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**BARRIERS TO ACCESSING HEALTH  
CARE SERVICES FOR CHILDREN  
WITH DISABILITIES IN SOUTHERN  
AFRICA: THE CASE OF NAMIBIA**

## **ABSTRACT**

In developing countries there has been a reduction in infant and child mortality as a result of advancement in disease management and socio-economic developments. Within this survivor group are children with disabilities. Despite the high potential that adequate health care interventions hold for the improvements in quality of life for this vulnerable group, health care access has remained limited in many parts of southern Africa, Namibia included. This poor access to health care presents challenges to realizing the rights as envisaged by the United Nations Convention on the Rights of Persons with Disability and to the attainment of the health for all initiatives. In order to assist with improving the health outcomes of children with disabilities, this study was formulated to review the literature on the barriers to access which prevent children with disabilities from utilizing health services in southern African countries with a particular focus on Namibia.

The review found out that the barriers to access occur when the density of health care facilities is low and in settings where the transportation system, road networks and infrastructure is poor. Most of the studies under review further noted that even in cases where health services are well distributed and available other factors act as barriers to access. These factors include limited financial resources and poor quality of health services. Of paramount importance was the interplay between poverty and access to healthcare. With the analysis finding that use of health care services is rationalized on a cost benefit ratio.

Given the complexities of the challenges that children with disabilities face when accessing health care service, it is becoming essential to strengthen the human rights based approaches to ensure equitable access to health care services.

Key words: children with disabilities, health care access, barriers to access

### **ACKNOWLEDGEMENTS**

Firstly I would like to say I have lost a lot of people that I have loved dearly. I remember and thank my parents without whom I would not have had these ambitions and drive to excel. My amazing sister Margret, great friend, mentor, for her countless contributions to my general well-being, I thank her. She is incomparable and I miss her fiercely.

To my supervisor Bennedichte R. Olsen, thank you for your invaluable comments, and critical view throughout this work.

To my second eyes on this work Sattwick Dey Biswas and Jairous Miti, I am grateful!

I am grateful to the MIS class of 2012; you have become part of me and my family. Thank you for broadening my mind and making me experience the world in a whole new light. I will forever cherish the moments and encouragement you provided.

Finally I would like to thank the University of Oslo and Arkeshus, the lecturers, administrators and colloquium leaders for valuable information which has shaped my world view.

## ACRONYMS

ACFP	African Child policy Forum
ACRWC	African Charter on the Rights and Welfare of the Child
AU	African Union
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disability
GRN	Government Republic of Namibia
ICF	WHO International Classification of Functioning, Disability and Health
MOHSS	Ministry of Health and Social Services
NDP	National Development Plan
PHC	Primary Health care
PWD	Persons with disability
Sintef	<i>Stiftelsen for Industriell og Tegnisk Forskning</i>
WB	World Bank
WHO	World health Organization
UNDP	United Nations Development Program
UNDISTAT	United Nations statistics Division and its Disability statistics Database
UN-DESA	United Nations Department of Economic and Social Affairs
UNICEF	United Nations Children's Fund

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## CHAPTER 1: INTRODUCTION

### 1.1 Introduction

In low and middle income countries there has been a reduction in infant mortality, due in part to the socioeconomic developments and to the advanced management of diseases such as HIV/AIDS, tuberculosis, malaria and acute respiratory infections. With this reduction in infant mortality and morbidity there has been an increase in the number of children with developmental delay and disabilities (Scherzar *et al.* 2012). These trends create new demands on the healthcare services, which are very far from being met especially in the developing countries (WHO and WB 2011).

Despite the growing strength of human rights movement and the recent adoption of the United Nations Convention on the Rights of Persons with Disabilities<sup>1</sup> (CRPD), the right to health care for children with disabilities in southern Africa is yet to be realized. This calls for urgent social and health reforms to ensure equitable access to health care for children with disabilities. I argue that the health care needs of children with disabilities<sup>2</sup> should be given reinforced priority to ensure betterment to their quality of life. As such this thesis will review the barriers to accessing government-supported health care services for children with disabilities in southern African countries, with a particular focus on the case of Namibia.

### 1.2 Background

According to the World Report on Disability (2011) by World Health Organization (WHO) and The World Bank (WB), it is estimated that one billion people are living with some form of disability and of these 200 million are children. Most importantly, the report notes that people with disabilities are among the poorest of the poor, and do not have equal opportunities and equal access regarding employment, health and education. Consequently their rights are violated more so in low income countries and those living in the poorest quintile of the world's population. This means that disability is compounded by social disadvantage which may lead to a cycle of health inequalities and health disparities. The reality of the inequalities particularly for children with disability are depressing; almost all of

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<sup>1</sup>The UN CRPD was adopted on 13 December 2006, opened for state signature and ratification on 30 March 2007 and entered into force on 3 May 2008. Details can be viewed on [www.un.org/disabilities/](http://www.un.org/disabilities/).

<sup>2</sup>For purposes of this thesis children with disabilities will include all children with disability under the age of 18 years. It will be defined as limitations in mental and/or physical functions relative to age-specific norms that become apparent prenatally, perinatal or during infancy, childhood or adolescent. These limitations can affect one or more domains including cognition, movement, language, speech, hearing and vision.

the disabled children in developing countries do not attend school translating to low literacy levels; a third of the world's street children are living with some form of disability and social marginalization and limited access to social services (UN-DESA 2007, UNICEF 2008). Perhaps most relevant to this thesis, there is evidence that nine out of ten of children with disabilities will not survive past the age of 20 and the mortality rate for children with disability has been recorded as high as 80% in countries where the general mortality for under-five is 20% (UNICEF 2008). Not only are children with disabilities at a greater risk of impairments due to their low socio-economic status, but their right to health has been disregarded.

Although health care needs for persons with disabilities are similar to others, they however also require services which are specific to their impairments such as health related rehabilitation and appropriate specialist care (Scheer *et al.* 2003). Many children with disabilities suffer from associated health problems. Thus children with disabilities have a greater need for health care than the non-disabled population. However due to lack of appropriate services and the failure to use primary health care services they often utilize emergency room services more often than the non-disabled population (Drainoni *et al.* 2006). This translates to higher expenditures and catastrophic out-of-pocket<sup>3</sup> payments for persons with disabilities thus pushing them further into poverty. Of profound importance is the impact of barriers to access on the health outcome and quality of life for children with disabilities. The inadequate access to health care services presents a daunting challenge to the attainment of the health for all initiatives.

Several global health initiatives have continuously advocated for health equality for all, especially for the vulnerable members in the communities. The World Health Organization has been on the forefront advocating for equitable access to health care and the promotion of health equality. This is evidenced by its constitution of 1946 which states that everyone has the right to enjoy the highest attainable standard of physical, mental health and social well-being but at the same time should not merely be considered as the state of absence of disease

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<sup>3</sup> Out-of pocket health expenditures comprises self-reported payments for co-insurance and deductibles, payment of items not covered by insurance as well as cash payments for services and supplies such as medical consultation and prescription drugs. It has been noted that large out-of-pocket payments prevent access to health care services, affect health status and quality of life and leave little available resources for other household necessities (Hwang *et al.* 2001).



or infirmity (WHO 1946)<sup>4</sup>. And by the Alma Atta “Health for all” declaration of 1978<sup>5</sup>, which expresses the need by all governments to protect and promote the health of its entire people through Primary Health Care (PHC). Perhaps the most important development that has taken place over the last few years is the coming into effect of the UN CRPD (2006) which makes it clear that all persons with disability have the right to health. Article 25 and 26 of the CRPD highlight the role of the state in ensuring the right to health through specific elaborate provisions. This advent of the human rights perspective has brought a renewed focus on the health situation of persons with disabilities.

In turn most of the southern African countries have signed and ratified these conventions and have adopted legislation and policies<sup>6</sup> to remove the access barriers which prevent the utilization of primary health care services by the vulnerable social groups (Maulick and Darmstadt 2007, Mji et al. 2009). Notwithstanding these proactive and well intentioned move, people with disabilities still suffer from the double burden of disability and stigmatization thus remain the most marginalized group in any society, with their basic rights being violated (WHO and WB 2011).

### **1.3 Relevance of the study**

The choice of focusing on disability and provision of health care services is a result of my eight years of experience working with children with disabilities as an Occupational Therapist. Through my work as a clinical therapist in state hospitals (working in Zimbabwe and Namibia), I developed an understanding of the frustrations experienced by children and their parents/caregivers when accessing essential health care services. They face complex bureaucratic procedures to acquire the necessary health services to enable their children to lead a fulfilling life. These prejudiced attitudes and institutional constraints violate the human

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<sup>4</sup> Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Retrieve from: <http://www.who.int/about/definition/en/print.html>

<sup>5</sup> The Alma Atta declaration issued in September 1978 was the first international declaration which endorsed PHC as a public health initiative to remove health inequities. Retrieve from: [http://www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf)

<sup>6</sup> Malawi ratified the CRPD in 2009 and has the National Policy on Equalization of Opportunities for persons with Disabilities (2006); South Africa ratified the CRPD and the optional protocol in 2007 and has the Integrated National disability Strategy (2001); Mozambique ratified the CRPD 2012, and has The National Policy on Disability (1999) [only enacted after 2002, (Lang 2008)]. Retrieve from <http://african-decade.co.za/wp-content/uploads/2013/08/Study-on-Education-for-Children-with-Disabilities-in-Southern-Africa2.pdf>

rights of children with disability and limits their chances of being independent and contributing members of the society.

