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

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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” (Alma-Ata Declaration, 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 actually implementing changes which will improve the health care access for different groups 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 and Winslow, 1998, p.69), and this may include women, children, the aged, ethnic minorities, displaced people, people suffering from chronic illnesses and people with various types of disabilities. While different groups of vulnerable people share similar challenges in achieving equitable access to healthcare, there are also distinctive challenges facing different groups. People with disabilities are among the most vulnerable and marginalised groups of any population. They are often excluded from mainstream social, economic and health services, and lack educational opportunities to meet their full potential (UN, 1996; Eide et al, 2003a; 2003b; Loeb & Eide, 2004; Eide & Loeb, 2006a; Gureje 2006; Loeb, Eide, Jelsma, Ka'Toni, & Maart, 2008)

The EquitAble project 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 in to 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
- **Work Package 5**: Influencing Policy and Practice and Dissemination.

This report presents the findings from phase 1 of WP3. The aim of WP3 is to investigate the experience of health service users, non-users and health service providers. Phase 1 has focused mainly on users and providers, while phase 2 (to be conducted after WP4) will focus primarily on health service non-users. The report will also highlight the connection between findings from WP2 and WP3 and provide policy recommendations.

This report will first analyze how the needs of vulnerable groups are being met in the Sudanese health system by examining policies, perceptions of health and disability among vulnerable groups and services providers, perceptions of the health care system among vulnerable groups and services providers and the on the ground realities of access to health care services and resources. The findings were principally that the Sudanese health care system exists very differently in reality that it does in policy, that it is under resourced and understaffed and that there is little political will to do anything about these facts. We also found that the perceptions of illness, vulnerability and disability were very different between members of vulnerable groups, health care providers and policies. We also analyzed how health system users and health care providers perceived the health
care system, and what criticisms they have of it. Finally, we make several recommendations for how services can be improved.

The first section outlines how and where the study was carried out. The second section will detail the social context in which people seek and receive healthcare in Sudan and will then present the results of our study. The third section outlines the definitions and perceptions of concepts related to health and vulnerable populations. The fourth section outlines the challenges faced by vulnerable groups, and indeed by almost all Sudanese people, in accessing medical care. The fifth section investigates the quality of the health care services provided not just to vulnerable people, but to all. The sixth and final section takes the policy analysis in conversation with the field mapping study, analysing the twenty-one core concepts and twelve vulnerable categories.

1.1 Review and Analyses of Health Policies WP2

The Sudanese health policies examined were 16 different health policies enacted by various governing entities including those of South Sudan. These documents were analysed to examine whether issues related to universal and equitable access to health for vulnerable persons are being addressed. A framework for analysis was developed (EquiFrame) that allowed us to assess the degree to which activity limitations are considered in the promotion of accessible healthcare, and if any of the core concepts of equitable health policy, especially targeting persons with activity limitations, are included in national health policy documents.
Theoretical model for Equitable

The model below describes the theoretical basis for the 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: Analytical framework of the study

1.2 Health systems in Sudan

Health system:

Governance

The Sudanese health system is a three-tier system. The federal level is concerned with policy making, planning, supervision, co-ordination, international relations and partnerships. The state governments are responsible 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 18 states. 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 a huge investment in human and material resources, which most states and localities lack. Problems in the distribution of resources between the three levels of governance has rendered the local level service delivery feeble. The frequent amendments and changes in the function and structure of the local level is another factor affecting the development of a clear system of governance and organization. Central transfers are currently an important source of finance for the states and localities, however, its functionality and impact need to be studied. Many partners are involved in health care provision. In the absence of a comprehensive strategic framework there is marked inefficiency and fragmentation of the health system, and poor coordination between partners in the health arena. Primary Health Care was adopted as the key strategy for health care provision in Sudan in 1978, 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, states the commitment of the Government to provide universal and free of charge basic health services (Sudan 2005 Interim Constitution).

The recent 2009 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 administration of the systems, under funding and inharmonious actions of 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). It is imperative to state that the government policy of liberalization and free market economics, declared in 1999, led to increased privatization of the health sector. Furthermore, it led to a reduction in free and subsidized public health care, education, water and electricity services. The policy has led to an increased financial burden on citizens, who must now pay out of pocket for many services.

1.3. Disability policies in Sudan

There are no specific disability health policies in Sudan. The Ministry of Health has no specific policy targeting the disabled and no specific programme or unit to direct policy or services to them (Ministry of Health: policies and strategies 2010). Yet, there are general constitutional rights which apply to all Sudanese people.

The National Interim Constitution of 2005 (The Bills of Rights, article 46, Public Health Care) states that: “The state shall promote public health, establish, rehabilitate, develop basic medical and diagnostic institutions, and provide free primary health care and emergency services for all citizens.” Also, article 45, Rights of Persons with Special Needs and the Elderly, states that “The state shall guarantee to persons with special needs the enjoyment of all the rights and freedoms set out in this constitution; especially respect for their human dignity, access to suitable education, employment and full participation in society.” The elderly shall have the right to the respect of their dignity. The state shall provide
them with the recovery care and medical services as shall be regulated by law” (Sudan Interim National Constitution 2005).

These constitutional rights do not get the funding to translate into an accessible reality. Different sources give different figures on health expenditure. However, only 7.3% of annual government expenditure and of the GDP is directed to health (WHO Sudan Report 2009). Another estimate is that only 3.6 of the GDP is spent on the health sector, 6.1 government annual expenditure (World Bank 2009 and Sudan Public Expenditure Review). The social welfare sector and the ministry representing the elderly, disabled and poor (among other groups) receive much less. These groups are supposed to be served by the Zakat Fund and the social development Welfare Bank (Ministry of Social Welfare and Security Mandate 1999). There is, however, no clear policy on how the Zakat Fund should be spent, and the result is insufficient and low-quality services and protection for vulnerable groups.

In 2010 The Ministry of Social Welfare and Security developed and passed a national policy targeting people with disabilities. The policy framework is both an Islamic priority of helping disabled people as specified in the Quran, as well as an international policy framework for the disabled. The main features of the policy document are that there should be an overall strategy addressing the importance of gathering data about people with disabilities, targeting them with educational, economic, athletic, psychological and health services and programmes. Furthermore, people with disabilities should be fully integrated into society, making use of current technology geared to benefit them, in addition to budgetary allocations, tax exemptions for assistive devices, reduced transport fares as well as
targeted employment opportunities. Early detection of disability, as well as preventive and curative medicine for the disabled should be promoted. A new legal framework and a quota system to guarantee their full representation at executive, legislative and civil society bodies should be created.

Furthermore, coordination between executive bodies, civil society, educational institutions and families should be enhanced, so as to better serve the disabled and integrate them in society as full citizens. Also, campaigns of awareness raising about the rights for people with disabilities, celebrating national and international days of the disabled and encouraging publications, media and rehabilitation programmes should be included in the policies of the Ministry. Special councils for disabled persons are to be established at state level to better reach and serve disabled people. The policy document includes mechanisms and programmes to achieve the policy goals, as well as directives and programmes. This new policy still needs to be fully implemented. This research could be an important contribution to ensure coordination between the Ministry of Health and Ministry of Social Welfare and Security, as well as contributing to the development of a policy towards the disabled.

1.4 Activity Limitations in Sudan

While the importance of addressing the health needs of vulnerable groups in low-income countries is increasingly being recognized, there are many challenges in how this should be done for different categories of vulnerable people. Vulnerable groups are “social groups who experience limited resources and consequent high relative risk for morbidity and premature mortality (Flaskerud and Winslow, 1998, p 69) and this may include women, children, the aged, 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.

This study looked at the challenges that people with activity disabilities present to achieving universal and equitable access to healthcare. This is applying the most recent international thinking which conceptualizes disability along a continuum of activity limitation as described by the International Classification of Functioning, Disability and Health. Disability, along the activity limitation continuum, is at the more severe end of the continuum. 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. This classification system and its precursor, the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980), have been used to frame a plethora of studies on a diverse array of diseases and conditions (Rusch et al, 2004).

In Sudan, the government in 1993 conducted a national survey whereby they defined disability broadly in the same way as it is in the Islamic Quran. Hence, the survey on disability indicated that 1.5% of the population, a total of 323,595 people was classified as disabled. The percentage of those living in urban areas from this
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The total was 51.3% of, which males were 53% while females were 47% (Ministry of Social Welfare and Development Policy for the Disabled 2010). Those figures were also classified by type of disability, indicating that 24% were blind, 14.5% were deaf, 38.2% had physical disability, 9.7% had mental disability, 3% had more than one type of disability and 10.1% had other types of disabilities.

The report (2010 Ibid) indicated that the main factors leading to disability were in order of priority:

1. Accidents due to natural disasters or traffic.
2. War related
3. Chronic and infectious diseases especially during childhood
4. Genetic hereditary factors
5. Low primary health care services and health education
6. Harmful traditional practices
7. Addiction and Alcoholism

The above figures are considered to be under estimates as the survey was undertaken in eight states, excluded the capital and included several states in conflict zones. Further, the report acknowledged WHO estimates that 10% of the World’s Population faces some type of disability. The report (2010 Ibid) related the low percentage estimated in Sudan to lack of information given by families about disabled family members, in an attempt to conceal and isolate people with disabilities for fear of stigma. There is an assumption that disability is hereditary and may reduce the marriage opportunities, especially for girls in the family. The question may also have been worded poorly, which could explain the low
estimation. In addition, the only national survey of disability conducted was the 1993 survey.

This study provides an in-depth description of the perceptions and levels of satisfaction of vulnerable people, especially people with disabilities, with health care services, and how providers understand their role and the role of the health systems in providing equitable and universally accessible health care.

There is international evidence that people with disabilities face barriers when accessing health care services and that there is “inadequate specific information” available about interventions that work to improve the lives of people with disabilities. These findings call for “urgent attention to the issue of access to appropriate health care for people with disabilities especially in low income and middle-income countries” (Tomlinson et al, 2009: 1857). These findings are supported by numerous studies (Satz, 2008; Wanaratwichit et al, 2008; Morrison et al, 2008, Krahn and Drum, 2007, West et al, 2007; Sommers, 2006, Krahn et al, 2006, Kroll et al, 2006; Ruddick, 2005, McColl, 2005; Beatty et al, 2003, Neri and Kroll, 2003, Veltman et al, 2001).

Linked to the issue of access to health care services are the patients’ perceptions and levels of satisfaction with the health care services. Patients’ experiences at health facilities are becoming more important in health policy formation. Research on patient satisfaction can be an important tool to improve quality of services (White, 1999). Studies have shown that satisfied patients are more likely to utilize health services, comply with medical treatment and continue with the health care provider (Westaway et al, 2003; Larsen and Rootman, 1976). According to Donabedian (1988) patient satisfaction may be considered to be one of the desired
outcomes of care, and information about patient satisfaction should be as
indispensable to assessments of quality as to the design and management of health
care systems. According to Smith and Engelbrect (2001) measuring patient
satisfaction has become an integral part of health facility management strategies
across the globe.

2. Methods Used:
In this part of the EquitAble project we have used qualitative research methods.
The aim of Work Package 3 has been to investigate the perceptions and experience
of health service users, health service non-users and health service providers;
therefore in-depth, qualitative research methods were deemed suitable.

2.1 Data collection methods
The following data collection techniques were used:

1. In-depth interviews with users and service providers using an interview guide
which was translated to Arabic, adapted and tested to ensure that similar topics
were covered but also allowing for open descriptions by the interviewees. Few of
the interviews were recorded with providers. The interviews were kept,
documented and used mainly for the analysis. The interviews were conducted in
Arabic.

2. Each interview was conducted by a researcher and an assistant who helped in
writing up the notes, as the interviews were not recorded. Most of the informants
refused recording. Each interview took approximately one hour. Some took more
than 2 hours. A few informants were interviewed twice, in order to get more
elaborate information.
3. Observations of users’ experiences in accessing health care from the time of leaving home through to the exit from the health facility and return home. The data collected included describing the transport situation, the household situation, environment of the area, transport mode for getting to the facility, description of the arrival and initial processing of the user, description of the facility on the day of the visit (e.g. level of overcrowding, cleanliness, etc.), as well as a discussion with the user both about the reasons for the visit, as well as the experience of the visit at the end of the process. The actual consultation was not observed to avoid issues of breach of confidentiality. The data were reported as part of the analysis of the interviews to indicate context and give in-depth to analysis.

4. 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 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. The context of the Sudanese health facilities is so poor, resulting in the facility checklists for levels other than hospitals to be almost blank, and hence only hospitals’ checklists were filled.

