stops…that this is the patient that needs to be seen…Ja, that person must be prioritised and others will just drink and shout and swear" (South Africa).

> "You know, there is no such thing as a happy patient! Who wants to be sick!? Nobody wants to be sick. And when they come to the hospital or to the clinic and they don't know where to go and what to do there, they are frightened, and there is an element of impatience before they even get there. So that also compounds the fact that they don't know where to go. 'I don't know where to go, and I am scared" (South Africa).

> "During interviews some health workers said that some people such as chiefs demand special treatment when they come to the facility. Some chiefs become difficult to treat because when they are given a dosage they demand extra drugs. When the health service provider does not give them extra drugs, they shout at them and say that they are disrespectful. Sometimes chiefs demand that they should be treated in their homes. When they are ill, they send a message to the healthcare providers to go to their homes and treat them. They claim that they are too important to queue for medical services with their subjects. Existing regulations require that health service providers treat patients at the facility. The refusal of health service providers to treat chiefs in their respective homes creates enmity between health workers and the chiefs" (Malawi).

In the end it seems as if both users and staff can ignite or dissolve trouble:

> "I can't say that the patients are the ones causing the conflict nor can I say it is the staff. When you sit and watch then you can see it comes from both sides. Its like I'll show you if you come in here with an attitude then I will make you wait. There is no more of that humanity factor. And vice a versa it happens with the people here. People come in here being sick. But there is still that attitude. If I go to your place and you serve me I expect you to treat me like a human being. Not an animal. I am sick. It costs you nothing to smile, how are you, what can I do for you today, do you have your card?" (South Africa).

4.7.2   Conflicts resulting from user expectations

A common complaint the community liaison officer at the Gugulethu CHC is about users' expectations not being met: "…*they complain that the doctor did not treat them according to their specifications"* (South Africa). Conflict exists at times between the scope of the programmes and services offered, treatment prescribed and the expectations of the users. To eliminate the conflict, the user needs to understand the scope of the services offered, the fact that they may be referred elsewhere, adequate consultation time between the user and service provider, adequate resources and clear communication, interaction and trust. As the communication and trust fails, users are left unsatisfied and with an impression that their needs have not been adequately addressed. Conflicts between actual treatment received and treatment expected can be prevented by clearly explaining services offered at various levels, referral pathways and educating the client around his/ her condition, giving time for questions and ensuring that language is not a barrier to effective communication.

Primary Nurse Care Practitioners, who are able to assess, diagnose and prescribe medication independently, effectively attend to the patients who do not require the services of a physician. However, this creates conflict as it clashes with the patient's wishes and expectations to be seen and assessed by a doctor:

> *"Like sometimes they (nursing staff) write you a prescription and then you ask to see a doctor, then they will shout at you and ask why….They are not doctors… In my case I told them: I'm the one who is sick here I want to see a doctor or I will phone Manta, Minister of Health by then and tell her that you do your [unintelligible] here"* (South Africa)

This conflict between expectations and the scope of the services further emphasizes the user's perception that the services are not client centred.

A user explained his dissatisfaction when he received different medication from what was prescribed at a tertiary hospital. Although it may have been completely different medication, it may be that the particular medication was not in stock and that only a generic replacement was available, or that the medication was given in a different form, (e.g. tables instead of fluid), but it was obviously not clearly explained, leaving the user feeling that his problem was not being attended to:

> *"At Groote Schuur I was given a letter to give Nyanga clinic for my treatment. When I go there they give me totally different medication. I do not know that medication is going to help…"* (South Africa).

4.7.3   Understanding rights / empowered

A key force driving non-users of clinic services to find health care at other sources and levels is the fact that they have a good understanding of patient rights and are empowered enough to demand holistic, accessible and client-centred services at clinic level. Failure to find these services at primary level, coupled with a belief that *"not even the government can do anything to change the situation in clinics"* (South Africa), motivates these patients to manage their own health. As this is limited by available funds and accessing the informal sector or pharmacies instead of formal health services, it

may potentially have a harmful impact on health care outcomes, as chronic or acute conditions may not be managed timeously or with the necessary continuity.