While the right to health has been recognized as a fundamental human right for all persons, this right is far from being realized in most southern African countries. Children with disabilities continuously face barriers to accessing health service. These access barriers have far reaching consequences on their lives such as; increased number of preventable impairments and disabling conditions, disempowerment, lack of the necessary social capital, lack of ability to assert rights and greater risk exposure to poor living conditions (UNICEF 2007, Groce *et al.* 2011a and UNICEF 2013). To facilitate redress of these inequalities, there is an urgent need to strengthen the importance of a right-based approach to health for children with disabilities.

The UN CRPD (2006) defines discrimination on the basis of disability as;

“any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others of all human rights and fundamental freedoms in the in the political, economic, social, cultural, civil or any other field” (UN 2006, 4).

These discrimination stem from cultural and societal perceptions that do not regard them as fully human or right holders rather they are regarded as objects of charity. This is also reinforced by government and developmental policies that ignore, exclude, and are inaccessible or unsupportive of the rights of children with disabilities. This exclusionary practices lead to loss of productive capacity in later years and perpetuates the negative stereotypes attached to persons with disability (Parnes *et al.* 2009).

For children with disabilities having access to health care that treats their condition when the need arises, that prevents them from having a disease, and that promotes and maintains their health is a fundamental right. The right to health encompasses the right to medical treatment, access to safe drinking water, education, proper nutrition and other underlying determinants of health. It also includes certain freedoms such as the right to be free from discrimination and involuntary medical treatment, and entitlements such as the right to primary health care. Furthermore it includes certain entitlements such as equal and timely access to health services and that all services must be available in good quality, acceptable, accessible and affordable (Whitehead and Dahlgren 2006).

Despite being vulnerable to developmental risks, there is a lack of research and knowledge about the plight of children with disabilities with regards to prevalence and patterns of health conditions, disability specific strategies and policy-relevant research on best practices to improve health and functioning. It should also be noted that none of the Millennium development goals (MDG)<sup>7</sup> specifically mention disability. There is therefore a need to have a coherent understanding of the attitudes, laws and policies, household resources and the standard of services which prevent children with disabilities from accessing government-supported health care services.

It was against this backdrop that this thesis was formulated. It seeks to contribute to a better understanding of the barriers to accessing government-supported health care services for children with disabilities, with a particular focus on Namibia. Since the socio-economic conditions of most of the southern African countries are relatively similar, the review will include barriers to access as noted in these countries as this is also applicable to the case of Namibia. The thesis will provide a comprehensive but not complete answer to all the questions raised but hope that it will lead to further research in the area.

#### **1.4 Research question**

This study purposed to explore the barriers to accessing government supported health care services for children with disabilities. The research question guiding this thesis will be;

*“What are the barriers to accessing health care services by children with disabilities in southern African countries, and of what relevance are these to Namibia?”*

In order to comprehensively assess these barriers, the objectives of this thesis will explore the existing legislation, policies and international instruments as they relate to persons with disability in Namibia and most importantly to children with disabilities. It further seeks to analyze any potential gaps in terms of service provision with regards to health services

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<sup>7</sup> The MDG's are a series of time-bound measurable commitments for tackling poverty, gender discrimination, hunger, disease and illiteracy which are intended to be met by 2015 (Lindstrand et al. 2006). These have been criticized for not specifically mentioning disability and its impact on the goals. Overlooking the needs of persons with disabilities or not investing in programs that directly influence their well being is one form of exclusion. However in 2010 the general UN assembly adopted a resolution recognizing that policies and their implantation must also focus on persons with disabilities to reach the goals of poverty alleviation (WHO and WB, 2011).

## **1.5 Structure of the thesis**

The thesis is divided into six sections that aim to contribute to the understanding of the aims and objectives of the thesis. Following this section 1 the thesis is structured as follows; the second section has the methodology of the thesis it includes the methods undertaken to analyze the literature and the theoretical frameworks, which underpin disability, health and poverty. The theoretical basis contains definitions of disability and how the models of disability affect health care systems; another subsection focuses on how disability is a human rights issue and the last section the inter-linkages between poverty and disability. This was done to understand more on how disability, health and human rights are interlinked. The third section covers the Namibian context, the disability legislation and how the health care system is structured. The fourth section contains the results from the literature review. The fifth section will cover the analysis of the thesis; it explores how the barriers to access relate to the case of Namibia and the explanations thereof. The last section will be the discussion and conclusions of the thesis.

## **CHAPTER 2: METHODOLOGY**

### **2.1 Methods**

This is a literature review study. A critical review was used to explore why children with disabilities are not benefiting from the policies and strategies put in place to tackle the barriers when accessing health care services. The absence of a consensus on the definition of disability does not allow for a systematic evaluation of the literature rather a critical review will be used (Grant and Booth, 2009 cited in Groce *et al.* 2011). Thus the Critical theorist approach will be used to analyze the literature. This theory will provide a means of analyzing the texts gathered which is an important part for this research. According to Horkheimer a critical theory seeks to create self awareness of the subjects and to change the situation .Critical theory views disability as a product of an unequal society and that contextual and ideological orientations places barriers and exclusion criteria which limit participation by disabled persons in activities of daily living (Oliver 1998, Burghardt 2011). This theory is used to analyze historical injustices (provide knowledge of social inequalities), to answer questions which might not have been asked, and to articulate ways of social justice through policy and legislation (Burghardt 2011). Critical theorists argue that disability is a question of power and context. Power with regards to who and what gets prioritized and who and what gets

marginalized. Therefore critical theorists link the solution to removing barriers to social action and change by those who have power.

### **2.1.1 Eligibility criteria**

An extensive search of the different search engines was used to collect articles in the English language literature on the health situation of children with disabilities in Southern Africa and Namibia in particular. It is however important to stress that available literature on children with disabilities in Namibia is scarce. Studies which focused on health issues for children with disabilities, and on persons with disabilities which had children as participants were included in the review. Inclusion criterion included articles published from the 1990's; articles which were published from reputable journals; working papers from reputable international organizations; and from commissioned country reports.

### **2.1.2 Literature search strategy**

In the course of this review online databases were searched for relevant articles using specific search strategies. The databases included Google scholar, EBSCOR, and BIBSYS paying particular attention to articles related to health, healthcare services and health outcomes as related to children with disabilities. In addition, white papers and grey literature were also reviewed with particular attention paid to publications from major multilateral organizations such as the UN, bilateral organizations, NGO's and Disabled Persons Organizations websites. The terms used to search for articles was, "*children with disability*", "*persons with disability*", "*health care access*", "*health equity*", "*health inequality*", "*health disparities*", "*vulnerable groups*", "*poverty*", "*southern Africa*" and the specific countries. The terms health equity, health inequality and health disparities are interchangeable terms found within the health discourse. The term "*poverty*" was also used in searching for literature since there is a wide acknowledgement that disability, health and poverty are interconnected. Emphasis was placed on articles that researched on disabilities in a broader sense rather than actual impairments.

All the articles identified by these searches were screened for relevancy by reading the abstracts. Electronic or hard copies of the articles that mentioned childhood disability and healthcare access were obtained and a snowballing hand search was performed of reference lists in selected articles to identify any other study that met the inclusion criteria. Intent was

on covering the broad themes of access barriers to healthcare services and not to present a focused systematic review designed to answer a specific question.

Each full article was further screened to ascertain relevance to the thesis aims and objectives.

### **2.1.3 Data analysis**

Data was extracted from these articles and combined for this thesis. A self-developed data extraction table was used to categorize data from these studies, using a criterion that was designed prior to the review. The data extraction form was designed to extract information such as the author, date, area of study, the type of study design and aims of the study.

Information that pertained to the reviews aims and objectives was coded manually by highlighting significant patterns in the data. This shed light on the dominant research areas and allowed for the categorization of the access barriers. A full analysis of the data extracted is illustrated in appendix 1.

### **2.1.4 Limitations of the study**

There are a number of limitations which are inherent in this thesis. One major limitation is that relatively few scholarly/scientific articles are available in the context of children with disability and access to health care in Namibia. Therefore the thesis will base its findings on results found in studies which had a combination of adults and children as respondents.

Further it will use studies conducted in other southern African countries to analyze the barriers to access as they relate to Namibia.

The study focused on children with disabilities covering a wide spectrum of impairments. This is a limitation since disability is a heterogeneous and diverse phenomenon. A barrier experienced by children with a certain type of impairment might not act as a barrier to a child with a different type of impairment. Thus a person with mobility problems and using a wheelchair may have difficulty accessing a building with a narrow doorway but a person with mental illness might not have problems in entering the doorway but will experience the shame and stigma associated with disability thus may not use the service. Due to limited research all impairments were included for this study though choosing a single impairment would have been more specific and comprehensive.