5. The analysis was conducted in the 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.
2.2 Respondents

Users were defined as people or households who use health care services within the study sites; users are residents of the locality for a period of at least three months. Disabled users and users with other vulnerability factors were purposively sampled to ensure case studies on people with a range of activity limitations 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; when we move to the quantitative phase (WP4), criteria will be more rigidly set, as is appropriate in mixed methods design.

A total of 50 users, 29 females and 21 males, were interviewed with different types of vulnerabilities according to the 12 vulnerable groups identified and defined in WP2. From these a total of 17 users with disabilities from the four localities were interviewed.

The health service providers were people providing health services at the different levels of health care provision (primary, secondary and tertiary care) and including both lay-health workers and key informants, from respectively professional sector (biomedicine), from the public and the private sector. A total of 67 males and females were interviewed of which only 18 were females.

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. An organogram of the facility was drawn with help from the manager/most senior staff member available,
after this one member of each grouping was chosen to be interviewed. Providers include all levels of staff working in the health care facility to provide health care. Tables I and II give more details:

Table 1: Type of Health Facilities Studied (Field data 2010):

<table>
<thead>
<tr>
<th>Localities</th>
<th>Teaching Hospital</th>
<th>Secondar y Hospital</th>
<th>Public Health Center</th>
<th>Private Health Centre</th>
<th>Insuranc e Health Center</th>
<th>Rural Hospital</th>
<th>Rural Health Center</th>
<th>Rural dispensary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kassala</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>×</td>
<td>×</td>
<td>✓</td>
</tr>
<tr>
<td>Umbada</td>
<td>✓</td>
<td>×</td>
<td>✓</td>
<td>✓</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>✓</td>
</tr>
<tr>
<td>Rabak</td>
<td>✓</td>
<td>×</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>×</td>
<td>✓</td>
</tr>
<tr>
<td>Sheikan</td>
<td>✓</td>
<td>×</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>×</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Table 2: The Number of All Those Interviewed by Vulnerability of Users of Modern Health Services:

<table>
<thead>
<tr>
<th>No.</th>
<th>Users by Vulnerability Groups</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Female</td>
</tr>
<tr>
<td>1</td>
<td>Adult Blind</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>Adult Poor</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Old with hearing problems</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Old needing assistance</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>Youth male with chronic disease</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>With HIV/AIDS</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>Adult physically disabled</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>Child under five</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>Mother</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Provider Type</td>
<td>Female</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>10</td>
<td>Pregnant women</td>
<td>6</td>
</tr>
<tr>
<td>11</td>
<td>Female with HIV and TB</td>
<td>2</td>
</tr>
<tr>
<td>12</td>
<td>Females divorced, widow, head of household</td>
<td>6</td>
</tr>
<tr>
<td>13</td>
<td>Poor adult</td>
<td>2</td>
</tr>
<tr>
<td>14</td>
<td>Nomad adult</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>Deaf adult</td>
<td>1</td>
</tr>
<tr>
<td>17</td>
<td>Youth with physical disability</td>
<td>1</td>
</tr>
<tr>
<td>18</td>
<td>Adult with chronic disease</td>
<td>1</td>
</tr>
<tr>
<td>20</td>
<td>Deaf children</td>
<td>2</td>
</tr>
<tr>
<td>21</td>
<td>Child under five</td>
<td>1</td>
</tr>
<tr>
<td>22</td>
<td>Refugees child</td>
<td>0</td>
</tr>
<tr>
<td>23</td>
<td>Convict</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>Disabled Persons from total</td>
<td>7</td>
</tr>
</tbody>
</table>

(Source: Field Data 2010)

**Figure 1: Numbers and types of provider’s interviewed**

(Source: Field Data 2010)
Key* Medical assistant include those who received 4 years of education above secondary (2 years university + 2 years further studies). **Key Informants: Included popular committee members, local municipality administrators, civil society members).

2.3 The Sites

Choosing the states:
Selection of the states was done to guarantee a representation of all parts of Northern Sudan. The Southern Sudan region was purposefully excluded taking into account its specific context as a protracted conflict zone and the possibility of it being an independent country by January 2011 after the referendum. The rest of the country is geographically divided into four parts of North / Central; East; West and South (see the attached map). Based on these four states were selected namely, Khartoum State, to represent North / Central Sudan; White Nile State to represent South part of North Sudan, North Kordofan State to represent Western part and Kassala State to represent the Eastern part.

Criteria for Selecting Localities:
1) includes rural and urban districts and populations,
2) The population must be socially, ethnically and economically diverse,
3) There must be multi-levels of health services i.e. from hospitals (secondary/tertiary) to dressing units (basic primary health care)
4) Locality must include vulnerable populations/users affected by vulnerability factors and various disabilities.
The Localities:

A locality in terms of size, population and administrative authorities is an independent entity within a state. The state has a government, headed by a governor and has an elected parliament. The locality, according to the constitution, should have independent authorities, elected parliaments and commissioners. It is supposed to offer all health and educational services below the tertial level and all health services below teaching hospitals. (Sudan Interim National Constitution 2005).

The locality has to secure its income mainly from local taxes, other local revenue and from what the state receives from the central government, or through the Federal Ministries, the States Development Fund source of remittances from the Zakat fund, which the latter can use directly to offer help to individuals/ families or contribute to basic service provision by building health centres, schools, contributing to medication fees or for sanitation and water provision (wells, hafir “water collection points etc). The Zakat is collected from all states but administered at federal level centrally from Khartoum ( interview key informant 2010).

The Federal Ministry of Health (FMOH) in 2008 undertook the Health System Mapping which indicated a great variation between states regarding the health services provided and distribution of health services. With reference to that study, localities identification within the four selected states was undertaken.

In North Kordofan, the Locality of Sheikan represents the diversity of ethnic groups mainly of West African and Arab claims; more than 95% Moslems, inflicted by drought which led to displacement.
Kassala and Wad Sharfi localities in East Sudan are communities in which large numbers of people are from non-Arabic, or non-Black East African ethnic groups, who have a non-Arabic mother tongue. Many of them were displaced due to floods or are refugees from Eritrea and Ethiopia.

Umbanda locality in 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 third class residential areas, as well as having a large number of internally displaced people’s camps.

The four Sites Coverage

The mapping of 2010 was undertaken as a preparatory stage for WP3 to identify health sites and get other socio-economic data that can be used to strengthen analysis. The mapping resulted in selecting health centers, health units and
hospitals to be studied. It also helped in identifying possible different vulnerable groups. And lastly the mapping gave a clear picture regarding the infrastructure in the localities, as well as socio demographic characteristics of the population and lastly the actual health services provided. The data collection took place between the end of April to end of June 2010 for all the localities.

**The Selected Sites Main Characteristics:**

**Umbada locality:** Is one of seven localities in Khartoum State, where the capital is located.

Umbada is situated in the western part of Khartoum state. On the west it borders Kordofan state, and on the north, it borders the Northern State, and it falls in the desert/semi-desert part of Sudan.

It is one of the oldest, most densely populated and largest geographical areas in Khartoum state, with a total size of 22,700 KM2 and a population of one million (Locality Records 2010).

The population is diverse. On one hand it includes a small population who enjoy better economic conditions, living where health care is concentrated, having better quality and more choices for health service provision. On the other hand, it also includes the largest IDP camps in Khartoum state with a majority of Christian Southerners and many from Darfur. Umbada also includes a rural district, which gives a rural-urban dimension to the study. Furthermore, the locality includes a large number of medical centers (23 governmental and 64 private) and one large governmental hospital, in addition to a large number of popular traditional healers.
Kassala Locality: Is one of the 11 localities forming Kassala State

Kassala State is located in Eastern Sudan, bordering El Gadarif and the Red Sea in the North, NahrElNile State to the West and Eritrea to the east. The size of Kassala is 36,710km2, with an estimated population of 300,000 (State Records 2010).

Kassala locality has many tribes and a variety of different ethnic groups, the most dominant being Beja. Kassala locality can be considered a rural/urban locality where the state capital is located, and it is surrounded by farms and rural areas.

The other state localities all have strong links to Kassala for health and other services.

Wad Sharafi is a poor rural area in the locality with a variety of ethnic groups, neighbouring the Ethiopian borders. Due to this it has large refugee populations (Ethiopian and Eritrean) some of whom date back to the 1960s. Both areas have a large number of medical services; there is a governmental hospital (Kassala Teaching Hospital) and Refugee Hospital in Wad Sharafi area. The 1993 national survey on disability indicated that 15,191 persons of the state face some type of disability (Report of the Ministry of Social Welfare and Security 2010).

Rabak Locality: Is one of the 9 Localities of the White Nile State

Rabak locality is mainly situated in the Eastern bank of the White Nile. It borders southern Sudan from the South and North Kordofan to the west. The locality has a population of 268,185, with 123,909 living in urban setting (34 urban neighbourhood and 9 villages), and 57,333 living in Assalayia Sugar Scheme (in 60 labourers compounds)- a mixture of rural and urban. Rabak represent a middle level of health services available in the White Nile state according to Ministry of Health, Health System Mapping Survey 2008. Rabak locality is the seat of the state
capital – Rabak (State Records 2010). The 1993 survey for the Disability indicated that 6890 persons of the state population face some type of disability (Ibid 2010).

**Shikan Locality: is one of 7 Localities of North Kordofan State**

North Kordofan State occupies the Western central part of the Sudan and shares borders with Khartoum and the North States to the north, North Darfur to the northwest, White Nile to the East and South Kordufan State to the South. The State covers an area of 244,700 squares Kilometre and according to the 2008 Fifth Population Census has a total population of 2,934,872 persons (population density is approximately 12 persons per sq. km).

North Kordofan State witnessed many years of severe droughts and almost three decades of desertification. In 1983/1984 the area witnessed a devastating famine. In early 1990s it experienced severe food shortages and food insecurity. Sheikan locality is where the state capital Elobeid lies; Sheikan locality has a population of 617,704 and size of 30,000 Km.

**Conclusions:**

There is a profound lack of recent data concerning disability and general vulnerability at state- or locality levels. Secondary Data from the Health System Mapping is in most cases not specified by locality and does not include detailed information about population categories. Consequently, most of the information was collected from field work primary sources.

The most recent survey on disability was undertaken in 1993 where by only two of the states we studied were included (Kasala and White Nile) but with no information specified by locality.
It is worth noting that few female doctors and no female medical assistants were functioning at the visited health sites. There is, however, a higher female concentration in the capital. The Ministry of Higher Education records (Higher Education Statistical Annual Review 2009) indicate more women are enrolled in medical faculties than men. This situation, if continued, may present the Ministry of Health with a shortage of medical personnel to serve in rural areas. The Ministry needs to address these challenges by offering packages of good services (residence, schools, electricity, and water) to encourage medical doctors from both genders to work in rural Sudan. Further, to train more women from rural areas as medical assistants in order to bridge the gender gap in this profession.

SECTION II: The Social Context and its impact on Health:

2. Introduction

The section aims to contextualize the study by highlighting various factors that influence health at national, community, household and individual level.

This section will include national level policies, funding, general population characteristics, poverty and services. Community level support of civil society activities or outreach programmes at the localities will be highlighted. The household general context in terms of availability of basic services (water, toilets, electricity, size etc.) will be described. Other issues specific to respondents’ (users mainly) health seeking behaviour will be briefly discussed and integrated when discussing perceptions to health, access to health and quality of health.

2.1 General National Context:
The vast size of the country and decades of internal conflict have made it difficult to provide an adequate level of services across Sudan. Further, of the scattered population of 30 million people, 64% live in rural areas and many of these 64% are nomadic. Access to services is substantially lagging in areas such as Darfur and other rural areas of Sudan. Inadequate infrastructure, including transport, water and electricity, are binding constraints for productive and service sectors. Road transport provides over 90 percent of inland transport services in Sudan and the extreme low density of roads in war-affected areas causes isolation of rural areas.

Only 22 percent of the population of Sudan has access to electricity, either on the national grid or isolated electricity networks. The existing national grid covers only nine of Sudan’s states. Most of these consumers are in Khartoum, where 57 percent of the available electricity is consumed (Sudan Road toward Sustainable and Broad-Based Growth: World Bank Report 009). Eight million people in rural areas require access to water supply and sanitation facilities. After decades of conflict in some areas, access to safe and adequate water supply and sanitation services is extremely constrained. Around 75 percent of the rural population lacks access to safe water. UNICEF records from 2009 indicate that of the 6.500 rural water points that have been recorded on the national database, only 35 percent of these may currently be operational.