Others are not empowered to fight for their rights at all and just give up trying to seek health care:

> "If I'm seeking for help to the clinic and I don't get it I usually give up because I don't have money for private doctor all the time" (South Africa).

Some patients are empowered enough to find solutions within the clinics and understand their role in informing health care staff of their special needs. A user with ankolysing spondilitis explains:

> "My situation does not allow me to walk in the early hour, I cannot sit for long hours. I have to be attended in a short space of time so that I can leave. ….In my case I go to them (the nursing staff) and explain my situation, but if I keep quiet they are going to do as they usually do. … To other people they did not get it" (South Africa).

4.7.4   User responsibility and compliance

Going hand in hand with demanding your rights, is the insight and knowledge that users themselves also have responsibilities. This example clearly illustrates the user's insight into his responsibility to be on time for appointments: *"Most of the time I am always punctual so that if they don't help me at right time I can complain better"* (South Africa). This means, for example, rescheduling appointments when he is unable to keep them:

> "Because of my artificial leg it also affects me a lot sometimes so that I used to miss my appointments but fortunately I also make a call to ask for another date" (South Africa).

Providers were of the opinion that users did not always take responsibility for their own health and that they show a lack of compliance:

> "I think the bigger problem is patient responsibility. I think we have a bigger problem with patients not understanding that just because you're drinking a little pill everyday doesn't mean that they don't have to stop smoking and start walking and cutting out your fats" (South Africa).

> "Patients do not show up for appointments. You make an effort to get them an appointment at a specialist clinic and then they just do not show up" (South Africa).

> "Now TB medication, you need a 93 % compliance. In other words, in your six month period, you can have two parties where you drink alcohol...alcohol inhibits the liver from making the tablets work. And people drink, so then the pills don't work, so they come back. It's the same with ARVs, the first regime ARV1 works wonderfully, if you drink it and you drink it properly, and you don't drink alcohol, and you eat with your pills. Regime two costs about R800 per person per month, as opposed to 130 or 150 for regime one, and if it doesn't work, you're pretty buggered, so that kind of thing is very important. Now they've got all kinds of systems; they've got the DOTS system for TB, which is assisted drinking your tablets. But it still means

that the patients have to go to the clinic and drink those tablets, and go home and not party, and… " (South Africa).

" About ten percent of our moms coming in don't come for early check-ups…they don't come to the facility until they are about to give birth, so we can't put them on ARVs, so they're delivering babies that could have been treated, so they could have been born negative, that are now being born positive, so that's very, very sad" (South Africa).

4.7.5   Knowledge / insight

Service providers often observe what appears to be lack of knowledge or insight from users. Problems, such as festering sores or growing cancerous lumps are not attended too until very advanced stages:

"People do not realize what is serious and when you should be really worried" (South Africa*).*

"The level of poverty and illiteracy compromise our quality of service as I know that the patient will not understand if I explain his case, he will not afford the medication which I prescribe. It is a useless situation" (Sudan).

5   Conclusions

The comparison of results across the four countries shows a great number of similarities in the level of access to health care and the barriers and facilitators to accessing equitable health care. The equitable access to health care has not been fully realised in any of the sites in the four countries. The problems in accessing health care are numerous for people with disabilities but remain important for other vulnerable groups.

5.1   Amplifying the model

Considering the model presented in figure 1 the introduction to this report, we can now provide more detail on the different types of factors analysed in this report and regarded by users and providers to be affecting equitable access to health care. The focus is on barriers that hinder the equitable access to health care. The categories described in the model are analysed in relation to factors mentioned by participants in the WP 3 Phase 1 interviews across the four countries.

5.1.1   Personal variables

The major factors that relate to the individual who is vulnerable (with a focus on people with disabilities as a vulnerable group) were varied. Health care providers that were interviewed spoke about a number of characteristics of users that create barriers to accessing health care; for example: a lack of knowledge which led to late presentation of complications; lack of compliance and a sense of responsibility on the part of the user (e.g. in attending appointments and taking care of themselves); and user behaviour and attitudes including violence often related to substance abuse and alcoholism.