## **2.2 Conceptual frameworks**

The following conceptual frameworks were used to understand the policy climate and to analyze the literature.

### **2.2.1 Conceptualization of disability, health and functioning**

The word disability is difficult to define. It is a relative, complex term and is subject to a variety of interpretations depending on the perceptions being used, the different classifications and the cultural and national contexts<sup>8</sup> (Loeb *et al.* 2008). The medical model, social model and more recently the bio-psychosocial model are tools used for defining disability and they affect how health systems respond to issues affecting persons with disability. How these models affect health and disability policy will be described in this section.

Historically disability was viewed using the medical model which views disability as a pathology, impairment, or capacity limitation thus falling within an individual model. It viewed disability as an aspect that could be evaluated, defined and diagnosed. With this model the focus of health care was to compensate persons with disability for their loss, or adjustment through medical intervention and rehabilitation (Shakespeare and Watson 2002). This perspective of disability together with negative attitudes viewed disabled people as second-class citizens or charity who needed to be taken care of.

Activism and lobbying by disabled peoples organizations (DPO), civil society and the limitations which were inherent in the medical model gave rise to the social model of disability. The social model theorists argue that disability is due to systematic exclusion, marginalization, oppression and discrimination of persons with disability by the society. These barriers inherent in the society prevent the active participation of people with disabilities in their communities. Therefore inclusion of persons with disabilities is about removing the barriers (Shakespeare and Watson 2002). It delineates between impairment and disability and views disability as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social barriers. The view is liberating for persons with disability since the problem lies in the society and it also paved a way for a political strategy to remove barriers to access thus working

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<sup>8</sup> The definition adopted by the National Policy of Disability in Namibia states that "disability is the loss or limitation of opportunities to take part in the everyday life of the community on equal level with others due to physical and social barriers" (GRN 1997, 1). This definition closely follows the definition by WHO in an earlier version of the ICF, which was the International Classification of Impairment Disability and Health (ICIDH). Like the ICF it recognises the environment as a possible facilitator or barrier for persons with disability.

towards social justice. Policy responses would for example focus on universal design to make buildings more accessible (Loeb *et al.* 2008). However disability should not be viewed as purely medical or social as it encompasses both the health condition and contextual factors. It should be conceptualized as a process involving the person, environment, activity limitations and restrictions in social participation.

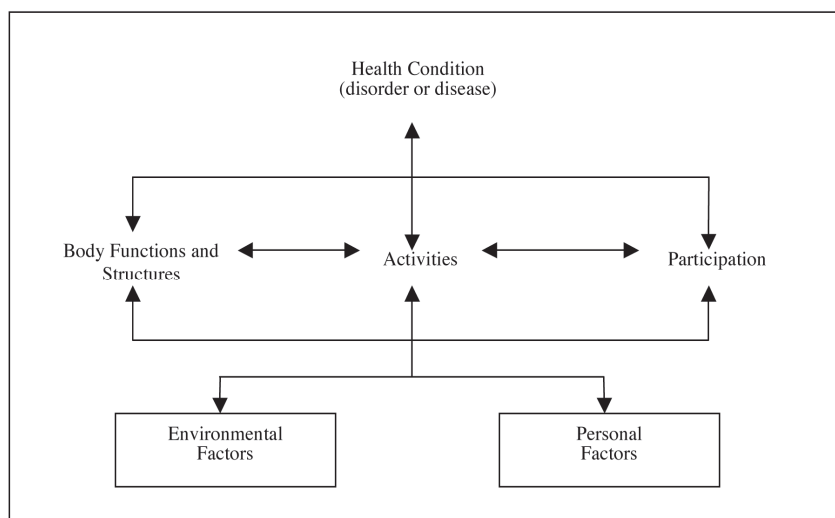


Figure 1: The international classification of disability health and function. Source WHO and WB 2011, 5.

This view is well captured by the WHO International Classification of Function, Disability and Health model (ICF) of 2001, often called the bio-psychosocial model. The ICF is a balance between the social and medical model and it is diagrammatically represented as figure 1 above. The ICF understands disability as a multidimensional concept with the interaction between the health condition (diseases, disorders and injuries) and contextual factors (both personal and environmental). Personal factors include sex, age, coping mechanisms, educational background and behavioral characteristics, while environmental factors include social attitudes, architectural design, climate and terrain. The ICF acknowledges that disability arises from three areas these are impairments (problems in body functioning), activity limitations (difficulties in performing a task) and participation restrictions (problems which arise from discrimination) (WHO and WB 2011). Thus it gives equal emphasis to all factors that impact on health and functioning. In addition it also provides a platform for regarding persons with disability as equal citizens with equal entitlements to life which is the human right for every individual.



### **2.2.2 The barriers to access**

Access to health care services is a major health and developmental goal the world over. It is concerned with allowing persons with health problems to seek health care resources in order to preserve their health or promote it (Gulliford *et al.* 2002). Access has been defined as “the use of services relative to the actual need for care; lack of access occurs when there is a need for services and those services are not utilized” (Aday 1975 cited in Scheer *et al.* 2003, 221). Penchasky and Thomas (1981) cited by Wyszewiansk (2002) gave a broad concept to access describing it as the fit between the characteristics and expectations of the service providers and the service user. This fit has five main core components which are availability, accessibility, accommodation, acceptability and affordability. In addition Gulliford and colleagues (2002), further use the term utilization as a proxy to access, which is dependent on affordability, physical accessibility and acceptability of the services.

“Barriers to access are those factors that contribute to preventing a person from utilizing the available services when needed” (Scheer *et al.* 2003, 221). These barriers can be broadly categorised under environmental, structural and process barriers. Environmental barriers have been well described by the ICF (see section above) these include social attitudes, architectural design, climate and terrain (WHO and WB 2011). Transportation barriers, such as access to public transportation, publicly funded ambulance system, and private transport are also included under environmental barriers (Smith 2008). Structural barriers are barriers due to financial limitations and they denote the ability to pay for services such as medical rehabilitation services; high-quality, well-fitted, and functional durable medical equipment and repair of these (Smith 2008).

Process barriers are difficulties inherent in the delivery of service. It includes provider knowledge, timeliness of service, communication between the provider and the user, receipt of preventative care and scheduling of appointments (Scheer 2003, Drainoni *et al.* 2006). Communication is important especially in family- or patient- centered management. Effective communication is communication that is understood by both the health worker and the service user. Barriers to access due to communication is a result of language differences and cultural differences which affect one’s understanding and perception of words. When there is a communication barrier the provision of health care proceeds with errors, poor quality and risks to patient safety (Schyve 2007).

### **2.2.3 The vicious cycle between poverty, disability and health?**

In order to alleviate the barriers to access experienced by persons with disability it is important to acknowledge the link between poverty, disability and ill health. Poverty is both a cause and consequence of disability due in part to the mutually reinforcing nature of the two. It is commonly understood that persons with disability are more likely to be poor and that poverty may accentuate the likelihood of getting a disability. Poverty is embedded in structural imbalances that perpetuate exclusion, marginalization and isolation. This causes deprivation on the economic, political and societal levels of human functioning. Several scholars (Elwan 1999, Yeo 2001, Yeo and Moore 2003, Trani and Loeb 2010, Mitra *et al.* 2012) have established a firm evidence base which has established that the socioeconomic status of persons with disabilities is much worse than that of the non-disabled particularly in low income countries. Widely referenced statistics from the WB has shown that 15-20% of the world's poorest are persons with disability. However these regular citations have been criticized for not standing up to rigorous analysis (Groce *et al.* 2011b)<sup>9</sup>.

Disability leads to poverty due to a number of interdependent exclusionary processes. It is associated with high illiteracy rates, high unemployment and under employment, malnutrition, lower immunization coverage and less occupational mobility. Persons with disability are also especially vulnerable to the extra costs of having a disability for example transportation, assistive technology and home health care or caregivers (Groce *et al.* 2011b). In this respect, poverty has influenced access to health services which ultimately leads to persons with disability having poorer health. To overcome poverty by persons with disability the UN CRPD (2006) has also acknowledged costs associated with disability in article 28 and it obliges governments to honor the rights of persons with disability to proper housing, food, clothing and decent living standard by assisting with costs through social protection measures. In reverse, poverty may also lead to a disability, since it is linked to other health conditions that may cause impairments such as low birth weight, poor sanitation, malnutrition, poor working conditions and substandard housing. For instance malaria which is a linked to poor water management and housing can lead to preventable impairments (Groce *et al.* 2011b, WHO and WB 2011).

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<sup>9</sup> According to Strauss 2007 cited in the article by Groce and colleagues (2011b), he refers to the evidence base of the interaction between poverty, disability and health as 'evidence by citation'. These frequent citations of previous publications have misled scholars to associate the interaction between poverty and disability.