As for telecommunications, many areas of the country lack mobile access and advanced ICT services. In the North, there are extensive mobile networks, but they are largely limited to urban areas, with relatively sparse network coverage in small towns and rural areas.
However, given the enormity of the challenges presented above, progress to date has been limited. Availability of financial resources is yet short of meeting infrastructure and service needs. Poor implementation capacity and human resources as well as difficulty in coordinating policies among different levels of government further challenge the country in addressing the needs of the people and establishing clear priorities.

Most areas in Sudan, including conflict-affected areas and rural areas, lack access to affordable basic services and there is little connectivity between regions (Sudan Road Toward Sustainable and Broad-Based Growth: World Bank 2009).

2.2 Population Characteristics:

The population of Sudan, where the study is undertaken, is approximately 30 million distributed between 15 states. They are predominantly urban, Moslem low-class groups (National Census 2008). Some are rural, displaced, Christian, refugees. All regions of Sudan are ethnically and tribally diverse, but Khartoum is particularly so. Vulnerable categories, including the physically disabled, those with HIV/AIDS, displaced/refugees, the poor, those living far from services, the young, those with chronic diseases, pregnant mothers, young under aged mothers, children with chronic diseases or disabilities are all represented in the sample interviewed. The country has a high prevalence of poverty. 81% of the population was classified as poor by a 2004 IFAD study; while the Sudan government numbers peg the rate at 56% (MDGs report, 2009).

Further, those with HIV/AIDS are estimated to be 1.5% of the population, which is believed to be greatly underestimated due to lack of sufficient examination centers or policies for compulsory examination. As Sudan borders countries categorized as
high-risk countries for HIV/AIDS, the number is believed to be higher (MDGs Report 2009).

Physical disability is high due to long years of conflict among other factors. Deafness in Sudan is considered to be wide spread. The Sudanese Association of the Deaf estimated that 8% of the population faces some problems related to impairment of hearing and speaking.

Chronic or infectious diseases such as tuberculosis, malaria, diabetes and schistosomiasis, represent a high risk for many Sudanese, and the first two are targeted with policies and national campaigns (WP2 Sudan Report 2010).

It is crucial to contextualize the studies to have a brief summary of the human development indicators profile in Sudan. Life expectancy is 57.9 years. Estimated yearly earned income among women is 1025, and among men is 3119 (PPP) US Dollars. Prevalence of child malnutrition is 35%, 41% of children under five are under weight and prevalence of acute child malnutrition is 16% (FAO report of Sudan 2008). 62% of children are enrolled in school, but only 21% of children complete primary school. The adult literacy aged 15+ is estimated to be 52% for females 71% for males. The combined gross enrolment ratio in education is 37.6 for women and 42.2 for men in 2007. There is a clear gender gap in favour of boys/men and disparity between states and regions. The under-5 mortality rate (per 1,000) * is 105, the infant mortality rate (per 1,000 live births) * is 70 and one-year-olds immunized against measles is 78%. The maternal mortality ratio (per 100,000 live births) is 638 and only 57% of births are attended by skilled health staff. Contraceptive prevalence (% of women ages 15-49) is 7%, HIV Prevalence (% adults ages 15-49) * is 1.6%. Incidence of TB (per 100,000 per year) is 90 and
children under 5 with fever treated with anti-malarial is 54.2%. 58.7% of people have access to improved drinking water, and 39.9% have access to sanitation. Despite all of the above problems, public expenditure on health was just 6.3% of total government expenditure in 2006. (UNDP Sudan – Status of MDGs 2008).

Sudan’s low development indicators are undoubtedly linked to the protracted conflicts in many regions, and lack of economic development, but are also the result of the lack of rights of afforded to much of the population and people’s inability to claim those rights that have been afforded to them. Governance in all aspects is poor, and this translates into poor or absent service provision. This has led to citizens developing strategies to cope life almost independently from the government. For example, is estimated that 75% of the population’s economic activities take place within the informal sector; including traditional cultivation and nomadism. In addition, traditional culture encourages acceptance and satisfaction with the minimum, as well as espousing the idea that fate or God’s destiny is behind whether one is rich or poor, healthy or sick. This can mean that people do not see themselves as entitled to certain rights, and so they are not strong advocates for themselves. More important, however, is the poor governance, lack of political will to provide citizens with adequate services and the unresponsiveness of the government to the needs of citizens. In addition, most local governments simply do not have the funding or resources to provide high quality care to citizens.

2.3 Beliefs

There are certain beliefs, values and customs that are interlinked with health issues in different ways. An interesting one is the value given to those who give services. These providers (teachers, medical personnel etc) are considered to be offering
Valuable services to help others, and hence they should be credited for that regardless of the quality of the provision of the service. Complaining is viewed as unethical, and as gossip that is a poor repayment for the favour of providing a service. Educated urbanites are less likely to respond to poor service provision in this way and more likely to advocate for themselves. This has implications for the quality of services that people have access to. Another relevant aspect is the belief that health and sickness are from God. Sickness is seen as a sanction for wrong deeds, a test to assess human tolerance and belief in God, or as a means to eliminate bad deeds in life so as to reduce possible punishment in the afterlife. Disability or long-term disease is seen as an aspect of God’s concern which will improve people’s standing in the afterlife. Also, if the disabled person is a child, God offers the supporting family members credit in the afterlife and sends the disabled person to paradise in the afterlife.

Such beliefs can result in a delay in seeking medication, or not seeking medication at all because it is believed that disability is the will of God. Further, helping and supporting the disabled is an act that boosts one’s prestige in the community, and means that they will receive heavenly rewards, both now and in the afterlife. Also, people fear God’s punishment if one neglects those who need help. All these are beliefs and sentiments that mean that people have solidarity with each other, and that they help each other. Another cultural component is related to the belief that supernatural powers or the evil eye that can inflict misfortune, including disability and disease the mean to relieve these misfortunes are several, and can result in patients not seeking medical treatment, but rather to turning to other types of traditional treatments.
2.4 Poverty Context:

Based on observations, almost all the people who are using public health services are poor. Poverty has a huge influence on their quality of life. One can see this in the way they are dressed, especially for the children. The shadow of poverty is well felt in all the houses visited. They lack the basic services like running water and decent toilets. In rural areas, people build their homes from woods and grass. Most people in rural areas and the periphery of towns live in houses with a single room and poor sanitation facilities.

2.5 Health Services and Health Seeking Behaviour in the Studied Sites:

There are common characteristics in all the study sites. One is that all the towns have a main hospital that acts as a teaching hospital for the school of medicine in the town. In some of the sites there is also another hospital run by an NGO, private sector or by donors (Kwaito in Elobeid) or UNHCR (Kassala). Health centers in urban and rural settings are of two types; public and private. The same health providers (doctors, medical assistants, nurses) may work in both types of centers in different shifts (morning at public, afternoon or evening at private). The private health centers have an advantage over the public in terms of quality and type of services offered, such as better availability of laboratories and pharmacies, or in terms of more careful attention by medical doctors or assistants.

This study found that, in one locality, the National Health Insurance Fund was a provider of services (building health centers, contracting health practitioners). These centers offer better quality and more integrated services and use referral systems. Some are like small day hospitals.
The study also included rural hospitals, which are small hospitals in rural settings that are not that far from an urban centre and with a substantial rural population (they usually serve around 3 – 4 villages). The last category is the dispensary and dressing units which are smaller, first entry health units not served by a medical doctor. According to the Ministry of Health policy these should be closed or promoted as a health centre, but practice indicated a gap from policy. Some are served by health workers and not medical assistants. The former receives only 6 months training on community health as health promoters, but they still end up giving some medical service. The medical assistants that serve such units, or in most health centres in rural settings, are usually referred to as “doctor” by the local people and actually perform all functions of a medical doctor. In some cases, they were even found to be undertaking the ultrasound for pregnant women.

There is no functioning referral system in any of the sites visited. Patients can enter the health system at any point and move through the system almost entirely on the basis of their own choice and ability to pay. Irrespective of the costs and who covers it, the absence of a good referral system has contributed to the significant misallocation of health resources in the localities and led to consultants at secondary health level wasting most of their time dealing with cases that could have been effectively dealt with at primary health care level.

Most of the users that have been interviewed stated that they have either used alternative medicines prior to moving to the modern health facilities or have done so at some stage in their life. Many stated that not all kinds of sicknesses require one to see a medical professional: “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,” said one woman.
Hence, the service seeking behaviour of a sick person does not follow a clear referral system but rather one can choose any of the below options. Several socio-economic and cultural factors influence the decision as to which system can offer better help/service. Moreover, personal and family perceptions of the severity of the illness influence decision making processes.

The diagram indicates how the sick individual or the family determines where to seek help when sick.

2.6 Civil Society Serving Disabled people:

There are few civil society organizations working with disabled people in localities outside of Khartoum (Two NGOs in 2 localities only (Umbada and Kasala) were identified as working with deaf people and HIV/AIDS patients). The Zakat Fund
directs some of its funds to disabled people but has no targeted policy or earmarked funds available. This issue needs to be highlighted for future policy directives. Most NGOs focus work in the capital and in relatively better serviced localities within the capital.

2.6 Community, Family, and Individuals Level Health Related Information:

The following information is from the researcher of native ethnographers, from observation of the households visited and from health sites where all patients were accompanied by at least one co-patient.

2.6.1 Almost all of the households in the rural sites and displaced communities studied have a few livestock, such as a donkey for transport, goats for milk, chickens or sheep. Animals are kept as a source of security and may be 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 center or hospital, and to pay for the needed medical services and medicine, which are not free. As health insurance is newly introduced in Sudan (since 2008), only a few states have some coverage and most are not covered at all. Some poor households do not have livestock. In urban settings the majority do not own any, other than a few chickens.

2.6.2 At a community level, crime, alcoholism or drug abuse were not reported as patterns or forming a threat to the community, except in Umbada locality where alcoholism and crime were reported. The poverty prevalence mean consumption of cigarettes is not popular, but there is a traditional substitute called snuff which is mainly a male practice and reported to impact negatively on one’s health.
SECTION III: Meanings and Understandings:

This section will provide information related to meanings, definitions, knowledge, perceptions and attitudes related to key terms or concepts of relevance to this study. These are the following:

- Equitable health.
- Health and wellness/non-wellness – being sick.
- Disability.
- Vulnerability.
- Quality of health and quality of life.

3.1 Perception of Equitable Health Care:

Equity means social justice or fairness; it is an ethical concept, grounded in principles of distributive justice. Equity in health can be, and has widely been, defined as the absence of socially unjust or unfair health disparities. The issue of equitable health care was understood differently by providers and users. Most of the users interpreted the concept as equality and availability of service, while medical personnel associated it with the availability of primary health care services for everyone. None of the respondents identified social justice as a principle for equity. One middle aged male medical assistant in a rural hospital was very expressive in the way he defined equitable health care: “To me it means that everyone in this country should have appropriate health service, free and of high quality, it is unjust that a pregnant woman in my village would die from obstructive delivery while in Khartoum they are building a five-star hospital for the rich. We are all Sudanese, we should be equal”. The quote “Equitable services are the available services” reflects the link between the concept of equity and availability of services expressed by many respondents. Some users also discussed equity as part of the
quality of health care; “it is when the service is close to the users, it should have all the care needed by patients, for example, good laboratory services, good doctors” (a middle-aged man living with HIV/AIDS in a rural hospital).

On the other hand, health providers were asked to identify the meaning of equitable health care and not health as an abstract concept. This may have led the majority of them, mainly medical doctors, to define equitable health as “availability of primary health care to everyone” (a physician in a teaching hospital). On the other hand, they also went beyond availability of primary health care and included aspects of affordable and quality of care to everyone.

3.2 Perception of Health & Wellness:

Most respondents at the areas studied conceived of health and a healthy life to mean the following: “Healthy means eating your food and being able to do your work. Both health and illnesses are from God, he gives both and takes both, everyone, especially believers, becomes sick at some stage. This is natural.” (67 years old man, from a rural area but relatively better off, with hypertension, walking, hearing and sight problems, interviewed in his house in a village). It was considered the opposite to being sick. “Health for me is clean water, good nutrition, cleanliness of the body”, an old man with physical disability in a rural health center indicated. For others “Unless psychologically well, one cannot be 100 percent fit, physical wellbeing counts for only 85% of the health”. Yet some of the ladies talked about it as being judged by weight. “My health was good before but now I lost some weight” (a middle-aged female with a chronic illness at a health center). For others it is measured by production and appetite, as stated by one respondent.
The concept of health translated into Arabic was hard to understand by some respondents. The overall trend in comments was being able to do daily activities and not feeling any pain. A pregnant female, who lived far from services, identified health as "simply to be fine, not to visit the health clinic, your kids are fine and to have the money to buy medication". A mid-fifties male respondent who was highly educated and suffering from renal failure said "health is being able to work and support your family, then you feel valued and satisfied, then your overall health would be better." This user included aspects of productivity and psychological wellbeing when he defined health. Also, one can cautiously postulate that the definition of health among users is not far from the WHO definition "a state of well-being with physical, cultural, psychosocial, economic and spiritual attributes, not simply the absence of illness". Others link good health with seasonal availability of nutritious food such as milk, vegetables and meat. According to a 29-year-old deaf mother, educated but unemployed interviewed in a specialist clinic in a teaching hospital, "if you have enough money to buy good food, you will not get sick."