Other factors mentioned that relate to characteristics of an individual are: level of education which is often low; high unemployment; and religion and spirituality. While a high number of users reported being satisfied with the services, this is coupled with a sense that many users are not

knowledgeable on their rights and are not empowered. In Sudan, for example, the culture of not complaining leads to users accepting what they are given.

5.1.2 Community variables

Community variables refer to aspects of a person's environment which is limited to their community or neighbourhood including but not limited to the local health care services. The factors noted as being barriers to equitable access to health care include: a) attitude towards people with disabilities generally and particularly of health care workers; b) linked to attitudes is the support provided or not provided by people in the community; c) general cultural features such as the culture of not complaining in Sudan; d) the presence of alternative forms of health care such as traditional healers; e) cost of transport and covering long distances to reach the facility; and f) crime which make the journey to the health facility dangerous, especially in the dark.

5.1.3 Context variables

The context variables refer predominantly to the health facility characteristics, including: the staff and their attitudes and morale (e.g. disrespect, apathy, favouritism, rudeness); the physical accessibility of the buildings and pathways to the facility; communication between users and providers and provision of information as health education broadly and within individual consultations.

Household support and household poverty were also seen as important factors in limiting access to health care services for all poor people.

Within the facilities the typical issues raised were the space within the facility and waiting areas with overcrowding being a common finding, poor levels of cleanliness and access to water and sanitation, lack of accessible toilets for wheelchair users, and limited times when facilities were open.

The quality of care was also noted as being problematic with wrong diagnoses being given by nurses and by medical doctors, lack of medication, limited time for individual consultations and poor follow up of serious complaints, lack of choice, and poor communication between users and providers.

The context variables are specific to the health facilities in the selected sites.

5.1.4 System variables

System variables are those broad factors related to national policies and systems that govern the implementation of the health services. Some of the factors noted by participants as contributing to inequitable access to health care include government support and legislation; transport at the policy and systems level; lack of efficiency; limited privacy and confidentiality; and lack of choice of health care providers. Some positive factors mentioned included the provision of social assistance grants (especially in South Africa and Namibia); the presence of NGO or faith based services (especially in Malawi and Sudan); institutional support (such as provided for deaf people and blind people in the Worcester site in South Africa); and some implementation strategies that push for preferences to be given to people with disabilities and other vulnerable groups in accessing health care. These strategies include fast tracking them in facility waiting queues.

Lack of certain services, such as rehabilitation and assistive devices services, poor referral systems, lack of equipment and personnel, and lack of support for health facility staff were all seen as factors that negatively affect the provision of services, and hence, access.

5.2 Comparison of findings across the four countries

The findings described above in the amplification of the model variables were remarkably similar across the four countries, with the same or similar barriers being reported across all sites within the four countries. However, there are a few points of difference worthy of a mention.

- The Sudan interviews raised the issue of a culture of not complaining being evident in Sudan. This led to users not complaining about providers. In other countries this was not noted as a cultural factors but was rather seen as a lack of awareness of rights to health care access.
- While all countries raised the factors of religion or spirituality being key to understanding health and to health seeking behaviours, the interviews in Malawi provided the strongest example of this in the explicit non-use of the formal health system by members of the Zion church.
- Findings from South Africa and Namibia highlighted the benefits of having more resources in providing a more comprehensive health care service. This was noted particularly in the rehabilitation and related therapy services (e.g. physiotherapy, occupational therapy, speech therapy) and provision of assistive devices (e.g. wheelchairs, hearing aids, prostheses).

In addition to country differences, there were some urban/rural differences noted. Rural areas provide less transport and more challenges in terms of distances to health facilities. Transport was a big issue in rural areas, although it was also mentioned as a barrier in urban areas. Crime was more prevalent in urban areas especially in the urban South African sites.

In conclusion, the review of the model and of country and site differences emphasises the complexity of the different factors and their interrelationships. This report presents the start of an exploration of these complex and multidimensional relationships that lead to outcomes of inequitable access to health care.

A number of recommendations arise from these findings. These are presented and discussed in a separate paper on policy implications of the WP3 Phase 1 results.