Data from low income countries Lesotho (Kamaleri and Eide 2011), Mozambique (Eide and Kamaleri 2009), Zambia (Loeb and Eide, 2006), Malawi (Eide and Loeb 2004), Namibia (Eide *et al.* 2003a) and Zimbabwe (Eide *et al.* 2003b) have shown that persons with disability in low income countries are poorer in terms of monetary consumption (consumption expenditure) and in terms of non-monetary aspects of living standards such as access to basic social services both at household and at the individual level. Their experience is compounded by environmental/physical and institutional barriers which also limit persons with disability participation in civil and political issues which concern poverty reduction and poverty alleviation. In a review of these data Eide and Ingstad (2013), have however called for a more rigorous analysis to exclude other factors that may influence the disability poverty nexus. A study by Muderedzi and Ingstad (2011) cited in this review, is a step towards explaining the poverty-disability nexus as it describes and analyses how the political and structural forces which violate basic human rights in Zimbabwe are responsible for perpetuating poverty in people with disability more so in children with disabilities.

#### **2.2.4 Human rights and Persons with Disability**

It is a recognized fact that health and human rights are interlinked. There is wide acknowledgement that health is a precondition for achieving full and equal opportunities, enjoying human rights and living in dignity. Health access is a fundamental requirement for the advancement of human rights (WHO and WB 2011). Lack of access to adequate health care increases vulnerability to preventable and infectious diseases, increases secondary co-morbidities and further isolates and excludes them (Mji *et al.* 2009). It is therefore imperative that society organizes its health services equitably so that access to the resources is available to all.

There are a number of international and regional conventions that have been adopted to oblige signatory states to uphold the rights of persons with disabilities<sup>10</sup>. These conventions pay attention to disability based discrimination through their various instruments. They are based on the principle of equality for the achievement of full participation of persons with disability

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<sup>10</sup> These disability specific instruments include the Declaration on the Rights of Disabled Persons; World Programme of Action Concerning Disabled persons (1982); the Standard Rules on the Equalization of Opportunities for persons with Disabilities (1993); the African Charter on the Rights and Welfare of the Child (1999) and the UN CRPD. These instruments except the CRPD are declarations, resolutions and normative guidelines adopted to guide the states in mainstreaming and the inclusion of persons with disability in the society (WHO and WB 2011). Namibia is a signatory to these conventions (Lang 2008) and this has important implications for children with disabilities.

in all aspects of social, political and economic life. More specifically the African Charter on the Rights and Welfare of the Child (ACRWC 1999), the Convention on the Rights of the Child (CRC 1989) and the CRPD (2006) all contain articles which highlight the rights of children with disabilities. Under these conventions all children have the same right to the highest attainable health and the best interest of the child is of primary consideration. The ACRWC (Article 13) and the CRPD (article 7) specifically mention the rights of children with disabilities which should be accorded the same as the non-disabled child (ACRW 1999, CRPD 2006).

Similarly the CRC (1989) contains two articles which specifically mention children with disabilities-Article 2 and Article 23. Article 2 has elements of non-discrimination as a general principle and obliges states to provide inclusive services without discrimination to children with disabilities. Article 23 is comprehensive in its statements for the rights of the child. It encompasses children with disabilities rights to a life of dignity, the provision of services such as health care which must be provided free of charge according to available resources, and the dissemination of evidence based treatments for the prevention of disabilities.

Furthermore in terms of health care provisions the ACRW (article 14) and the CRPD (article 25 and 26) highlight the role of the state in ensuring the right to health through specific elaborate provisions (ACRW 1999, CRPD 2006). The CRPD (2006) obliges states to make accessible medical, rehabilitation and social services for persons with disability including early identification and intervention. And that these services must be available in the people's communities, including the rural areas. Under the principle on non-discrimination it states that health service providers must not deny care on the basis of disability and that health and life insurance should be provided on an equal and fair basis. It further states as the aim of habilitation and rehabilitation as to attain the highest possible independence and the provision of assistive and orthopedic devices. Thus under these conventions society and the government are obliged to ensure that barriers that prevent persons with disability from enjoying their full rights are removed.

## **CHAPTER 3: THE PRESENTATION OF NAMIBIA**

In order to understand the nature of disability in Namibia it is important to take into account the socioeconomic and political status of the country which gives rise to the health care system. The development challenges being faced by the country are a result of a combination of factors, among which are; the geographical factors, the demographic factors, the legacy of the colonial and apartheid system and public policy options. These will be elaborated in the section below.

### **3.1 The national context, people and culture**

Namibia is a vast country located in the south-western part of Africa; with an area spanning more than 800 000 square kilometer, it is considered one of the largest countries in the region. The preliminary results of the Namibian Population and Housing census of 2011 estimated the population to be just over 2 million inhabitants and these are sparsely dispersed over the regions. It is sparsely populated with its inhabitants spread over a wide area, often beyond the reach of road infrastructure and basic services. This is due to the fact that large parts of the country are inhabitable due to the irregular rainfalls and fluctuating temperatures (GRN 2012, WB 2013). Geographically Namibia is characterized by three physical regions: a low lying coastal belt largely made up by the Namib desert along the western parts bordering the Atlantic ocean; a central plateau; and, the Kalahari desert along the eastern border(AHO undated).

Despite its small population Namibia has a diversity of ethnic groups including Afrikaners, Basters, Coloured, Damaras, Germans, Hereros, Namas, Ovambos, Sans, Tswanas and others. With more than 30 Bantu, Khoisan and Indo-European languages spoken in the country, this brings much diversity to the population in terms of culture, religion, and traditions. English is the official language (ibid). In addition you will come to realize that the Bantu and Khoisan languages have several dialects, as people used to live far away from each other each tribe developed its own dialect.

### **The legacy of apartheid**

Namibia has a colonial history. Formerly referred to as South West Africa, Namibia was at first colonized by Germany between 1845 and 1915 and later it was colonized by South Africa. It gained its independence from South Africa in 1990 bringing an end to more than a

century of colonial rule (Lang 2008). The administration neglect, military rule and population distortion pre-independence brought a lot of hardships and suffering to the majority of the population especially so the Northern parts of Namibia which is home to two thirds of the population. As was in the apartheid state of South Africa, there were racial and ethnic divisions which meant that different communities were segregated geographically, economically and socially. After independence the nationalist party South West African People's Organisation (SWAPO) adopted a policy of reconciliation as was the case of most of the countries in the southern part of Africa. This policy has been hailed as political maturity by many international bodies. However the reconciliation policy has benefited only a few, it has been said to entrench and maintain the status quo of the pre-independence gains by the minority and thus legitimizing patterns of social differentiation that had ensued in the colonial era (Tapscott 1993). From general observations these inequalities are more evident in the sprawling informal township in the northern and north-western areas of Windhoek which are characterized by small tin houses and poverty. Although some households in these informal areas have access to electricity and to safe water, communal taps are within considerable walking distance and few households are connected to a sewerage network. And a contrasting picture is evidenced by just a twenty minute drive towards the East of Windhoek where the affluent community resides, characterized by plush homes.

As of 2008, The World Bank has placed Namibia as an upper middle income country. The economy is very vibrant and growing, with a gross domestic product of \$US 13.07 billion and a gross domestic product growth at approximately 5%. However because of the extreme levels of inequality and poverty, these figures are particularly deceptive measures of welfare. The poverty levels and vulnerability is somewhat similar to other African countries; a high poverty incidence in the rural areas; sharp urban-rural income differences; and a high prevalence of female headed households (Subbarao1999). Namibia has further been ranked as one of the most unequal societies in the world as evidenced by its ranking in the Human Development Index (HDI) and the high Gini coefficient<sup>11</sup> of 0.5971. According to the recent ranking by UNDP (2013), it has been ranked 128 out of the 187 countries surveyed in the HDI of 2012. The HDI is an indicator of society's welfare as measured by composite index that includes Gross Domestic Product, life expectancy and education (WB 2013).

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<sup>11</sup>The Gini coefficient of inequality is a measure of deviation of income or wealthy inequality among individuals or households in a country. The absence of inequality is represented by 0, this is referred to as perfect equality and 1 or (100%) represents complete inequalities. It is an important dimension as a welfare measure, where welfare is considered as relative poverty (WB, 2008).

## **Existing challenges**

Although the government has made progress in alleviating poverty and providing access to education, good sanitation and health care services, a lot of developmental challenges are still encountered which ultimately impact on the health of children. In Namibia malnutrition is major underlying cause of illnesses and death in children under the age of 5 years. According to reports a third of the children are stunted or too short for their age. The prevalence of stunting is higher among rural children which is 31% compared to that in the urban areas which is lower by 7%. Regional variation in the number of children who are malnourished exist (MOHSS and Macro International 2008, MOHSS 2011). These figures are of concern since disability can also lead to nutritional problems as children with disabilities often have feeding and swallowing difficulties.

### **3.2 Situational analysis of disability in Namibia**

Disability is not only endemic to Namibia but it is a global phenomena affecting more than a billion of the population. WHO estimates that 80% of these are living in developing countries (UNICEF 2013). Whilst there is limited research on the quality of life for persons with disabilities in Africa, there is even less research on children as a specific group of persons with disability. This has been attributed partly to the difficulties in counting the health situation when there are limited public health and community infrastructures for pediatric patients, the hidden nature of disability in children, and the little attention which is given to disability by development agencies in populations where child mortality rates are still in excess (Parnes *et al.* 2009). This invisibility means that fundamental issues affecting children with disabilities have been neglected.