In addition, many respondents associated sickness with normal life or with ibtilaa (faith testing). The following statements represent some of the views expressed by respondents in relation to sickness and good health: "Believers have the strength of their faith tested, and sickness is one way they are tested" (middle aged very poor woman, with chronic disease interviewed in an urban maternity ward).

Another definition provided by respondents linked health to the balance between the exerted effort, nutrition, the environment around the individual and lifestyle, such as cleanliness, hygiene and good nutrition. "Health is an outcome of the balance between the effort expended and the nutrition in a good environment" said
a female user in private facility, complaining of chronic disease. Respondents also explained how health is reflected in the person’s good nutritional status. Two of the respondents said that “malnutrition and bad eating lead to illness and poor health”.

A male physician at Rabak Teaching Hospital said “health is not only physical. All other dimensions of life need to be tackled here.” Another male physician at Aljazeera Aba rural hospital said “if quality services are available people will be healthy”. However, none of the providers talked about their perception of health, but rather focused on the issue of accessibility to health which will be discussed in details later in this report.

3.3 Perception of Being Sick:

The social disruption and destitution associated with seeking expensive health services away from one’s home and village tend to be major concerns for many sick persons, especially women (as they view sickness as something that hinders their ability to fulfil their social and reproductive roles). Many female respondents used statements such as “I have abandoned my kids” or “I disrupted the schooling of my children”. While for many men it seems that it was their ability to remain productive, earn money and provide for the family that worried them during sickness. A 29-year-old man, poor and a wage labourer from a remote village, hospitalised for a day in a rural hospital stated: “I am sick and unable to work, so I am no longer able to provide for my family. In fact, they are using the very little money that I have saved from working in the gold mine areas to buy me medicines.”

Being sick or unwell, is viewed by most respondents as an integral part of normal life, or as part of their being as human. For example, one 40-year-old male in a
teaching hospital said “falling very sick most of the time or for a long period of time, is the only cause for concern for me”. Although many respondents associate sickness with normal life or with ibtilaa (faith testing), some associate it with poverty as a middle-aged woman with a chronic illness at a health centre said “when I have no money or my money is not enough to eat enough food or buy good food then I become sick and my family too”.

Another example referring to feeling unwell and taken to a faraway hospital/clinic one respondent stated: “I have disrupted the whole village” (a comment by a 71 year old blind man, poor, interviewed in a rural health centre), another middle aged very poor woman, with chronic disease interviewed in an urban maternity ward said “I messed up my family’s life and livelihood”, a third woman stated: “I abandoned my kids”(22 years old nomadic woman, interviewed inside a ward of rural hospital); and a fourth woman added, “I disrupted the schooling of my children and I used all of my family money and time” (32 Year old woman, coming from a remote village, interviewed in a rural health centre).

According to a Medical doctor in Obied Teaching Hospital most patients come to them “very late” or sometimes “too late to be saved”. He added “people in rural areas rarely come to our hospital walking on their feet. They continue to receive traditional healer treatment or resist transfer from rural clinics and hospitals until they collapse or lose consciousness, then their families bring them to Obied Hospital”. Such health seeking behaviours are often due to lack of cash in rural areas, especially during the rainy season, and the high social and economic costs involved in travelling to Obied for medical treatment. Valuable time for controlling
and treating patients is often wasted while family members are rearranging their household priorities.

3.4 Perception of Disability:
The term disabled was difficult to translate into Arabic, since various synonyms are used to express the term disability. When translated into Arabic, especially local collegial Sudanese Arabic, the word disability does not convey the exact meaning of the English word. In any case the word ‘muagh’ is associated with not been able to move/walk freely and independently, but not as a result of old age. If restriction to movement is related to old age, people see it as “kubur” (natural aging process) and not a disability that has to be treated. Another very dominant concept is the disability seen as a fate; acceptance is a major reaction towards this question. One usually hears this statement “Disability is a blessing, a test of faith, not a curse”.

The concept of disability for most of the users is linked to loss of one of the main senses. Some also talked about it as the loss of an organ or a function of it. A middle-aged lady living with HIV/AIDS in a rural hospital explained that disability is “an obstacle in one’s life... it’s a physical thing that stops the person from doing his/her daily chores and duties”. She explains further that it can be financial, physical or mental disability. Another blind, middle-aged, man interviewed in a health centre identified disability in relation to his own status where he said “when one of the eyes cannot see, this is disability”. An elderly respondent at a teaching hospital also explained disability in relation to his status where he said “it’s the illness associated with getting old where the person is always ill”.
A dominant concept is that disability is fate and acceptance is a major reaction towards this question. As stated above, one will usually hear this statement: “Disability is a blessing, a test of faith, not a curse”. One may argue here that it is also derived from their definition of illness (something which is accepted as a test of faith). These beliefs have implications for health care seeking behaviours. Moreover, and interestingly, most of the people with disabilities the researchers interviewed believed that other disabled people are more disadvantaged than themselves. For example, a physically disabled man said that “the worse type of disability is blindness”. On the other hand, a blind young man at one of the teaching hospitals believes that “deaf people are the most disadvantaged group of disabled people because of their inability to communicate with the world”. An eighteen-year-old female with artificial legs said “I am not disabled I can walk and move around. Before I had my artificial legs, I was disabled because I had to be carried around and could not assist myself and I couldn’t work”.

The concept of mental disability is still not recognised by either patients or even providers of health service, as part of what they define as disabled person. Although both saw mental illness as a matter of concern that has to be dealt with in some way. As with other matters related to health, mental disability is viewed 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. This is despite the fact that most providers understood the English meaning of the term disability well and most used English in their interviews. The majority of them mentioned that disability means inability to move and function normally. “Disabled people are those who cannot do
what the normal people do.” (a male physician at a private clinic). Also, some providers considered disability in terms of the degree of dependency of the person. One male physician at Rabak Teaching Hospital said “Not all the disability is disabling, most of the disabled are made dependent because of how the public deal with them”.

3.5 Perception of Vulnerability:
When users were asked about how they understand vulnerability and how it affects their health and wellbeing, most respondents stated that “if you are poor, 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”. Vulnerability was thus defined as being poor or with low income. One of the female divorced respondents in her fifties at a hospital said “I am vulnerable because I cannot afford to buy my asthma drugs and so I have to go to Zakat (endowment) to get assistance to buy it”.

Female respondents’ defined vulnerability as when the person is exposed to an unhealthy environment which may induce illnesses, such as living near a place where waste is burned, which can lead to recurrent chest infections.

Gender dimensions of vulnerability were raised twice in two contradicting statements. For example, a physically disabled old man at Rabak Teaching Hospital said “females are less vulnerable because they are socially protected”, while another female viewed woman as most vulnerable as they are poor and shoulder many reproductive roles. When asked about how she understand vulnerability and how it affects their health and wellbeing, one middle aged deaf mother, educated, but unemployed, interviewed in Specialist clinic in a teaching hospital stated that
“if you are poor and do not have money to eat well they you are always vulnerable”. Some elderly people say if you do not have working sons to support you then you are vulnerable. This was echoed by a 34-year-old woman, who headed a household, interviewed in a rural health centre, who said “if you do not have working sons to support you then you are vulnerable”.

One of the female respondents who lives with a physical disability and in remote rural area, “when we live far away and are very far from health services we are vulnerable but not like what I have now. It’s because I live far this makes me vulnerable”. They believe that physical disability can increase a disabled person’s contact with the ground, such as leg deformities and getting around by crawling, can be a major source of vulnerability from a hygiene and health point of view. One disabled old man at a rural health center justified this saying: “They are vulnerable due to their direct contact with the dust and dirt. They beg people by crawling and humiliating themselves on the ground most of the time”. Also, they perceive themselves as a disadvantaged group who should be given a priority within the health system as explained by this blind man in his early forties interviewed in a health center: “We have many needs and we cannot get things quickly like others. Therefore, we should have priority when we go to the services and when we have health needs”.

3.6 Perception of Quality of Life:

The concept of good quality of life was defined in many ways, including as economic security, as a diabetic woman in her early thirties, attending a teaching hospital for her treatment, said: “If we have the money then we can be better, be in good health
and have a better house, cleaner water, electricity, we eat the food we need and good [food]”.

One of the medical doctors in one of the rural hospital explained the overall condition of the people and how these affect their quality of life saying: “People here live in poor houses. They are not very clean they have no running water and they have to pay for having a lot of water, so they cannot have good hygiene all of the time... these make them live in very poor conditions”.

Discussion:

It may be concluded that the concept of health and wellness is viewed by patients from an individual perspective, while providers viewed the concept as the supply of services for everyone. Nevertheless, both users and providers incorporated aspects of affordability of service, which is a very central concept in this study and was evident as a crucial one in the analysis, pertaining to accessibility to health care for vulnerable groups of all kinds. Many aspects of health were also mentioned, such as nutrition and a clean environment, showing some level of knowledge among some users.

A concern among users, is the impact of getting sick on reproductive and productive roles disruption. Many respondents were more concerned with the impact of sickness on their lives and livelihoods and those of their families than with the impact of illness for their personal wellbeing. Therefore, disrupting the lives of others and keeping them busy or away from home is a major concern for sick people who have to be transported to a faraway health facility and cared for while there. Statements made in this regard tend to have a tone of guilt and were different between men and women, indicating a gender difference the view of
health, wellbeing and illness. This may reflect their perceptions of their socially constructed roles in the society. This has great implications for existing programs and policies and more gender analysis is required in the making of policies so that health care is more accessible for all.

Regarding who is considered disabled, the comments made by users and providers show that disability is predominantly a physical condition, and the concept of mental disability is not recognised by either users or even providers of health services, although both saw it as a matter of concern that has to be dealt with. This indicated that people have little knowledge of mental disabilities, and that the concept of disability is confined to physical conditions only.

Respondents’ definitions of illness and being sick were characterized by a high level of acceptance of illness, which reflects the idea that the acceptance of illness, and change in wellbeing is a test of one’s faith. This may have important implications for any form of health seeking behaviour. The health belief model (Becker, 1984) has shown that individuals act on any form of health promotion or treatment of ailments based on their perceived risk to them or on the aetiology of the illness itself. A sound belief that enduring illness or disability is a means of showing strong faith, may well influence any action for prevention in future. Moreover, this also reflects that people still do evaluate their health, illness or disability in terms of their ability to contribute (their value) to the community and people around them. Our analysis of the core concepts among existing policies for Health and Disability, showed that policy focused mainly on protection from harm, and prevention. While these are valuable aims, there is clearly a big difference between the policy
on disability and the understanding of disability held by the public, as well as the priorities of the disabled and their support networks.

The concept of disability was explored. By some, it was simply considered a vulnerability. However, some government key informants commented that they believed that disability was used to manipulate the system and that disabled people present themselves unfairly as the neediest group. This highlights a serious gap between the way disability is perceived by the patients as a form of vulnerability, and the way providers and the formal system address it. Perhaps this is an issue of integration of people with disability in everyday services and programs as well as an issue of ensuring antidiscrimination, empowerment and increased participation of these people in the community and health system. The analysis of the Sudanese Policy for Disability, showed that the core concepts of antidiscrimination and integration were well addressed in the policy document, but the policies did not include empowerment and societal participation (Manne et al. (2011)). The results above thus reflect another gap between the policy and the reality and the needs of people with disability.

Based on the study eligibility criteria, all of the interviewees were vulnerable, falling under one or more of the 12 categories of vulnerability outlined in EquitAble WP2 (Amin et.al. (2011)). But, none of them identified himself or herself as vulnerable. However, people with chronic illnesses, such as hypertension and diabetes, and disabled people are particularly vulnerable because of their socioeconomic status and their health/medical conditions. Socioeconomic vulnerability and vulnerability due to disability or health conditions have a direct adverse impact on people’s ability to access to health service, in terms of physical access, affordability and
access to available information and options. This situation has been further compounded by the poor quality and the uneven distribution of health services in all studied sites. Most people who would be classified by policy or EquitAble as a vulnerable group did not see themselves as vulnerable and were often not perceived by the community as being vulnerable, especially mothers of children under five and pregnant women.