6   References

Declaration of Alma-Ata (1978).

Eide, A. H., & Loeb, M. E. (2006). Reflections on disability data and statistics in developing countries. In B. Albert (Ed.), *In or out of The Mainstream? Lessons from Research on Disability and Development Cooperation*. Leeds: The Disability Press, University of Leeds.

Eide, A. H., Nhiwatiwa, S., Muderedzi, J., & Loeb, M. E. (2003). *Living conditions among people with activity limitations in Zimbabwe. A representative regional survey*. Oslo: SINTEF.

Eide, A. H., van Rooy, G., & Loeb, M. (2003). *Living Conditions among people with Disabilities in Namibia. A National, Representative Study*
 Oslo.

Flaskerud, J. H., & Winslow, B. J. (1998). Conceptualising Vulnerable Populations Health-Related Research. *Nursing Research*(47), 69-78.

Groce, N. E. (2004). *HIV/AIDS & Disability: Capturing Hidden Voices*: The World Bank/ Yale University.

Loeb, M., & Eide, A. H. (2004). *Living Conditions among People with Activity Limitations in Malawi*. Oslo: SINTEF Health Research.

Loeb, M., Eide, A. H., Jelsma, J., Ka'Toni, M., & Maart, S. (2008). Poverty and disability in Eastern and Western Cape Province, South Africa. *Disability & Society. , 23*(4), 311-321.

Manderson, L. (Ed.). (2005). *Rethinking Wellbeing*. Perth: Curtin University of Technology.

Mannan, H., Amin, M., Maclachlan, M., & EquitAble, C. (2011). *The EquiFrame Manual*. Dublin.

UN. (2006). *Convention of The Rights of Persons with Disabilities*.

WHO. (2001). International Classification of Functioning, Disability and Health (ICF).   Retrieved 31 March, 2011, from http://www.who.int/classifications/icf/en/

7 Appendices

7.1 Appendix A: Data collection instruments for WP3 Phase 1

7.1.1 Observations by researcher while accompanying patient on visit

Patient study nr
Facility code
Investigator code
Date of observation
Day of the week
Time of observation

1. Description of the physical location of the facility
2. Description of the outside of the facility in terms of general upkeep and neatness
3. Description of the inside of the facility (upkeep, cleanliness)
4. Describe how patient travelled to and/or from the facility (include, mode, time, cost, attendants needed as well as the general experience)
5. Describe the patient entrance into the facility (Ease of access, support provided by staff, greeted and guidance on what to do)
6. Describe the administrative process (Did patient have an appointment, Include time it took and staff attitude, availability of medical records, interpreter if needed)
7. Describe waiting facilities and passages (chair numbers, suitability, ventilation, crowding, noise, lighting)
8. Observe crowdedness over certain periods of time during the day thus busy and less busy times. Indicate time of day that patients came.
9. Describe the toilets (type, access, adequate numbers, cleanliness, state of repair) Describe availability of refreshments (water, other, availability, accessibility, cost, suitability)?
10. Describe waiting times (for registration, consultation, pharmacy other – How long did it all take)
11. Was the person charged any fees (how much, mode of payment required, process, patient's ability to pay these fees, if patient could not pay what happened)
12. Describe issues around consultation (how was patient called, greeted, directed where to go, time spent in consultation, patient's experience of it) – ADD 'WHO DID THE PERSON SEE? – DR, NURSE, ASSISTANT, ETC.'
13. Describe waiting at pharmacy (time, waiting area, availability of drugs, explanation re use)
14. Describe follow up process (was patient given an appointment, told what to do, or when to come again)
15. If patient had any special needs where they addressed?
16. If you observe any critically ill patients what is your opinion on how they were managed?
17. Give your impressions of the number and availability of staff (for this and subsequent questions provide examples if possible)
18. Give your impressions on the attitudes of the various members of staff
19. Give your impressions on the general morale of staff
20. Describe the ambiance at the facility