### **Prevalence of disability**

The Namibian housing and population census of 2001 surveyed six types of disabilities and these were, blindness, deaf, impairment of the hands, impairment of the legs, impaired speech and mentally disabled/mentally ill. Based on the categories used, 35% of those disabled are blind, 24% have an impairment of the legs, 21.4% are deaf, 13% have an impairment of the hands and 11.4% have an impairment of speech. The results further show that 5% of the Namibian population is disabled and most live in the rural areas (GRN 2003). However the living conditions study done by *Stiftelsen for Industriell og Tegnisk Forskning* (Sintef)

estimated the prevalence rate to be 1.6% of the total population<sup>12</sup>. These differences in prevalence have been attributed to; the definition of disability used, the data collection method, quality of survey method and to issues of shame and social stigma attached to persons with disability in the developing countries (UNICEF 2008, Loeb *et al.* 2008). This means that that most statistics for disability in developing countries are inaccurate, incomplete and biased towards those individuals with obvious physical and mental disabilities and exclude those with hidden disabilities. The lack of reliable statistics in Namibia, as in most southern African countries has resulted in the plight of people with disabilities being ignored in the development arena (Banda-Chalwe 2012), with governments lacking a sense of urgency to accommodate the daily needs of persons with disability.

### **Living conditions of persons with disability**

Surveys on the living conditions of persons with disability which were done by Sintef in collaboration with local universities and disabled peoples organisations in these southern Africa countries; Lesotho (Kamaler and Eide 2011); Mozambique (Eide and Kamaleri 2011); Zambia (Loeb and Eide 2006); Malawi (Eide and Loeb 2004); Namibia (Eide *et al.* 2003a) and Zimbabwe (Eide *et al.* 2003b), have shown disparities between persons with disability and the non-disabled when accessing education and healthcare services- among other things. According to the survey results for Namibia, the proportion of persons with disability who had never attended school was twice as high compared to the non disabled. Unemployment both among the disabled and the non-disabled was also noted to be very high, nine out of ten persons with disability reported that there were not formally employed compared to eight out of ten of the non-disabled. On household level more than half of the households surveyed which had a person with disability reported that no one was working compared to just under five percent of households without anyone who has a disability (Eide *et al.* 2003a).

These surveys on living conditions further assessed nine services and these were health services, welfare services, assistive devices services, medical rehabilitation services, counseling for parents, counseling for persons with disability, educational services, vocational services, and traditional healing. These were assessed whether the disabled person was aware of the services being offered in the country, and determine whether they had used the services and if they needed the said service. The compilers of the report found out that there were gaps

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<sup>12</sup> Both these surveys do not cite separate data for children with disabilities.



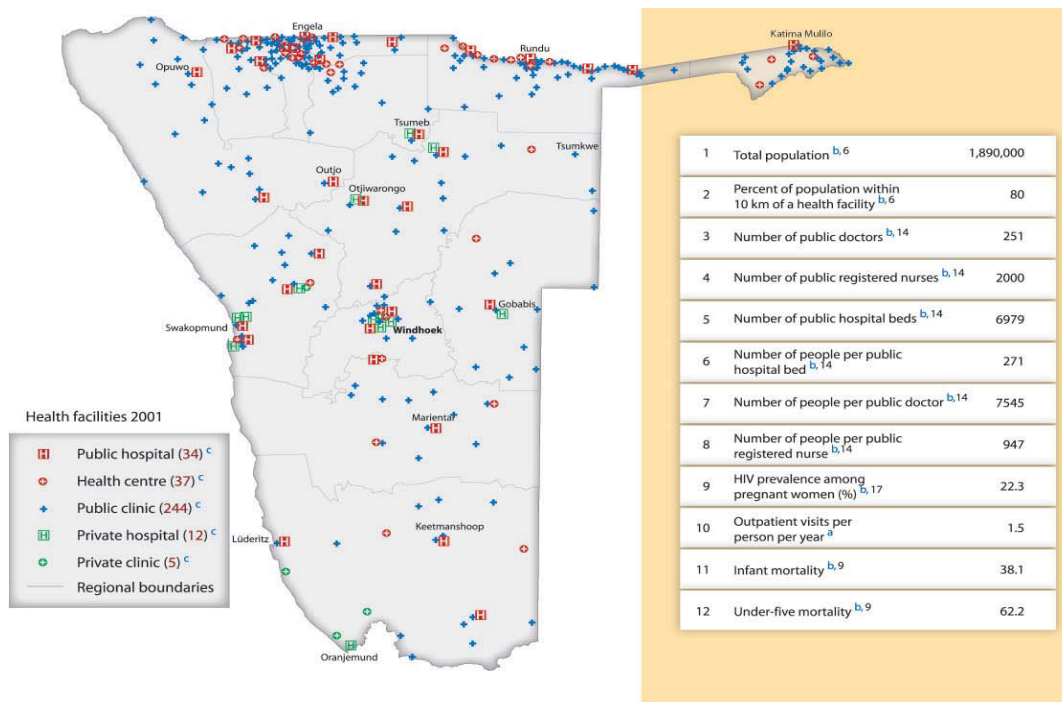
between needing a service and utilizing the required service even in cases where persons with disabilities were not aware of the service.

### **3.3 Understanding Namibia's health care system**

The Ministry of Health and Social Services (MOHSS) is the main implementer and provider of public health services in the country. Namibia inherited a health system typical of colonial Africa, with services centrally located in urban areas and few services in the rural areas. The apartheid system also influenced the health care system in terms of health care models, accessibility and the disparate nature of health care provisions. With the attainment of independence in 1990 the health care provisions are now based on the Primary health Care (PHC) approach which tackles the main health problems in the community and includes promotion, preventive, curative and rehabilitation services in collaboration with different partners and sectors.

The PHC is backed by equity oriented health policies which are based on the country's Vision 2030; this is a long term strategy document for every sector in the country. Vision 2030 advocates health for all by the year 2030 where the people are protected from diseases and become contributing members of the society (GRN 2004). The same concepts and values are adopted by the national health policy- Towards achieving Health and Social Wellbeing for all Namibians of 1998. These frameworks aim to achieve equitable, accessible, affordable and sustainable healthcare for all Namibians through 5 year national development plans (NDP) and it is currently implementing NDP4 (GRN 2003, MOHSS 2011).

Image 1 below is a map illustration of the distribution of the health centers in Namibia as of 2001 and lists the health personnel for the whole country. As is evident on the map, most rural households are likely to be near a clinic than urban households and urban households are more likely to be near a hospital than a rural household. It also shows that a large number of clinics are situated in the northern parts of the country which are also areas of high population density. It should be noted that these clinics only provide basic medical services and rarely no specialist services are available and the residents have to resort to travelling long distances when there is a need. However outreach rehabilitation services and community based rehabilitation is available in some regions of the country (MOHSS 2006). Although these services are based on availability of funds they are a welcome alternative for most families with children with disabilities.



**Image 1:** Map illustration of the distribution of health centers in Namibia and tabulation of health personnel. Source: Obeid *et al.* 2001, 13

In terms of health expenditure, Namibia's total health expenditure as percentage of GDP for 2006/2007 was 8.3% and as percentage of total government spending it was 12.2%. Like most of its neighboring countries this figure falls short of the Abuja declaration<sup>13</sup> made by African leaders to allocate 15% of total government spending to healthcare (MOHSS and Macro International 2008, MOHSS 2011, WB 2013). Despite this relatively high expenditure in health it has proven difficult for the government to reverse the effects of under-investments for the majority of people which existed prior independence. There are still stark inequalities in the provision of health services in the country, characterized by the public and the non-profit health care system serving 85% of the population who are usually in the low income groups and 15% of the high and middle income population being served by the for-profit private sector (AHO undated).

<sup>13</sup> The African Union countries met in Abuja Nigeria in 2001 and pledged to increase health care spending to 15% of total expenditures. Retrieve declaration from: [http://www.who.int/healthsystems/publications/abuja\\_declaration/en/](http://www.who.int/healthsystems/publications/abuja_declaration/en/)

### **3.4 Strategy for implementation of disability related issues**

#### **The Namibian constitution**

Over the past decades the Namibian government has put up several initiatives to tackle the barriers and inadequate service provisions faced by its people through legislation and policies. The Namibian constitution has fundamental principles based on integration and non-discrimination and the rights of persons with disability are included under these umbrella principles. The Namibian constitution article 10, states that, all individuals are equal before the law and no persons shall be discriminated against on the grounds of sex, race, ethnic origin, religion, creed or social or economical status. Although it does not cite persons with disability specifically, there are included in this clause of non-discrimination. Further article 23 on affirmative action requires the state enact legislation to target people who have been previously disadvantaged such as persons with disability (Dausab 2012)

#### **The National Policy on disability**

On a national level the Namibian government has policies and guidelines which aim to remove the social inequalities for persons with disability. The most relevant legislation and policies pertaining to children with disabilities in Namibia include the National Policy on Disability, the National Disability Council Act and the Mental Health Policy. The National Policy on Disability of Namibia (1997) was formulated by the Ministry of lands, Resettlement and Rehabilitation which was the ministry in charge of disability issues from 1990 until 2005 when the MOHSS took over (Lang 2008).