People with disabilities were among the few who acknowledged their vulnerability among those who were interviewed. This could be attributed to the fact that it is a visible vulnerability. Yet, disabled respondents focused more on the problems with the health system, government and the authorities than they did on their own vulnerability. They perceive themselves as a disadvantaged group who should be given priority within the health system. This failure to accommodate their needs shows the gap between what policies indicate and what the system actually provides.

The providers’ point of view on vulnerability is varied. The notion that most people are vulnerable emerged many times during the discussion with providers, yet very few health providers identified specific vulnerable groups, including children, pregnant women, and elderly people. The providers view vulnerability as factors that put one in great danger, and we believe they refer here to economic deprivation since poverty and socioeconomic vulnerability are widespread in many of the studied localities. People were not aware that children under five qualified as a vulnerable, at-risk group or that having recurrent pregnancies put women at risk. Also, disease by itself was not considered a defining aspect of vulnerability; but as a disruption of normal daily life. Lack of access to resources, stigma and
discrimination contribute to people’s self-identification as being a member of an at-risk group.

Implication of meanings & understanding for existing policies
The analysis above shows many gaps between the assumed level of knowledge of both community and health care workers by existing policies and actual on the ground knowledge. It also showed a large gap in how illness, health and vulnerability are understood and classified by policy, health care workers and community members. This is despite the fact that access to information and utilization of information to improve both policy and services are important aspects of Sudanese health policy. Concerns related to poverty overshadowed almost all of the definitions: the value the individual places on their ability to contribute is greater than the value given to their own health. Guilt over causing disruption to family life, ideas of one’s role in society, differences in gender roles, beliefs about the causes of illness and many other cultural and social factors influence how people access and utilize healthcare.

The health system makes assumptions which need to be reassessed within the existing policies as well as in programs. The interviews with health care providers also reveal gaps between they studied, what they see in reality and the perceptions they have of their roles towards their users. Also, the assumption that individuals will prioritize their health and seek care for illness and disability is clearly a vast over simplification. There are many factors which come into play in making decisions about how and when to access health care, the foremost among them being poverty. One’s perception of one’s own role in society and understanding of human rights, and
what rights people are entitled to also comes into play in making health care choices, as well as in one’s perception of health care. For example, gender profoundly shapes how sickness, disability and vulnerability are seen and dealt with in society and within the family. In addition, it is clear that illness and disability cannot be viewed individually, for example household expenditure is disrupted when someone is sick, which can be particularly impactful in an impoverished household. In sum, there is a gap between how illness, vulnerability and disability exist in policy and programming, and how they exist and are understood by health care providers, patients and society at large. The next section will be a more in-depth look at how these factors, as well as other factors, impact access to health care among vulnerable populations.

SECTION IV: Access to Health Care

4. Introduction

There are a number of interrelated factors that facilitate or hinder access to health services in each of the four sites of the study. There are also factors that are specific to individuals or households. A few common hindering and facilitating factors have emerged from the analysis of the data collected from across the country. The key common factors were found to be: the location and transportation, the ability to pay, access to relevant information, the attitude experienced by patients at the facility, the perceived quality (in terms of choices and preference) of the service and having a health insurance policy and coverage. The following section will present each of these factors.
4.1 Location, Transportation and Access

The place one lives and the means of transportation available there affects access to health services. Those living in inner urban areas, especially in the capital city Khartoum or the state/locality capital, tend to have the best access to health services, which are often available within walking distance or by taking a short trip by local transportation (often less than two kilometres).

There are also location and transportation differences for the different types of services. All secondary health services and most of the primary health care facilities in the country are based in large cities and towns (often the capital of the locality/state). Therefore, those who live in these urban areas are better placed to access health services of better quality, at a reasonable distance and for longer opening times (emergency services at teaching hospitals are open 24 hours a day and the National Health Insurance Centres stay open up to 22h00 every day).

However, as most services are located in the city centre, there are also differences within urban centres themselves. Those who live in the outskirts of the city or the squatters’ settlements established by the new migrants and IDPs, do not have adequate facilities in their own neighbourhood and many of them have to travel for up to 9 km to get to the nearest health centre or hospital.

In rural areas, the lack of access to health services is even more severe. Many do not have any facilities of any kind in their areas and most have to travel for up to 50 km to reach a health centre or a hospital. Therefore, for people who live in remote rural areas, the distance from adequate health facilities is a major factor that impacts access for all, whether poor or relatively better off. There are however, some positive aspects to medical care in these areas. For example, since
villages are small in size and in population, if there is a health centre, dispensary or health unit in the village, travel time and distance are not an issue. It has also been observed that health workers in rural areas, who are often from the village or a nearby area, tend to keep flexible opening hours compared to the strict hours in urban areas (08h30 to 15h00). Many rural and semi-urban health workers allow patients to call them at home and most of them are willing to open their facilities in the evening or at night if there is an emergency. We have also observed that some health workers visit elderly patients, very sick people, and women with newborn babies at home, in order to examine the patient, give advice or administer medical drugs and injections.

The location of the village also impacts people’s access to health care. For example, people whose villages are located at, or adjacent to a tarmac road or a regular travel route, especially towards Obied city, have better physical access to a variety of health facilities, often wait for shorter period and pay less to reach these facilities.

In contrast, the issue of transportation was not viewed as a major problem for most people in urban areas because transportation is available, not very expensive and most of the health centres are within walking distance from people’s homes. Public transportation is, however, usually needed to access secondary or specialised health services, such as maternal care clinics, which are often located in the city centres. Safe and timely transportation of patients who are in an emergency situation or are critically ill, is a major problem for both urban and rural populations. For example, there were no free ambulance vehicles in any of the research areas. The very few available ambulances are in urban hospitals, are not
fitted with all the necessary emergency kits and do not have qualified paramedics. These ambulances are also ‘commercial’: meaning that patients must pay to use them.

In rural areas, the issue of transportation was seen as one of the major hindrances for health access. A pregnant woman in her third trimester said:

“We live in a faraway village and that is a big problem. I have been living in the dispensary for two weeks as I can not go back to my village and come back again. I am now pregnant with my third baby. I left my husband and other children, I stay here with my mother and [my] relatives bring food, water and clean clothes to us. I cannot go back as my house is one-hour ride with a donkey cart.” (22-year-old, poor woman in her third trimester of pregnancy, interviewed at a rural dispensary)

Another woman, in her early 40s who was a mother with three children, who was also spending the night in the second examination room of the dispensary said:

“My children need Penicillin injections so I cannot take them back but I can’t stay here because there is no food and I did not tell my husband.”

The dispensary is the only health service in 27km and two hours from the nearest hospital. It provides free services, free medications and has a relatively well-equipped delivery room. Villagers are often in desperate need of its services and walk long hours or come with the local “ambulance”: donkey cart. Explaining the patients’ transportation problems in her area, the mother of the three children added: “We need an ambulance in the area to take our sick children, now we only use our cell phone to call the donkey cart or rent a car to the town”.

4.2 Ability to Pay and Access

Health services in Sudan are privatised; patients have to pay fees to use them. For example, the fee rate for seeing a medical assistant in government facilities in Sheikan locality ranges between 2 SDG to 5SDG, and for a medical officer between 5 SDG and 10 SDG. If a patient needs to see a specialist s/he can pay between 10-20 SDG. In addition to this, patients have to pay between 3 SDG to 5 SDG for each laboratory examination test they require and also pay for the medication prescribed to them. Malaria tablets are however provided free at all urban centres and many rural clinics. Some centres also have a limited monthly stock of free essential drugs such as antibiotic for children under 5 years old.

The cost of medical treatment has multiple layers and does not only involve the direct costs of seeing a doctor, but also additionally include, in many cases, the cost of investigations, laboratory tests, and x-rays, which are significantly higher than the doctor’s consultation fees. Medical drugs are privatised and therefore extremely expensive. Other indirect costs include transportation, food during the stay in the hospital and other social costs. When added to the overall cost, it creates a significant financial burden for patients. Reflecting the contrast between the cost of seeing a doctor, and the total cost of getting medical treatment, a woman said: “Although, the cost of seeing the doctor is around 3 SDG, unless I have 50 SDG, I won’t go to the hospital, because of the investigation, drugs and transportation cost.” (Displaced woman in her forties, interviewed inside a health centre).

Although government policy provides free emergency health service for the first 24 hours and exempts children less than five years of age and women undergoing C-Section, the reality on the ground is rather different, and all patients do pay fees of
different amounts. A young mother of a child under five in her late twenties, interviewed inside a hospital said: “at the door of the hospital they let you enter free, however inside they ask you to pay for investigations and medication, though it is half price but still it is too much for me. Even for the plaster I paid 50 cents”.

Another woman interviewed at a rural health unit said: “I usually have to sell a sheep or a goat, so that I can afford coming to the hospital in Umbada as the cost to reach the hospital and to see the doctor is almost 250 SDG (100US$).” When asked what you do when there is an emergency, she stated that: “we borrow money from the village cantina and he takes our goat as an advance” (a hearing-impaired widow in her late 50s who is a head of household a household, interviewed inside a hospital).

Although very few patients in the research areas have an insurance coverage, it is clear that having a health insurance will eliminate most of the cost for the insured people and provides them with affordable services. According to one insured woman: “honestly speaking, the health insurance is very successful so far” (29 years old, a poor wage labourer from a remote village, hospitalised for a day in a rural hospital).

Recognising the importance of having an insurance policy, an uninsured disabled young woman in her late 20s, said: “If I had health insurance, it would have solved all my problems”.

Patients who live in urban areas and are relatively better off can pay 30-60 SDG to see specialist consultants in their evening private clinics. Patients who use these private clinics can drop in at top specialist clinics, as they do not need a prior
appointment. Moreover, such private patients often receive better attention and treatment. As most consultants in these clinics are also working in the largest hospital in the locality, there is a perception among the public that a visit to these clinics can also serve as a short cut to the rare beds at these teaching hospitals’ wards or the Intensive Care Unit (ICU).

Government officials such as teachers and health workers and some private sector employees such as bankers, are covered by the national health insurance policy. They do not pay consultation fees and only pay 25% of the cost of their drugs. They also have access to all facilities operated by the national insurance fund, which are often of a better standard and quality in terms of staff, equipment and general services, such as opening hours, waiting places and waiting time. Although health insurance is theoretically available for non-government officials to join, because of cost and complexity of procedures, very few people join it.

Cost not only hinders access to health services, but it also determines the quality of the service a patient can receive. Although government policy indicates equal service for all, the reality of the implementation of policy is different. For example, Umbada hospital has a private ward where costs are equal to the private sector; the ward offers the possibility of specialist consultations and a private room with a toilet. Further costs determine what sort of provider one can afford. For example, the cost of seeing a medical assistant at the health centre/clinic is between 3 to 5 SDG, in comparison to that of 5 SDG to see a medical doctor at the hospital. In order to see a specialist in the hospital you have to go to the outpatient clinic which is held once a week and where there are long waiting times. The cost of consulting a specialist in the private sector ranges between 15 to 70 SDG in the study areas.
An elderly retired teacher who was on renal dialysis, interviewed inside a hospital said: “I come to the governmental hospital because I can’t afford private centres. I already sold my house and I have little pension so this all I can afford and I know it is not the best service.”

Some patients believed that cheap health services are bad health services, and they prefer to go to places where they pay more, even if the facility is run by the same person that runs the less expensive or free facility. A male medical assistant (in his mid-fourties) interviewed in a rural health centre said that he has his own private clinic in the evening:” Each evening I see double the cases I see in the governmental medical centre in the morning”.

A pregnant woman in her late thirties, interviewed at a rural health centre said: “I prefer to go in the evening although the waiting is longer and the cost a bit higher but he cares more about patient[s] in his private clinic”.

Another mother (early forties), living far from any health facility and with a child under five, also associated cheap with bad quality. She said she does not buy the subsidized medications that cost a quarter of the full price as she is worried about their quality. She explained: “they must be expired or not good to be sold so cheap”.