21. Any other observations / reflections.

7.1.2 Interview guide for in depth interview with health care users

Participant nr
Study site nr
Investigator code
Date of interview

Demographic information

1. Gender:

Male	Female

2. Age group:

0 – 4	5- 14	15 - 19	20 -34	35 - 49	50 -64	65 -79	80 and older

3.
4. Educational status

No formal education	
Some primary school education	
Complete primary school education	
Secondary school education., but not grade 12	
Grade 12	
1 – 3 years tertiary education	
> 3 years tertiary education	

5. Current employment status

Self –Employed	Employed	Home-maker/unemployed – not looking for work	Scholar / student	Unemployed - looking for work	Retired

6. Income of household unit

No income	
R1 – R1000	
R1001 – R2000	
R2001 – R5000	
R5001 – R10 000	
R10 001- R15 000	
R15 000+	

7. Number of people in household unit

1	2	3	4	5	6	7	8	9	10 or more

8. What type of dwelling do you stay in?
   Number of rooms?
   Wall. roof and floor
   [Change question from table below to asking about roof, wall and floor types and number of rooms (incl. Kitchen, bathroom and lounge)]

House on separate stand	
Traditional dwelling	
Flat, town, cluster, semi detached house	
Informal dwelling/shack	
House, flat, room in backyard	
Institution	
Other	

   If other please specify

9. Do you have the following inside the house?

	Yes	No
Electricity / other source of power		
Toilet		
Bathroom		
Running water		

10. If you have a disability, can you tell me about your disability - what happened to you and how did you get your disability?
    (ask about types of activities that are difficult for the person to do in addition to their classification of their disability type – 'What activities are difficult to do because you have a disability?')

The relevance of the topics for each specific interview will vary from one interview to another. It is the informant's history and experience that will decide which topics are important in the various interviews.

Explain to participants the nature and purpose of the study, why they were specifically asked to participate and gain informed consent.

Guiding questions:
1. What is your understanding of health and health related issues?
   - Hygiene
   - Nutrition
   - Medication
   - Training
   - Related to the disability

2. Tell me about your general health status. How would you describe your health today-excellent, good, poor, very poor?

3. What are your health needs?
   - Hygiene
   - Nutrition
   - Medication
   - Training
   - Related to the disability

4. Do you access health care in the same way as everyone else a) in your family b) in your community?

5. What factors/problems according to you make it more difficult for a person to access health care (vulnerability factors) and why?

6. Do you experience any of these factors? If yes ask person to explain (with examples) and also to relate how this affects his/her health care access.

7. Please describe the different kinds of health service and/or medical care you know about. These can include modern health care (professional sector), traditional health care (healers and indigenous practices) and self care in the family. What are your feelings about each of these services and why do you have these feelings?

8. Which of these types of services do you personally use and why do you choose to use them?

9. Please discuss your use of health care services and experiences while accessing these in the past six months (or further back if they want, but focus on past six months)
   - Why did you need health care?
   - What services did you access and receive?
   - How did you experience the service? Was it 1) excellent 2) good 3)neither good nor bad 4) bad 5) very bad
     With regards to:
     o Making and getting an appointment
     o Convenience of the services hours
     o The physical surroundings
     o Accessibility
     o Crowding, availability of seats, water and other refreshments, restrooms, cleanliness
     o Registration procedures
     o Security
     o Privacy
     o Status of the equipment
     o Availability of your medical records
     o Number of staff

- o Attitude of staff
- o Support received when needed
- o Skills of staff
- o Waiting times
- o Length of consultation
- o Explanation on procedures, condition and management strategies, prognosis, prevention, medication use and your questions answered
- o Equal treatment, exceptions
- o Confidentiality
- o Autonomy and informed consent
- o Treated in an acceptable manner
- o Drug dispensing: Availability of drugs, asked about – allergies, side effects, use of other drugs, Verbal and written directions given – dosage, frequency and route, follow-up

10. Were you satisfied with the service? Why / why not

11. How did the care impact on your health status and quality of life? Did you feel better after the health care?

12. Tell me about any other obstacles you face when you are seeking health care/accessing health services

13. What mode of transport do you use to get to the health care facility (Walking, Private car – own or rented, horse cart, wheelchair, bicycle, bus, taxi, train, ambulance)?
    - Does the facility assist with transport or arranging transport?
    - Cost of transport, time it takes
    - How happy are you with the location of the facility and
    - how happy are you with your travel arrangements?
    - Other issues around transport that the person would like to mention