The national policy is underpinned by the social model of disability as evidenced by its vision which is to strive for a society for all where all services are made accessible for persons with disability. The policy framework follows the principles outlined in the UN Standard Rules on the Equalization of Opportunities for Persons with disability and incorporates various rights protecting the disabled persons. It also recognizes that persons with disability are an integral part to development and they should be accorded equal access in all areas such as rehabilitation, assistive devices and orthopedic services. Thus creating an enabling environment where persons with disability are empowered leading to self-sufficiency, independence, integration and inclusion into society (GRN 1997). This proactive approach includes the recognition of priority areas where different ministries are tasked to provide equal opportunities and inclusion of persons with disability in their national plans and programs.

In addition to other subgroups of persons with disabilities the policy specifically mentions children with disabilities it states;

“ the state shall ensure that children with disabilities have equal opportunities and equal access to education, sports and recreation and all other services in the community such as health care” (GRN 2007,4).

Despite women and children with disabilities being particularly mentioned in this policy, they remain susceptible to the effects of power and gender dynamics. It is also not clear in any of these initiatives, that the particular issues affecting children with disabilities will be explicitly addressed.

### **The National Disability Council Act 26 of 2004**

The National Disability Council Act of 2004 was formulated in 2004 and set up under the MOHSS. It makes provisions of formulation of a disability council which is tasked with; ensuring implementation of the disability policy; identification of any hindrances existing in the current legislation which limit the implantation of the disability policy; initiating reformulations of the disability policy so that it is in line with changing circumstances; and taking the required steps to improve the lives of persons with disability In Namibia (Lang 2008). The council also has the duty to collect statistics on disability in the country and to collect information regarding the type of services offered for persons with disability by the government. It is however disappointing to note that by 2010 the council was still not in existence (ibid).

At present there is an enormous gap between the envisioned life of persons with disability and their lived experiences. Rarely are persons with disabilities aware of their rights as put down by the Namibian government and the DPO do not exert pressure on the government to provide these essential services. Therefore persons with disabilities are not benefiting from such initiatives.

## CHAPTER 4: BARRIERS TO ACCESS

It is widely acknowledged but little studied that children with disabilities do not receive adequate health care services throughout the southern African countries, Namibia included. Issues preventing access to these services vary from the severity of the disability, to the political commitments, to cultural reasons and to geographical localities. The barriers to access as discussed in section 2 will be elaborated further in the sub-sections below.

### 4.1 Environmental barriers

#### 4.1.1 Poor physical structures as barriers to accessing health care services

A number of authors have acknowledged that accessibility of the physical structures is one of the barriers preventing utilization of healthcare services for children with disabilities. Six different studies conducted in southern Africa, in Mozambique (Eide and Kamaleri 2009, Ravim and Handicap international 2010), two in South Africa (ACPF 2011a, Grut *et al.* 2012) and another in Malawi (Eide and Loeb 2004, Munthali *et al.* 2013a) assert that the built environment and physical structures such as the terrain affect utilization of services. According to a qualitative study done by Grut and colleagues (2012) in Amathole district in Eastern Cape Province, geographical inaccessibility of the health clinics limited utilization of the service. In the study they stated that the terrain had narrow gravel roads, with steep roads and in some instances only paths were available making health services inaccessible to children with disability.

The national representative surveys of living conditions of persons with activity limitations revealed that 21% of the respondents in Mozambique, 11% of respondents in Malawi, 11% of respondents in Namibia and 7% of respondents in Zimbabwe had problems with accessing primary health care services in their area (Eide *et al.* 2003a, Eide *et al.* 2003b, Eide and Loeb 2004, Eide and Kamaleri 2009). These figure show that health clinics services are found to be accessible for the large majority of persons with disability. As can be seen for the case of Namibia on image 1, there are a large number of health clinics situated in the North of the country which might explain the low number of persons with disability who have access problems to health clinics. Further the results for Mozambique living conditions survey are corroborated by a univariate analysis of health centers in Maputo and Matola municipalities, showed that 30% of persons with disability were affected by physical inaccessibility of the health centers (Ravim and Handicap International 2010). The accessibility of health services

can be linked to the PHC initiatives which was adopted by many southern African countries, Namibia included. These initiatives ensured that all persons even at grass root levels had access to health services.

The landscape of Namibia is comprised of sandy and uneven terrain which makes navigation by individuals with mobility aids and wheelchairs difficult. In rural Namibia a qualitative study with adults who had physical disabilities concurs with the fact that the inaccessibility of health service affects utilization of service by persons with disability. Wheelchair users in the rural areas of Caprivi, Kunene and Kavango region cited that the long distance from their home area to a tarred road poses challenges when traveling to the health center (Van Rooy *et al.* 2012). These results can be translated to children with disabilities due to the fact the geographical location of the children with disabilities is relatively the same as adults with disabilities and they will inevitable use the same health care centers and experience the same challenges.

After overcoming the geographical barriers in reaching health care services children with disabilities are further disadvantaged by the built environment. In many instances in northern Namibia rural clinics lack proper ramps and toilets make utilization by persons with disabilities difficult (Van Rooy *et al.* 2012). South Africa and Malawi face similar scenarios. According to a study which assessed health care facilities in South Africa , only a quarter out of the total of health services facilities was accessible to wheelchair users and only a third of the facilities had specially adapted rest rooms for persons with disabilities (ACPF 2011a). And a qualitative study in Malawi which focused on both educational and health facilities revealed that children with disabilities had problems in accessing the rest rooms in these facilities due to the design of the toilets. The toilets were inaccessible to the visually impaired, those who used wheelchairs and those who used both their feet and hands in moving about (Munthali *et al.* 2013a). Using hands and feet instead of mobility aids is an issue which will be discussed later on in the sub sections below. However an acknowledgement of lack of appliances to aid in daily living should be noted.

The findings presented in this subsection indicate that the geographical terrain act as barriers to accessing health care services for children with disabilities in all of the southern African countries, Namibia included. Further conclusions can be made about the built environment as

shown by the studies, inaccessible buildings and sanitation facilities discouraged the use of services.

#### **4.1.2. Inadequate government specialist services**

Barriers to access health care services have also been noted when there are shortcomings between supply and demand. Surveys on living conditions of persons with activity limitations revealed that there was inadequate service for children with disabilities when providing health services and specialized services such as medical rehabilitation services and assistive devices. The surveys in Lesotho (Kamaleri and Eide 2011), Malawi (Loeb and Eide 2004), Mozambique (Eide and Kamaleri 2009), Namibia (Eide *et al.* 2003a), Zambia (Eide and Loeb 2006) and Zimbabwe (Eide *et al.* 2003b) showed that there was inadequate service delivery as there were gaps between expressing a need of a service and actually receiving the service. The results of these surveys are shown in Appendix 2, figure 2, 3 and 4 which show the gaps of needing a service and actually receiving the service in health service, rehabilitation and assistive devices respectively. The results show that most persons living with disability have limited access to assistive devices and medical rehabilitation services compared to health services. They further reveal that Malawi is one of the countries lagging behind in terms of both providing health services and assistive devices for persons with disability. This has also been noted by a study done by Munthali and colleagues (2013a) which stated that in theory the government is supposed to be providing these services but it is rarely the case.

The evaluation on rehabilitation services by Saloojee and colleagues (2006) found similar tendencies as those of the living conditions surveys. They write:

“Of the 143 (92%) children who could have substantially benefited from rehabilitation therapy, as judged by the researchers, only a quarter [37 (26%)] were receiving either physiotherapy, occupational therapy and/or speech therapy. Children with motor impairments were more likely to have received therapy than those with intellectual impairments (44% vs. 8%,  $P < 0.0001$ )” (Saloojee *et al.* 2006, 232)

These same sentiments were echoed in separate studies South Africa. One of the studies was conducted by Barrat and Penn (2009) in Tonga, a rural village in Nkomazi municipality Mphumalanga Province. One of the respondents in the study pointed out that she has been waiting for more than three years to get an assistive device for her child. The second study was done by Maart and Jelsma (2013) in a deprived urban residential area in Cape Town. This study had similar results as the majority of the respondents reported that they were in need of rehabilitation and assistive devices. According to their results the largest shortfall in

terms of service provision was in medical rehabilitation where a third of the respondents reported that their need was not being met. The unmet need for assistive devices was 35% and under 3% reported that they had unmet health care needs. These results can be explained by the fact that the availability of rehabilitation services in government health care institution is limited to the central hospitals. For example in the case of Namibia, nine out of ten allied health professionals are based in Windhoek (MOHSS 2006). Thus these figures reveal a need to expand both community based rehabilitation and institutional based rehabilitation to ensure that the needs of children with disabilities are provided.

These results illustrate the frustrations that children with disabilities and their caregivers experience when wanting to utilize health care services. The need for a service is well articulated by the government has not responded adequately- or has not responded to fulfill the needs as set out by the different policies and international conventions.