The aspect of cost from the providers’ prospective was expressed differently, a young medical doctor (late twenties) interviewed in the emergency room said: “It is not my concern if the patient paid or not. I care about their ability to get the needed medications and tests; the situation is frustrating. People are very poor here, so I try not to demand so many investigations and I think of affordable medications. When I started here I used to give patients money to help them but then I stopped as I cannot afford to do so.”
The Medical Director of a teaching hospital (mid-forties) thinks that:
“*The government is doing its best to provide subsidised medication, free emergency service and free service for children under five. However, the number of poor patients overwhelms our attempts to help... the health insurance has helped in making the facility accessible.*”

**4.4 Information and Access**

Users of health services in Sudan operate within a context of severe lack of information and misinformation. Health information is not seen as a top priority for government and is, neglected. This can impact the quality of health care.

We found that in the research areas, information concerning available services or health promotion are limited to three categories only: HIV/AIDS, maternal health and childhood Immunization - all supported by UN and other aid agencies. The available billboards, leaflets and posters were all from the Federal Ministry of Health and are mostly designed and produced in collaboration with the World Health Organization (WHO). Information on service availability it is usually transmitted by the word of mouth. Information regarding rights and eligibility, for example; the right of children under five to receive free service, is not available. A diabetic mother (mid-forties) of a young child with walking difficulties said “*The doctors don’t tell you what services are available unless you ask for the information. Me - I did not know that I can bring my young child to the clinic for free until my cousin told me so*”.

Information regarding the hierarchy of employees in the clinic and the immunization schedule is standard in each health centre visited. However,
there is also a problem in relation to presenting medical advice and information in simple nontechnical language that a lay person can understand. Health professionals are not trained to do this but each person interviewed seemed to have created their own strategy for dealing with this. An elderly patient said: “Those doctors talk 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”. (A 67 years old man, rural but relatively well off, with hypertension, walking, hearing and sight problems, interviewed in his house in a village).

We noticed huge gaps in information concerning various aspects that affect access, such as: information about costs of services, type of services offered at each facility, criteria for exemption from fees, physical access for disabled persons, sign language interpreters, health promotion and awareness, options for treatment, use of medical drugs and possible side effects, opening hours and closing days. There is also a tendency among health professionals to not distribute and disseminate even the little available information to patients and members of the public. Most respondents say they “have to ask to be told” (35-year-old very poor woman, with a chronic disease who was interviewed in an urban maternity ward), and sometimes “you do not get told even when you ask” (29-year-old deaf mother, educated, but unemployed, interviewed in a specialist clinic in a teaching hospital).

Information on the organisation of work and health care services was easily accessible. For example, we could easily access to the number of patients, salaries, available equipment, and expenditure from the different health services we visited.
This kind of administrational information was well kept and easily accessible. However, the health units did not utilize or transmit health information to their patients. For example, none of the facilities visited have employees who know sign language or can communicate with a deaf person. In addition, most patients stated that they rely on their social networks, family and friends for information about services, and even the way they use medical drugs as well as for more general health related advice, like how to maintain a healthy lifestyle.

There is very little information made available to patients, and even the information that is available is poorly presented, and not accessible. The problem is in both the production and the presentation or distribution of knowledge. Barriers to the spread of information include illiteracy, language barriers, and the fact that the sometimes complex and technical information about health is not explained in an understandable way to patients. This serious lack of information often increases the cost of treatment, wastes patients’ time, can interfere with treatments and lead to spreading of misinformation and myths about health, sickness and wellbeing.

**4.5 Attitude at Facility, Perceived Quality and Access**

Affordability of services, physical accessibility and access of information are crucial factors that can facilitate or hinder access to health services. However, the attitude of health providers experienced by patients at the facility was also found to be a key factor. One patient explained the importance of this by saying: “I came to this centre because they are very humane and kind, though I had to travel for a long distance.” (An 80-year-old man with hearing problems, interviewed in a government health centre).
Those who are able to choose which health centre they use report that the attitude of the staff is one of the most important factors in selecting where they go for care. They will even pay more to be served in facilities with ‘kind’ or ‘polite’ staff because they feel they are receiving higher quality treatment. Most of those who mentioned the quality of the facility as the factor which determined their choice of facility saw politeness, positive attitude and nice interactions with the provider as the best services. Also, the relationship built with the provider and previous successful experiences with a provider are indicators of quality and influence the choice of facility. A young poor pregnant woman interviewed in a health centre said: “The doctor is polite and nice. That is why I come here... 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”. Another said: “I came here because the doctor is very nice”. (34 years old women, head of household, interviewed in a rural health centre).

Another middle-aged women interviewed in a clinic said: “I prefer to go to the private health centre because the doctor is very humane. His words make one feel better”. And this was echoed by a young disabled woman: “I prefer the Palestinian doctor because he deals with me better, though his centre is more expensive”.

The desire to build a relationship with a health care provider and to seek out ‘kind’ providers is also reflected in the negative opinion of patients towards Health Care Providers (HCP) in hospitals. An HCP in a PHC said: “People prefer the HCP and not the hospital because in the HCP they will see the same doctor each time and they will build a good relationship with him, not like in the hospital”.

Another barrier is that many people only seek the advice of a doctor as a last resort. For instance, one of the respondents said: “Unless it is very severe I would not go
to the clinic” (32-Year-old woman, coming from a remote village, interviewed in a rural health centre.

Another barrier to accessing care is that disabled people often need a friend or family member to accompany them to the health care facility. In addition, women need an escort regardless of whether they are disabled or not. If they cannot find someone to go with them, they may not be able to go and receive care.

With regard to people with disabilities, they are sometimes exempt from paying fees, but this is a practise which is at the discretion of staff rather than a matter of policy or rights. In fact, the whole model of service delivery to disabled people in the country seems to be based on charitable contributions, rather than rights and policy. Both providers and vulnerable groups do believe that vulnerable groups should receive priority service, but only because it is ‘kind to allow them to go first’, rather than because it is a matter of rights. This means that there is no expectation that they will be given priority. Also getting free service is considered part of ‘being kind’.

A young disabled man interviewed at a government health facility said: “Here the people are very kind, they never ask for money. I have never paid for service”. A disabled user in a public health centre and a key informant said: “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.”

4.5 Health Insurance and Access

The insurance coverage by the National Health Insurance Fund, which falls under the Ministry of Social Affairs, is a key method of accessing health services for urban and semi-urban residents. It is compulsory for all government employees to be
covered by insurance, and therefore they tend to use the services it provides more
than others. Deductions are made from the monthly salaries of these employees,
even if they live in remote rural areas (e.g. teachers) where there is no health
insurance operated facility.

The Zakat Chamber also provides some coverage for certain vulnerable groups
including widows, orphans and disabled persons. This Zakat coverage is limited,
largely urban based and requires an individual to be part of certain social or political
networks to benefit from it, although we met a disabled young man in a village over
50 KM away from Obied who said he was covered by the Zakat through the support
of his uncle who lives in Obied.

Health facilities owned or operated by the NHI fund are of better quality and
generate a higher level of satisfaction for patients compared to government ones.
Health insurance facilities are all operated by medical doctors and not medical
assistants or health workers, as in the case of government health centres. Insurance
facilities also have a better referral system, whereby patients can be transferred to
a specialist in town or even in Khartoum for further consultations, laboratory test
or surgery. In all cases insured patients get free consultation and only pay 25% of
the costs of their drugs. For the reasons explained earlier, health insurance is,
however, practically unavailable for those not working in government or in large
private companies and banks. Poor and vulnerable people, such as displaced
persons and new migrants, almost never benefit from it. Many government
employees who work in remote rural areas are also unable to benefit from health
insurance because they live in areas without facilities operated by the NHIF,
although they are technically covered and have the employee contribution deducted from their monthly salaries.

**Discussion**

Access to health services in Sudan varies significantly from one place to the other and from one person to the other. In order to understand the challenges faced by the population in the research areas, it is imperative to place this research in a wider context and be mindful of the following crucial factors that affect all users of health services at varying degrees.

1. The privatisation of health services since 1999 not only ended the free health services which had existed since independence, but also removed most of state subsidies to health and health related services. In recent years the government introduced a health insurance system which relies heavily on the public health facilities and staff and is still limited in its geographical and social coverage and largely covers public sector employees (although as we have seen above, it does not even reach all of them).

2. Successive regimes have put into place policies with a strong urban bias, which has led to an over concentration of health facilities in urban areas, particularly Khartoum and the state capitals. In the research areas almost, all secondary health services and most of the primary health facilities are located in the capital of the states/localities. In addition, the facilities in urban areas are placed at the commercial city centres rather than in the, often densely populated, urban peripheries.

3. The poor infrastructure of the country (e.g. roads, communication, bridges, dams etc), and lack of essential services for a large section of the Sudanese society (e.g.
adequate housing, drinking water, sanitation facilities, schools etc). Education, water and electricity have particularly been increasingly commercialised and privatised.

4. The widespread poverty in the country and the growing urban poverty, largely effecting new rural to urban migrants and IDPs. Some estimates suggest that over 80% of the Sudanese live below the national poverty line and 45% of adults are illiterate.

5. There is a noticeable contradiction between stated health policies, the stated structure of the health system and the reality on the ground. Many policies are not implemented and structures and systems introduced by the Federal Ministry of Health do not exist on the ground.

6. The notion of ‘rights’ or ‘the right to equitable health care’ does not enter into the actions of the government. In addition, there is a lack of awareness among the public that free health service was enshrined as a right in the country’s Interim National Constitution. This further limits access to care.

7. The newly introduced federal government system and the way it has been implemented at both federal and state levels has led to the disintegration of health systems because it has left some states and localities with few financial and human resources.

Within the above context and web of factors, cost was found to be the main factor that facilitates or hinders the accessibility to health services throughout the research areas. Although the government announced a policy of exemption for emergency cases, patients under the age of 5 and women who need C-Section operation, our study showed clearly that all users of health services make some sort of payment in order to use the service, whatever that payment is labelled (fees,
contribution, drugs, and laboratory tests). Cost also determines the quality of service and the facility chosen by patients, and which provider they will see in a facility.

Because there are different fee rates, the quality of service and the level of the health professional that one is able to see are also determined by one’s ability to pay. Inability to pay fees, and for laboratory and drug costs were mentioned by many respondents as a major factor that hinders their access to modern health services and forces them to seek alternative medicine, such as from traditional herbal and religious healers.

There is also a clear rural-urban divide in the choices of facility that one has, costs to be paid, the type of services available and qualification of providers in the research areas. Health services, especially secondary health facilities, and all highly professional staff (medical doctors and consultants) are based in urban areas. Thus, those who live in urban areas have better access, while those in remote rural areas have no or limited access to health care services. Living faraway from facilities means that it takes more time health services and that patients must also pay for transportation, making it more difficult and expensive for them to access care. Those users who live near main transport routes or tarmac roads are able to access urban based care more easily. In cases of emergency, especially at night, the spread of mobile phones in some areas has helped in the arrangement of private transportation to take patients to hospital.

Access to health information is a challenging issue in Sudan not only due to high rates of illiteracy but also because it is not a government priority. None of the policies reviewed addressed issues related to the quality, accessibility or
dissemination of information. Yet, access to information about type and nature of health services, options available to patients and their cost is a vital factor that affects access to health services. Despite this, there is no system in place in either rural or urban areas, which provides members of the public with information about health services in their area, treatment options available to them, opening hours of health facilities, and the costs for each procedure or test they have to undertake.

Finally, although very poorly served, physical access to health facilities for disabled persons, language, sign language, and fear of crime are not factors that hinder access to health in Sudan. For example, physical access and use of sign language are often facilitated by the accompanying person (known as co-patient) and some hospital staff, and this was seen as appropriate. Crime is not an issue of concern for patients in either rural or urban areas of Sudan. In addition, the majority of people in northern Sudan speak Arabic, so language should not hinder access.

SECTION V: Quality of Health Service

5. Introduction

Quality is a measure of whether services increase the likelihood of desired health outcomes and are consistent with current evidence-based practice (WHO, 2003). This definition incorporates two components. For vulnerable populations, their families and the population as a whole, it emphasizes that services should produce positive outcomes. For practitioners, service planners and policy makers, it emphasizes the best use of current knowledge, technology and other resources.

The EquiFrame for policy analysis used six core concepts to assess quality related concepts (EquiFrame, 2011). Each policy was analysed with regard to its support for quality services to vulnerable groups. The overall score for Sudanese policies
analysed was moderate; hence one would have expected at least moderate quality of services to be provided.

To analyse quality, it is important to look into availability and acceptability of medical services. These two sub concepts were looked at from the perspective of users of the service, ‘quality’ health care means that they receive the care they require and that their symptoms and quality of life improve. From the perspective of a family member, ‘quality’ health care provides support and helps preserve family integrity. From the perspective of a service provider or programme manager, ‘quality’ health care ensures effectiveness and efficiency.