14. Cost of health care and other costs (Care, medication, bribes, loss of income, hidden costs)
    - What are all the costs you have to bear in order to access health care?
    - In your opinion is this cost acceptable
    - How do you finance these costs/ could you afford it? [Where do you get the money to pay for these costs?]
    - How does it impact on your and the family's general financial status – both the cost and possibly the source of financing (e.g. if use a loan shark)

15. What happens if the facility you usually access cannot perform the services that you need?

16. What in your opinion are the main difficulties these health facilities experience if any?

17. Do you have any ideas on how these challenges can be addressed?

Additional questions if participant is disabled:

18. Tell me about the rehabilitation you received?

19. Tell me about any assistive devices you might need or have received – waiting times, fit, usefulness, cost, education and training, follow up

Closing the interview: Acknowledge the informant's cooperation, time spent and information shared and ask whether any other information that they want to give that they feel was not covered adequately.

7.1.3 Interview guide for interviews with health service providers

Participant nr
Study site nr
Investigator code
Date of interview

Demographic information

11. Gender:

Male	Female

12. Age group:

<34	34 - 49	50 -64	65 -79	80 and older

13. Educational status

No formal education	
Some primary school education	
Complete primary school education	
Secondary school education., but not grade 12	
Grade 12	
1- 3 years tertiary education	
> 3 years tertiary education	

14. Profession / job

1. Could you explain to me what your understanding of equitable health care access is

2. What factors according to you increase people's vulnerability to poor health care access / which patients struggle to access the services at the facility?

3. How accessible is the facility where you work for patients (physical, costs, time, type of services, equipment, number of health care workers)

4. What is your understanding of vulnerability? Name possible groups.

5. What in your opinion can be done to improve access to health services if improvement is needed?

6. Tell me about how patients are treated in general in the facility (fairness, equality, respectfully, patiently)

7. How satisfied are you with your job and the service you deliver?

8. Are there any challenges in this facility that prevents you from performing your duties as you would like to perform them?

9. How satisfied are you with the support you receive from your employers and superiors?

10. Tell me about the general morale at the facility that you work?

11. What is your relationship with the community that you work for?

12. Can you tell me about your experiences (stories & examples) of providing health services at this facility (Have there been situations/ people/ cases that have been particularly challenging/ difficult/ positive/ successful?) Can you give an example of patients that are easy to treat and others that are difficult?

13. How do you understand disability?

14. Have you any experience of treating people with disabilities? Can you tell me about that? (physical/ emotional/ intellectual/ sensory/ epilepsy/ albinism) (do you find them more challenging than other patients?).

15. Are disabled people frequently seen? Which categories of disability do people who come have?

16. How does follow-up of people with disabilities take place?

17. Knowledge about disability policy?

18. Knowledge about disability in health policy and legislation and how this is implemented at the particular health service

19. Do you want to share any additional information with me?

Acknowledge the informant's cooperation, time spent and information shared and ask whether any other information that they want to give that they feel was not covered adequately.

Introduction to EquitAble WP3 code book: Principles

The codes presented in this book have come out from a combination of the following considerations:

1. <u>Focus of the study</u>: formal health care system, activity limitations (disability), access to health care and vulnerability factors.

2. <u>Coding of a range of different interviews</u>: using the work done by Namibia and South Africa (the only ones we had in preparing these) in coding user, non-user, key informant and health care provider interviews.

3. <u>Examples of codes</u>: these are taken from the interviews coded so far in Namibia, Malawi and South Africa

4. Discussions: Discussions with all the country teams on the draft codebook in March 2011

These are SUGGESTIONS for coding and aim to provide some standardization across countries to allow for cross-country and cross-site comparisons. While we think that these cover most of the relevant areas, there are endless codes that can be developed within each major area (theme) and there may well be more major areas identified as we go along.