#### **4.1.3 High cost, unreliable and unavailability of transport**

The distance to a health care center is taken into consideration before utilization of services. The distance affects the mode of transport utilized and the time taken to reach a health facility. Several of the studies under review showed that travelling to a health center was challenging for children with disability. These studies were conducted in South Africa (Saloojee *et al.* 2006, Barrat and Penn 2009, Grut *et al.* 2012, Maart and Jelsma 2013), Mozambique (Ravim and Handicap International 2010), Namibia (Coomer 2012), and in Malawi (Munthali *et al.* 2013a, Muntahli *et al.* 2013b). The authors from these studies noted the high cost of transportation, unreliability and its unavailability as the main obstacles to accessing healthcare services. The high cost was related to the price persons with disability had to pay for the service and also for the extra charges. The extra charges were incurred in instances where a person using a wheelchair was required to pay double the fare and also the fee of the care giver as they need assistance in daily activities. Barrat and Penn (2009), in their evaluation sum up the transport problem, they write;

“Common complaints among the caregivers included travelling long distances from sites barely accessible by motor vehicles, combined with expensive, unreliable transport, making regular follow-up visits difficult to achieve” (Barrat and Penn 2009,199).

Although as noted in earlier sections health services maybe accessible to the majority of the children with disabilities, the distance to the health facility acts as a barrier to accessing the service. The time taken to travel is considered when wanting to utilize a health service.



Munthali and colleagues (2013b) conducted a study based on the living conditions surveys done by Sintef in Malawi. Their study however focused on only persons suffering from epilepsy. According to their results the respondents in the study who had to travel a distance of at least 50 kilometers to the nearest health facility reported that this was time consuming and not economically viable as they could be engaging in other productive activities.

However Coomer (2012) reported that in Namibia the distance from the health facility to the residence of the child with disability did not pose as a barrier, as most health centers in the Khomas region (central region) were on average 5km away. However the disabling condition of the child made it impossible to walk on foot. She also noted that the cost benefit ratio of paying for expensive transport and getting a poor service at the health center is usually the main obstacle and not necessarily transport itself. This same sentiment of cost benefit ratio was observed by Saloojee and colleagues (2006). They conducted a qualitative study in a poor residential area in Soweto, Johannesburg, South Africa. Most of the key informants in the study were unemployed, or living in single headed households where the father rarely supported the child with disability, therefore their socio-economic status dictated whether they would prioritize paying for hospital and transport fees or use the resources for other needs. Therefore the non compliance with use of health services could be understood as a rational choice.

In Namibia most of the rural participants walked to the nearest clinic and this usually takes at least an hour to reach to the nearest health center. One of the adult respondents in the study stated:

“I have to wake up at 5am and walk 2 hours and 30 minutes to get to the clinic, and sometimes when I get there its already full. I have to wait in that long queue to get help and when I am done with the whole process I have to walk back home. The next morning I still feel sick and tired because of the distance I walked. (Amputated arm, Tsandi Clinic)” (Van Rooy 2012, 768).

These views as noted earlier can be translated to children with disabilities. Or the situation might be worse for children with disabilities as they will need to be carried to and from the health centers. Although the government of Namibia elucidate that most residents live within a 5km radius to a health facility, the mode of transport used affects the time taken and the use of health service. For example most people in the rural areas walk to the facilities. This poses challenges in terrains which are not accessible.

#### **4.1.4 Social attitude as barrier to access**

Barriers to access extend beyond accessibility and availability issues, negative social attitude acts as a barrier to accessing health care services. Disability is still shrouded in myths and misinformation which makes persons with disabilities inclusion into the society challenging. Socially there is still a lack of knowledge and acceptance for persons with disability in the community. This is usually the case in the rural areas where disability is still being viewed as an illness which is communicable, a shame, a result of witchcraft, a punishment from the ancestors for some wrong doing of the parent or extended family or a sign of promiscuity by the mother of the child (Ravim and Handicap International 2010). These are examples of the reasons that are given by able bodied persons in the community to shun persons with disabilities. Parents of children with disability are therefore often ostracized from the community and in most cases fathers abandon their families when a child with disability is born. Thus the majority of children with disabilities are being brought up in single-parent households (Barrat and Penn 2009). The impact of this is that children with disabilities are often hidden from the community and neglected by their parent.

Four of the studies highlighted the social-cultural challenges faced by children with disability and their parents in the community (Maart *et al.* 2007, Barrat and Penn 2009, Ravim and Handicap International 2010, Munthali *et al.* 2013a). According to a study conducted in Mozambique disability is viewed in the same as way as HIV which can be transmitted from one person to another. The discourse and their understanding that HIV is transmissible, irreversible and disabling in nature formed the basis for this conclusion. For example respondents had the belief that it can be transmitted from mother to child. This was the reasoning behind the isolation of persons with disability from the community and the society at large so that they could not pass on their illness to others (Ravim and Handicap International, 2010).

The study by Maart and colleagues (2007) in rural Eastern Cape Province and urban Western Cape provinces South Africa showed that there was no significant difference between the level of support offered in rural and urban settings. According to the study only 15% of the respondents residing in the Eastern Cape and only 10-20% of the respondents living in the Western Cape experienced the categories of relationship and support to be a barrier.

## 4.2 Structural barriers

### 4.2.1 Poverty and its limitations to accessing health care services

It should come as no surprise that among disadvantaged populations limited financial resources is negatively associated use of needed services. Poverty in the southern African countries creates barriers to access for families who have children with disabilities. According to a survey done by Sintef health Research in collaboration with University of Namibia, Central Statistical Office and National Federation of Persons with Disability in Namibia (NFPDN), over 70 % of persons with disabilities had access to health care services when the need arose. Those who did not make use of the services noted the cost of paying for the service and transport problems acted as a barrier to utilizing services (Eide *et al.* 2003a). Grut and colleagues (2012) also highlight the negative impact of poverty on utilization of health services. They conducted a study in Mathatha, Eastern Cape province, South Africa to assess how poverty influences access to and utilization of health care services. In their analysis, they presented a case study of “*Mthunzi*” a boy who has epilepsy. The case study was an illustration of how people with disabilities who live in resource poor settings experience health care access barriers. The study conclude that non compliance with health services is associated with individual and societal poverty thus the choice of utilizing health care services is bound by lived poverty and the struggle by the individual and family to cope with limited resources(ibid).

In addition, similar sentiments were also echoed by parents of children with mental health problems in Namibia (Coomer 2012), by respondents from a study in Lilongwe, Malawi (Munthali *et al.* 2013a), by caregivers of children with cerebral palsy in Mpumalanga South Africa (Barrat and Penn 2009), by respondents from Mozambique (Ravim and Handicap international 2010) and by persons with disability in the metropolitan of Cape Town and Johannesburg areas of South Africa (Saloojee *et al.* 2006, Maart and Jelsma 2013). Maart and Jelsma (2013) contribution to how poverty-reinforcing forces acts as a barrier to accessing health care services adds valuable insights. According to their cross-sectional household survey which was done with persons with disability who resided in one of the areas with extreme deprivation according to the national Multiple Deprivation Index of South Africa, financial barriers were noted as one of the barriers to accessing health services. Inadequate finances leave parents of children with disabilities to forego using health services when the need arises and to the use of health services as a last resort. In Mozambique, the study

revealed that the high cost of consultation by doctors, the purchase of compensatory devices, and cost of buying the medicines was exponentially linked to not seeking health care services when the need arose (Ravim and Handicap International 2010).

These unmet health care need increases the use of acute medical services such as emergency room visits and hospitalizations by persons with disabilities leading to catastrophic out-of-pocket payments and to the use of alternative medicine by some as noted in appendix 2, figure 5 which shows that respondents in most southern African countries where making use of a traditional healer. In many instances the use of traditional healers and western medicine occurs concurrently.

### **4.3 Process barriers.**

#### **4.3.1 Negative health provider attitude**

The way persons with disability are received and treated at health center pose as either a barrier or a facilitator to accessing health care services. Past experiences of negative health worker attitude discourages the use of health services.

Several of the studies reviewed show that the health personnel have negative attitudes towards persons with disability (Barrat and Penn 2009, Ravim and Handicap International 2010, Coomer 2012, Maart and Jelsma 2013, Munthali *et al.* 2013a). Many respondents in these studies narrated experiences with regards to inappropriate or unprofessional conduct on the part of the service providers. The study by Barrat and Penn (2009) revealed that just under half of the respondents were unwilling to use healthcare facilities due to the negative attitudes of the health care workers. The negative attitudes included the use of demeaning and offensive language and the general lack of patient-health worker rapport. Further in some health facilities children with disabilities were the last to be attended to by the health worker. And in some cases where referred to the central hospitals without any intervention being done at the local level (Munthali *et al.* 2013a)

The study in Namibia by (Coomer 2012), noted that parents of children with mental disabilities in Windhoek area, experienced unsatisfactory service delivery from nurses at the health centers and described the nurses as being “*rude*” or “*difficult*” when managing children with mental health problems.