The interviews covered three main areas related to: 1) quality of the medical care; 2) quality of non-medical care; and 3) quality of health providers.

5.1 Quality of the Medical Service:

Availability of equipment, providers, medications and rehabilitation services were investigated using a checklist filled by the management staff at each facility (results are available in annex 3). Users were asked to rate their satisfaction with the available medical services and the care they received. According to pregnant middle-aged poor patient: “Unlike others, 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”.

Referring to a health provider in a poorly resourced rural centre, a male middle-aged physically disabled user, interviewed inside the centre, said: “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 as it will cost me a fortune”.
The checklist used in the quality assessment included a list of medical equipment ranging from stethoscope, wheelchairs and emergency trolleys, among other items. One Emergency Room (ER), female, middle-aged doctor said: “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. Sometimes 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 colleague they will not know what it is”.

The availability and continuity of the services was a major concern. Most of the places are served by doctors only in the morning, even in the hospital, with the exception of Umbada hospital in Khartoum state where they have a resident ER doctor. An emergency doctor (male and young) working in a city hospital said: “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 co-patients to buy plasters”. A male medical assistant in a rural health centre said: “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 [safe drinking] water, no computer and no air conditioning; so, I have to help my people”.

5.2 Quality of Non-Medical Service at the Health Facilities:
Four aspects were included in this category, namely, basic services at the health facility, upkeep of the facility, physical accessibility of the facility for persons with
disabilities, and waiting time and appointments. Each of these is discussed in more detail.

1. **Basic service at the health facility:**

None of the visited facilities met any of the criteria set for wheelchair accessible toilets (room size at least 1.6m x 1.7m, support rails in near and rear side wall, 800mm from floor, seat height not lower than 480mm, basin no higher than 830mm from floor and clear space underneath, wheelchair accessible hand drying facilities and emergency call button within reach from toilet). In almost all the visited facilities, toilets in particular were generally extremely poor by any standard and sometimes non-existent. Drinking water is either offered for free in local mud pots or sold in modern plastic bottles for 1 SDG. An elderly man undergoing dialysis said: “The waiting area is not suitable for sick people and women. The water is not always available and not cold”. Other users were either very satisfied with them or not bothered about them.

2. **Up keep of the facility:**

Staff at the facilities make efforts to keep them clean. However, Sudan is a dusty country and there is minimal budget allocated for cleaning materials, so the standards are not optimal. However, in Umbada locality, which is located in the capital city, the facilities visited were clean, and in the hospital had a cleaning company which was responsible for the upkeep of the facilities. In contrast, facilities in other areas were dirty to the point of being a health hazard. A mother of a child under five said: “I stay next to him all day using a handmade fan to kick the flies and I let him sleep on my tobe (Sudanese ladies gown) as their sheets are so dirty”. Waste disposal was another problem. None of the visited facilities have any special methods except burning of waste. The waste bins are full and syringes
are 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 crisis in Sudan.” A female hospital medical assistant Director said when asked about waste disposal.

3. **Accessibility for persons with disabilities or activity limitations:**
The checklist covered 16 items that assessed if the facility is disability user friendly. The items include entrance, parking areas, and signage. In all facilities visited these were non-existent. When an elderly blind man was asked how he navigates the health care facility (which includes a set of high steps at the entrance) he said: “My family and the staff help me to get through and move around, you don’t expect the engineer to change everything for few blind people; after all we have our family to assist us”. He was not being sarcastic; he truly believed that aiding a disabled person in navigating a health care facility is a family responsibility. However, a young female with artificial legs, met in the health centre, said “I don’t know why they make these high steps in the entrance, it is a hazard for people like me”. None of the facilities had personnel who knew sign language or braille signs. A mother with three deaf children, met in the health clinic but interviewed at her home, said “when I go to the centre I take my three children with me even if one only is sick; I cannot leave one of my deaf children at home or send one to the facility with my sister. No one understands my children but myself”.

4. **Waiting time and appointments**
As for operating hours, waiting time and crowding, the system of appointments is based on “first come, first served”. The waiting time seemed to be more of a problem for women than men; as one female with a five-month-old baby at health
centre said: “If I come late and the queue is long, I go back and try the next day I cannot wait. I have other children at home and my mother is old and ill. I have to hurry back.” Users living far from the services were particularly affected by the waiting times. An elderly female living in rural Umbada said: “We stay at the facility even if we sleep overnight because we cannot afford to go and come back”. A mother with a young child at hospital waited forty-five minutes for a blood sample to be drawn. However, she did not complain and when asked for the reason she said: “I am used to waiting and when the doctor finishes they will call me”. The opening hours of the facilities were not shown anywhere, but all those interviewed seemed to know this information.

Lastly there are noticeable differences in the quality of health facilities operated by the National Health Insurance Fund (NHIF) compared to those run by the State Ministry of Health (SMoH). NHIF facilities, which are used by those who are insured and those who can pay at a point of use, provide a wider health package. They are also cleaner, better organised, operate for longer hours and patients are better treated by the medical and administrative staff.

5.3 Quality satisfaction users prospective:

Most service users interviewed have no major complaints about the facilities they use. The interviewees generally indicated a sense of either satisfaction or accepting the status quo. When asked about the quality of the facilities they use and the service they get, many respondents either expressed satisfaction or gave a courteous answer. The following are some of the statements made by respondents when asked about their views of the quality of the health service and the facility they use: “It is a satisfactory service”, “It is a good service”, “Thank God, we are
lucky to have this service”, “They are doing their best and that is fine”, “This is better than nothing” and “We are better than many others in our area”.

5.4 Quality satisfaction from providers’ prospective:
Almost all interviewed health providers (medical and non-medical) are generally dissatisfied with the quality of the service they provide and the fact they are unable to provide adequate services for many people who cannot afford to pay. One male medical doctor in a rural hospital said: “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”.

In this regard there is a sense of helplessness among providers, because they face difficult situations every day, about which they feel they can do nothing. Medical staff, especially doctors, recounted many different situations in which they felt helpless, 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, prescribing cheaper drugs that are less effective because patients cannot afford the more expensive suitable ones, seeing patients discharging themselves from hospital because of the cost of staying longer, and delaying emergency procedures, tests and operations because patients and their family need time to raise the necessary funds.

The young doctors (house officers) were the most frustrated category of health care providers. When asked why he was not wearing a white coat or a badge, the young male doctor said “I receive 20 SDG (7 dollars) for my night shift and the hospital does not give me one, and with my salary it is enough that I come to work.”
As for ethical principles of privacy and confidentiality one young male medical registrar in a hospital said “People are illiterate. They have so many misconceptions about their illness, so I don’t waste time discussing diagnosis or treatment. They should listen to what the doctor says.” Another female ER doctor said, “The level of poverty and illiteracy [in the community] compromises our quality of service as I know that the patient will not understand if I explain his case, he will not be able to afford the medication which I prescribe. It is useless situation.” In smaller health facilities the providers seem to be more in touch with their patients, for example a middle-aged male medical assistant in a rural dispensary said “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.”

5.5 Quality of health providers from users’ perspective:

The findings indicated that users usually have both subjective and objective scales to assess quality of the provider of health services. From an objective perspective, providers were assessed by their patients along several criteria, including their follow-up, explanation, examination time spent and competence. A young man who had suffered a serious car accident and interviewed as an in-patient said: “I lay here in this hospital bed for two days. No doctor comes to check on me or tell me my status. My wife has to nag the nurse to come and change my dressing. “A young mother with a sick infant in a health centre said: “The doctor did not even look at my child he prescribed the medication after what I said”. A fifty-year-old man undergoing dialysis in the hospital said: “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 changes my Caniola.” Some of the users were more subjective in assessing quality of care by including aspects of kindness
and respect. A young, poor, pregnant woman at a health centre said: “The doctor is polite and nice. That is why I come here.” Another patient said: “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.” Hence, quality was based on characteristics of the care the provider provides, as well as how she or he was perceived as a person.

5.7 Accountability:
This issue was discussed in almost all the interviews, especially the ones with the key informants, though it was not part of the original guide. For instance, when we discussed issues of quality, this sentiment often came up: “If there were accountability things would have been better.” A male key informant in K locality said: “The whole health is based on a paternalistic system, where the MOH [Ministry of Health] is the father and the hospital managers are the children who won’t and can’t say no or [ask] why”. Another male facility manager said: “The cause of 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.” 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.” A Physically disabled young man pointed out.

Discussion and Recommendations
Several issues within the concept of quality merit discussion. The research used different tools to measure quality, including a detailed checklist, which was objective and quantifiable. Users and providers were also asked to relate their perception of the quality of health services available at the facility in in-depth
interviews. Using the data from the check list, one could identify serious gaps in the quality of services provided, such as: facility upkeep and equipment, procedures including waiting time and quality of providers.

Most rural facilities (health units and clinics) are very basic and do not offer most aspects of the primary health care package, as defined by the Sudan Ministry of Health. A typical rural health unit is operated by a health assistant with a basic education and a few months for training in the medical profession. Many rural health centres/clinics have no medical assistant or medical officer, no laboratory, no qualified midwife or any specialized child and mother health care, no vaccination service, no pharmacy and no day care beds.

The qualitative analysis of interviews with users and providers showed different aspects of quality assessment. From the users’ perceptions, ‘quality’ based on certain individual expectations, which are to be met by their providers. These included respect, compassion, kindness and competence. Differences were found among users, where by male, urban, educated and insured users have higher quality expectations and standards of the facilities and the providers. They are therefore highly critical and ready to openly complain about deficiencies in the service they receive. One should note that some users tried to avoid expressing their opinion about the service and the service providers. The exact reason behind this is not clear. However, the fact that local culture tends to equate criticism with gossip and demeaning others in their absence, and that all respondents were interviewed inside the health facilities may provide some explanation for this. The insured interviewees complained about the quality of care in the insurance dedicated services. Their complaints were about the comprehensiveness (or lack of
of the services, poor quality compared to the premium deducted from the salaries, and the complicated processes of referral.

The providers understand the existing gaps in the quality for health services. There is, however, a sense of apathy. But at the end of the day the providers considered themselves to be doing a lot, given the tough working circumstances. They believe it is better than providing nothing. The quality, if objectively assessed using WHO or even Federal MoH national standards, of almost all health facilities in the localities was very poor. There are also very serious shortages of qualified medical and administrative staff, especially in rural areas. Many providers also lacking training, suitable equipment and materials, even for their own personal health and safety. For example, in one health centre we found a senior health worker treating a bleeding young boy without using gloves or any other form of protection. In another facility we saw a medical assistant using his bare hands to check a woman with what seemed to be a serious skin illness.

Regarding accountability, the interviewees indicated that the lack of accountability is the cause of most of the failures of the health system. The users blamed the providers, the providers blamed the top management and decision makers, while the top managers blamed the government and the government blamed the users of the health system. This amounts to blaming the victim. Users, from the decision makers’ perspective, are abusing the system and not contributing enough. While from provider’s point of view, the whole system is lacking an accountability structure, and a proper reward/ punishment system.
**Recommendation to improve the services:**

As expected, users’ recommendations were patient-oriented, compared to the recommendation made by the providers, which were system oriented.

**Users’ recommendations:**

- The quality of health facilities should be improved, especially the waiting area and other services (water, toilets, ambulances, moving aides).
- The insurance for disabled people should be based on different terms, not like the mainstream one. Disabled people’s contribution should be waved.
- Free health services, inclusive of laboratory investigations.

**Providers’ recommendations:**

- Improve the work environment for providers, so they can excel in their job.
- Attractive incentives should be provided for attracting and retaining service providers.
- Build the capacity of the health system to accommodate the needs of all, with special consideration given to vulnerable groups.
- Improve information dissemination in the community, with the aim of increasing service utilization rates. Building the capacity of the current staff to provide better quality services and integrate quality standards into training.
- Provide free services to people in need.
- Build a management system that integrates issues of quality standards, monitoring, rewards and sanctions.

**Conclusions**

Improving the quality of care requires the ongoing monitoring of services and the integration of quality improvement strategies into management and delivery of
services. It will also be necessary to occasionally review the policy, standards and accreditation procedures themselves, in accordance with what is learnt from the quality improvement process.

SECTION VI: Relating the Policy Analysis with the Field Mapping Study:
The policy analysis undertaken in Work Package 2 included the development of a framework (Equiframe), including 21 core concepts and 12 vulnerable categories, to identify the inclusion of vulnerable populations and human rights concepts in health policies. In Sudan, 16 policy documents were analysed using the Equiframe. In chapter one of the Sudan policy analysis report, it is stated that main core concepts of privacy, contribution, liberty, integration, productivity, were never mentioned in Sudanese health policies. The other core concepts were mentioned with different frequency and elaboration in the health policies (WP2 Report 2010 P. 28).