Organization of codes:

Themes

The codes have been organized into ***four major themes*** with the themes being very broad topic areas. These themes are not necessarily very useful for the actual coding but help organize the topics into **broad areas. So these are not likely to be used as codes as such.**

Codes

The levels of codes are in **bold** and are the ones that will be most useful to use in the coding of interviews. Most of these are likely to be applicable across all countries.

The suggested strategy is that you use this level of detail in coding as a starting point and we will most likely use this level of detail for the country reports and joint report to be submitted to the EU at the end of August 2011. However, this is not a very detailed level of analysis. The next level is that of sub-codes.

Sub-codes

The sub-codes are in ***italics*** and provide the detailed analysis under each code. This level of analysis would be required for any further analysis beyond the codes, for example, for journal articles, or where the codes are not descriptive enough as they are for the country and joint reports. The sub-codes are the level at which the four countries are likely to add most other codes.

Variables for analysis

- Country (this will be for the overall report to be written by team South Africa)
- Site
- Type of informant:
    o Health user
    o (Non-user)
    o Health provider
    o Key Informant
- Gender
- Disabled/ Non-disabled
- Age

Themes and Codes

1. **Meanings and understandings**

This theme is referring to cognitive views, e.g. knowledge, perceptions, attitudes. This may include prejudice and stigma, aetiology (Cause or origin of disability/ illness/ vulnerability), etc.

Equitable health care	Health	Disability	Vulnerability
		Discrimination	
		Positive treatment	

2. **Social Context**

Individual (Health and health care seeking behaviour)	Household	Community factors	National
Self-help/ self treatment for health and well-being: - *Vitamins* - *Exercise* - *Healthy eating/ nutrition* - *Hygiene/ clean environment* - *Medications*	*Natural resources/ assets:* - *Water* - *Crop growing* - *Availability of food* - *Availability of stock*	*Community support*	*Impact of policy on services*
Religion/ spiritual perceptions	*Health promotion:* - *Sanitation (latrines)* - *Safe drinking water* - *Information*	*Cultural factors (attitudes/ perceptions)* - *Culture/ practice of complaining (right to complain)*	*Organisation of services in the past*

Resources: - Money - Health information - Housing	Family support	Crime	Political infrastructure (religion/ ethnic conflict/ differences, etc.)
Substance use: Alcohol, drugs, smoking, etc.	Lack of/ inappropriate housing - Informal areas	Alternative forms of health care - Herbalists - Traditional healers - Faith healers	Government support (No refusal of health services/ exemption of payment/ pensions/ grants/ insurance/ government institutions)
Lack of opportunity	Demographic and socio economic characteristics	Education/ training	**Civil society**/ NGOs
		Political division / power plays in community	Issues of democracy
			Issues of human rights

3. Access to health care

This theme is about facilitators and barriers influencing access to health care.

Transport	Physical at facility	Information	Geography/ environmental/ distance	
To/ from facility				
Ambulance/ transport between health services				
Language	**Safety**	**Cultural**	**Attitude at facility**	**Cost**
Spoken language	Crime			
Sign-language	Wildlife			

4. Quality of health service

Quality of health care	Availability	Acceptability	Recommendations for improvement
Medical	*Quantity:* - *Equipment* - *Providers (doctors, nurses, etc.) (turnover)* - *Medication* - *Assistive devices* - *Rehabilitation* - *Shelter* - *Support services*	*Patient- provider communication (not language barriers)* - *Attitudes/ morale of staff*	
Non-medical	*Facility status (cleanliness/ upkeep)* - *Toilet facilities*	*Patient responsibility (compliance)*	
Work conditions for health providers	*Referral (or lack of)* - *Continuity of care*	*Provider responsibility and competence (incl. confidentiality, accountability)*	
Gap between intention to provide and provision	*Organisation of services:* - *Operating hours* - *Outreach* - *Integrated services* - *Triage* - *Waiting time* - *Crowding* - *Team work* - *Health passport/ health card/ book/ paper*	*Ethics*	
	Preferential treatment (age/ disability, etc.)	*Patient satisfaction*	
	Choice of services		