The coming section will focus on the above five core concepts in an attempt to delineate the gaps between policy, as set out in the Equiframe analysis, and actual practices, as noted in the analysis presented in sections 1-5 above.

6.1 Core concepts: Comparing policy and practice
The top five occurring core concepts (CC) in the 16 policies analysed, were protection from harm (CC 7), prevention (CC 17), capacity building (CC 18), coordination of services (CC 6), and quality, respectively (CC 20). (For CC definitions please see the WP2 report on Equiframe, 2011)

6.1.1 Core concept 7: Protection from Harm
The policy documents indicated that the welfare of individuals should be protected, however no standards were seton how to actually enact this protection. Further,
no V.G was mentioned in particular, with the exception of women and children. In practice the WP3 findings indicated that the services did not include ways and standards to protect V.Gs. The services did not inform or educate the V.Gs about their rights or how to use health services, and how to protect themselves. The services did not provide information about what it meant to be a member of a vulnerable group, or what strategies could be used to overcome vulnerability. In addition, facilities in general lacked and visible information about the services they provided, had relatively short consultation sessions and were over crowded.

6.1.2 Core concept 17: Prevention
In accordance with the UN Economic and Social Council (2000), the right to prevention, treatment and control of diseases requires the formation of prevention and education programmes for behaviour-related health concerns, such as HIV/AIDS, and those negatively impacting sexual and reproductive health, such as education and gender equity.

The policy documents analysed state that preventive services are offered as part of a primary health package at primary health centres, secondary services through general hospitals and tertiary levels throughout specialized hospitals, and that those services are available for all individuals. The reality on the ground is that the only preventive service available at PHC levels is immunization. However, it is difficult to assess preventive service availability and accessibility to V.G, as there are not clear mechanisms for accessing the service or the referral system. For example, any patient can skip the PHC and go directly to specialized hospital or general hospital. Hence the system is based on individual preference, knowledge and ability to pay.
6.1.3 Core concept 18: Capacity building:
This core concept was mentioned in all 16 documents, and emphasis was placed on building the capacity of health workers including through training. However for a policy to achieve its preferred outcomes, the health care system must have the capacity to implement the policy, requiring sufficient resources (funding), a sufficient number of qualified individuals with pre-service or in-service education and experience to comprehend the policy goals and to apply state-of-the-art practices to secure those goals, effective organization and infrastructure, the ability to integrate services on an intra- and interagency/sector level, and the ability to establish partnerships among its professionals and administrators, as well as partnerships between them and the individuals and families they serve (Turnbull & Stowe, 2001). The WP3 facility checklist indicated deficiencies in training available for health professionals, as 60% of the sample said they have not received in-service training from the MoH. Further, most training packages are tailored for specific diseases and supported by WHO or UNICEF. For example, diseases of children under five, TB and HIV. For other vulnerable groups, no training was received by any of the 67 medical providers interviewed. Specifically, no training was provided in the areas of disability, sign language and mental health. No training was received on quality of care and quality standards for services.

6.1.4 Core concept 6: Coordination of Services
Each policy document analysed included a section on service coordination between agencies (federal and state levels). The core concept indicates that each professional in the system must be ability to work cooperatively with others, an ability derived from the interpersonal relationships that are established between health care workers, and between workers and patients, as well as the structural
mechanisms operating within and across service-delivery agencies, levels of government (local, state, and federal), and healthcare service systems (Turnbull & Stowe, 2001). However, the Sudan health system, as mentioned in section one, is complicated because each state has a minister of health under the federal ministry of health. Furthermore, the number one complaint from key informants and hospital managers is the lack of coordination and bureaucracy. The system is so complicated that it is no longer efficient. The state level minister depends financially on income from the health facilities themselves and from the state budget, which is determined by the governor and his cabinet.

6.1.5 Core Concept 20: Quality:
The UN Economic and Social Council (2000) affirms that health facilities, goods and services must be scientifically and medically appropriate and of good quality, necessitating skilled medical personnel, as well as scientifically approved and unexpired drugs and hospital equipment. Tamburlini (2004) asserts that quality of care is realized through delivery of effective interventions, competent staff, and appropriate supplies of equipment. The data collected indicated that there are serious shortages of supplies and staff. For example, in Umbada hospital there are 17 medical doctors for every 1000 patients. With regard to the quality of services for disabled people, Annex 1 shows the limited availability of services and equipment. Hence, quality as a concept is dependent on available resources and funding. This explains the differences identified between facilities operated under the MoH and those under the insurance companies. The current study did not include the private sector where there is a huge gap in quality of services compared to the public and health insurance funded facilities.
6.2 Vulnerable groups: Comparing Policy and Practice

As for the vulnerable groups; female headed households, ethnic minorities and those living far away from services were not mentioned in any of the 16 health policies analysed. The vulnerable groups clearly mentioned and identified in the policy documents are mothers and children under five (mentioned 56 times), youth (mentioned 32 times) and displaced persons (mentioned 16 times). Disabled persons were not identified as a special group for policy at the Ministry of Health.

6.3 Health Policies

The health policies surveyed related to malaria, TB, HIV/AIDS and Drugs. In total, eight sectoral policies received a low rating in reference to targeting vulnerable groups. (WP2 Report ibid p. 34). The Voluntary sector health policy did not integrate or adequately include the 12 VGs or the 21 core concepts. It was a generalized policy document emphasizing the role of the civil society sector in contributing to the general provision of health care (ibid p. 31).

The Private sector policy did not indicate special reference to any of the 12 VGs and made very limited reference to the core quality concepts, even though a substantial number of services are offered by that sector.

The National Health Policy, as an umbrella policy for all the other sections, draws from and builds on the 25-year health strategy and existing policies relating to reproductive health, child health, HIV/AIDS, the national drugs policy, the essential primary health care package and the 10-year human resources strategy. It also reiterates national and international commitments, such as the Alma-Ata Declaration, the Health-for-All Strategy, the Millennium Summit Declaration and other global strategies.
With regard to the core concepts, the most commonly occurring ones in the policy include prevention and amelioration, anti-discrimination, service coordination and collaboration, professional and system capacity building, and access. Whereas, the least mentioned included core concepts pertaining to quality of care, such as privacy and confidentiality, individualized appropriate services, accountability and quality. Also, amongst these are concepts related to individual empowerment, participation, productivity and contribution, indicating a weak focus on basic concepts of primary health care that are based on community participation and self-reliance.

On the other hand, concepts that are related to enabling the individual to have access to appropriate information were included, including specific policy actions to increase access to information. Such concepts include cultural responsiveness, professional and system capacity building, and protection from harm.

The health centres are mainly provided by the private or civil sector (NGOs / voluntary) which has no policy directives to give special attention to disabled people or any other vulnerable categories, nor to the quality of care core concepts. Consequently, the findings of the research indicated both a low quality of service and no special attention paid to meeting the needs of many of the vulnerable groups, especially disabled people.

Public Health Centres give low quality service and patients need to pay for it, though it is relatively less expensive than in private centres. They receive, consequently, lower quality services, in terms of the absence of laboratories for diagnosis, pharmacy to get drugs or, in most cases, no medical doctors, as the public health centres are mostly run by medical assistants.
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The Sudanese Association of the Deaf Report, 2010

The UN Economic and Social Council, 2000


UN Report, 1996


WHO Report, 1980
WHO Report, 2001


### ANNEX 1:

**SERVICES OFFERED AT MAIN HOSPITALS IN THE FOUR LOCALITIES**

<table>
<thead>
<tr>
<th>Service</th>
<th>Umbada</th>
<th>Rabak</th>
<th>Kasala</th>
<th>Sheikan</th>
</tr>
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</tr>
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### EQUIPMENT AVAILABLE AT MAIN HOSPITALS IN THE FOUR LOCALITIES

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<td>Dip sticks</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ophthalmoscope</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Weighing Scales (adult)</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Weighing Scales (infant)</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Weighing Scales (sit)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Emergency trolley</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ambu bag</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Oxygen</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Nebuliser</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Infusion kits for intravenous solution</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>ECG</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>X rays</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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</table>
### Devices Available at Main Hospitals in the Four Localities

<table>
<thead>
<tr>
<th>Device</th>
<th>Umbada</th>
<th>Rabak</th>
<th>Kasala</th>
<th>Sheikan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refrigerator</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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</table>

### Table of Devices

<table>
<thead>
<tr>
<th>Device</th>
<th>Umbada</th>
<th>Rabak</th>
<th>Kasala</th>
<th>Sheikan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchairs</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Wheelchair cushion</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
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<tr>
<td>Eye glasses</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Hearing aids</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Walking frames</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Crutches</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Walking stick</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Prosthesis</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Orthotics (leg/arm splints and braces)</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Continence devices</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Communication devices</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
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</table>
NUMBER OF (FULL TIME) POSITIONS CURRENTLY FILLED AT MAIN HOSPITALS IN THE FOUR LOCALITIES

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Umbada</th>
<th>Rabak</th>
<th>Kasala</th>
<th>Sheikan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>12 specialists and 40 House officers</td>
<td>15</td>
<td>27</td>
<td>45 Consultants, 12 Registrars, 54 Medical Officers, 120 House Officer,</td>
</tr>
<tr>
<td>Nurses</td>
<td>111</td>
<td>89</td>
<td>134</td>
<td>290</td>
</tr>
<tr>
<td>Midwives</td>
<td>4</td>
<td>4</td>
<td>Info Not available</td>
<td>10</td>
</tr>
<tr>
<td>Auxiliary nurses</td>
<td>19</td>
<td>NONE</td>
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<td></td>
</tr>
<tr>
<td>Pharmacists</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Pharmacy assistants</td>
<td>4</td>
<td>7</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Trained dispensers</td>
<td>Info Not available</td>
<td>NONE</td>
<td>1</td>
<td>None</td>
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<tr>
<td>Physiotherapists</td>
<td>NONE</td>
<td>NONE</td>
<td>3</td>
<td>Info Not available</td>
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<tr>
<td>Physiotherapy assistants</td>
<td>NONE</td>
<td>NONE</td>
<td>3</td>
<td>Info Not available</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>NONE</td>
<td>NONE</td>
<td>1</td>
<td>Info Not available</td>
</tr>
<tr>
<td>Occupational therapy assistance</td>
<td>NONE</td>
<td>NONE</td>
<td>1</td>
<td>None</td>
</tr>
<tr>
<td>Speech therapists</td>
<td>NONE</td>
<td>NONE</td>
<td>1</td>
<td>None</td>
</tr>
<tr>
<td>Audiologists</td>
<td>NONE</td>
<td>NONE</td>
<td>NONE</td>
<td>Info Not available</td>
</tr>
<tr>
<td>Rehabilitation workers</td>
<td>NONE</td>
<td>NONE</td>
<td>NONE</td>
<td>Info Not available</td>
</tr>
<tr>
<td>Traditional and faith healers</td>
<td>NONE</td>
<td>NONE</td>
<td>NONE</td>
<td>None</td>
</tr>
<tr>
<td>Profession</td>
<td>Number</td>
<td>Remaining</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>----------</td>
<td>-----------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managerial and administrative staff</td>
<td>37</td>
<td>7</td>
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<tr>
<td>Certified/registered HIV counselors</td>
<td>NONE</td>
<td>7</td>
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<tr>
<td>Trained HIV/AIDS counselor (any topics)</td>
<td>YES</td>
<td>NONE</td>
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<tr>
<td>Other counselors</td>
<td>NONE</td>
<td>NONE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutritionists</td>
<td>YES</td>
<td>Info Not available</td>
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<tr>
<td>Health management information system (HMIS) personnel</td>
<td>NONE</td>
<td>1</td>
<td>None</td>
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<tr>
<td>Community health workers</td>
<td>NONE</td>
<td>2</td>
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<tr>
<td>Laboratory technicians/technologists</td>
<td>1</td>
<td>14</td>
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<tr>
<td>Lab assistants</td>
<td>9</td>
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<tr>
<td>Social workers</td>
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<td>NONE</td>
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<tr>
<td>Porters</td>
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<td>Persons to assist patients with activity limitations</td>
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<tr>
<td>Housekeeping staff</td>
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<td>NONE</td>
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<tr>
<td>Kitchen staff</td>
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<td>5</td>
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</tr>
<tr>
<td>Maintenance staff</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No kitchen available