While it is possible that healthcare workers may be unprofessional and use inappropriate and demeaning language, working within a language barrier may create such perceptions by the caregivers. In defense to the assumed negative attitudes, Barrat and Penn (2009) bring attention to the fact that these perceptions are brought by a wrong interpretation by the parents/caregivers. They postulate that the perception is due to a miscommunication between the parent and health worker usually due to the use a different language, to the fact that most healthcare workers are from a different cultural background and also to the different worldviews between the parents and the health workers. They also observed that a power dynamic situation arises between the nurse and the caregivers as caregivers consistently reported that the nurses were not listening to their problems and often thought they were lying. According to Crawford (1994) cited in Barrat and Penn (2009), the language used in health seems to further marginalize the already segregated groups in the society as it demarcates the responsible from the irresponsible, the respectful and the disrespectful, and finally those who have a right to dictate and those needed supervision. This makes the sick and disabled responsible for their illness. With more than 30 languages with possible different dialects in Namibia, the language and communication problems are insurmountable.

#### **4.3.2 Poor quality of service delivery**

Health centers were not purely unavailable but they had a low reputation in terms of quality of service provided. The Institute of Medicine has adopted this definition of quality care;

“ the degree to which health services for individuals and populations increase the likelihood of desired health outcome and are consistent with current professional knowledge” (Campbell *et al.* 2000 1614).

Quality of health care is a multifaceted concept and it includes principles such as patient centredness, access and timeliness of service, capacity and safety of service. Quality of care must be provided with compassion, dignity, confidentiality and informed choice. Improving quality and outcomes at health centers offers an incentive for the utilization of a service.

In most of the countries in Africa quality has been noted as a hindrance to equitable access of services. According to the study by Coomer (2012) the negative experiences at the health centers ranged from not having a consistent physician and having to explain the child's health history many times, and to not finding a physician when they visited the health center and being treated by a student nurse instead. Inadequate staff compliment acted as a barrier to accessing health services for children with disabilities. This shortage of health care workers was noted in a report by the ACPF (2011b) and by Maart and Jelsma (2013). Shortage of

health care workers also affects the time it takes waiting for a consultation. The ACPF (2011b) report states that having to wait in a long queue is a challenge for a child with cerebral palsy who needs medication to control their spasms. Furthermore this long waiting period was exacerbated by poor administrative aspects which include the recording and filling of health information of the children. Due to the poor record and filling systems respondents noted that they had to wait at the hospital for a number of hours before their child's health records could be found (Barrat and Penn 2009).

Incorrect information, coupled with limited scientific knowledge of care, further contribute to health inequity. Focus group research by Coomer (2012) revealed that the respondents criticized the knowledge of the healthcare professionals who seemed not to know other treatment options (such as Occupational therapy) or the right medications or available support services and information regarding the care of the child. The respondents further complained that the medication that they are given are sometimes just painkillers and they do not treat or manage the underlying condition. She however discussed how prescribing painkillers is common not only in the cases of children with mental health problems but also in the general population. She attributed this to the fact that painkillers are a cheap alternative and are available in most government health centers. She also linked the prescribing of painkillers by physician to the lack of time available for each patient and the lack of adequate knowledge of the condition by the treating physician. Lack of medication in hospitals was also a problem as reported by Munthali and colleagues (2013b), persons with disability suffering from epilepsy in the southern rural town of Malawi had to travel a considerable distance to be able to receive medication to manage their condition. The lack of medication at health facilities also acted as a barrier to accessing health services. Instead the respondents ended up resorting to using traditional healers.

In addition outcomes of health care services affect the willingness to access health services at hospitals. In two studies outcomes in rehabilitation of the child influenced the discontinuation of therapy. Some respondents reported that they had reached their maximum goal and felt that there was no need for further therapy and others felt that therapy was an exercise program with no benefit to the child's wellbeing (Barrat and Penn 2009, Maart and Jelsma 2013). More than two thirds percent of respondents in the study by Maart and Jelsma (2013) reported that they were not satisfied with the service therefore they had discontinued treatment. This raises the issue of good communication methods between the parents of

children with disabilities and the health workers. The health worker needs to articulate the causes of the diseases and the outcomes of treatment (prognosis) in lay man language to remove the mismatch of expectations. It is equally important to understand the priorities and the expectations of treatment from the caregivers' point of view.

#### **4.3.3 Linguistic differences as a barrier to access**

Communication between health care providers and children with disabilities can prove difficult. Four of the studies under review indicated that communication barriers between the health workers and the children with disabilities posed as an obstacle to accessing health care services. Lack of health information in Braille for persons with visual impairments is noted as a barrier to accessing health services. This is also the case for those with hearing impairments. In Maputo, Mozambique none of the health workers had received training in sign language (Ravim and Handicap international 2010). Therefore this was a challenge when a health worker is presented with a patient who uses sign language as a means of communication. The situation is mirrored also in Malawi with respondents admitting that they had problems communicating with the health workers unless accompanied by a caregiver (Munthali *et al.* 2013a). According to observations by Barrat and Penn (2009), South Africa's health centers do not employ translators or interpreters and this gives rise to misunderstandings and misinformation being passed between the health workers and the cares. Thus it is particularly difficult for children with hearing impairments to gain access to health services.

Disease prevention and health information were in addition not available for children with visual impairments. Most visually impaired students have no access to HIV/AIDS information as most health pamphlets are not written in Braille (Munthali *et al.* 2013b). From the study by Ravim and Handicap International (2010), a third of the respondents said that access to information on prevention services was limited.

This is the case for the estimated 1800 persons with visual impairment in Namibia. The unavailability of information for the visually impaired in Namibia has been corroborated by Bjarnason and colleagues (2012). The authors state that “the experience of the deaf community within a concept of linguistic colonialism, where the power of spoken languages is thrust upon the deaf, who are disempowered and excluded without a recognized language”

(Bjarnason *et al.* 2012, 193). This signifies the need for empowerment of the deaf community.

## **CHAPTER 5: EXPLORING THE BARRIERS TO ACCESS**

The goal of the study was to understand the barriers to accessing government supported health care services for children with disabilities in southern Africa, with a particular focus on the case of Namibia. In doing so, three major themes were identified which posed as barriers to accessing health care services and these were environmental, structural barriers and process barriers. This chapter will discuss the extent to which conclusions about the barriers can be made.

### **5.1 Environmental barriers: Policy constrains**

#### **The physical structures**

Almost all the studies under review have highlighted physical accessibility of the built environment as a barrier to accessing health care services by children with disabilities. The inaccessible built environment limits access to health care and is a direct violation of what is advocated for by the UN CRPD (2006). In order to create a society in which all people can express their capabilities and participate fully a barrier free environment must be adopted based on the principle of universal design: that is designing facilities that are inherently accessible to everyone not just persons with disabilities (Banda-Chalwe 2012). Measures to achieve a barrier free environment have been adopted by Namibia, through legal provisions and recommendations from relevant ministries. The elimination of barriers in newly constructed facilities through legal requirements has progressed but overall progress as revealed by the literature has been inadequate. According to the Namibian Standards Institution (a regulatory body which ensures international standards which falls under the Ministry of Trade and Industry) the country still faces numerous challenges in adhering to international standards (\_\_\_\_2010). In some instances the constructions have not adhered to the recommended regulations resulting in the adaptations doing more harm than good. These instances include steep ramps which makes it impossible for wheelchair users to use without assistance (Dausab 2012). There are of course exceptions to this, where the design and angles are appropriate. It is thus necessary for governments to ensure that all new constructions and renovations adhere to the principles of universal design.



The review also showed that geographical distribution of health care facilities was a determining factor to the utilization of health care services. As the articles by Kadobera and colleagues (2012) elucidate, primary health care usage declines with increasing distance or time travel to a center. The vastness of the Namibia and the uneven distribution of health centers (as shown by image 1) attribute to the geographical inaccessibility and lack of transport faced by the population when accessing health care services (AHO undated). The Namibian government in their health facilities survey in 2008, acknowledged the fact that 80% of the population live 10 km away from a public health facility. In defense of this, the government rationalized the cost benefit of maintaining a facility in areas where the population density is low (MOHSS 2008). This has vast implication to children with disabilities who have mobility problems and need assistance in reaching health facilities. In addition the lack of financial resources by the government to ensure the effective running of mobile clinics poses an additional challenge.

### **Inadequate service provision**

The results for the living conditions surveys in Namibia which show disparities in needing assistive devices and rehabilitation and actually receiving the said service can be explained by the MOHSS National Community Based care and Rehabilitation Programme outline. This program outline states that in Namibia rehabilitation services are available at Windhoek Central Hospital a specialized referral hospital, at the three intermediate hospitals (Oshakati, Rundu and Katutura hospital) and at the district hospitals. However limited human resources means that some of the rehabilitation departments in the districts have no posts for rehabilitation workers and some are being headed by Medical Rehabilitation Workers whose training is insufficient for the positions. There is also an observed disparity between rural and urban areas, with shortages of staff in the rural areas. Over ninety percent of allied health workers practice in the urban areas. This shortage and unequal distribution in staff complement results in delayed and poor quality of services thus restricting the effectiveness and efficiency of rehabilitation services (MOHSS, 2006).

### **Transportation problems**

Another pressing need is the barrier imposed by inaccessible, unreliable transportation system. In the transport sector barrier free measures have not been adopted and persons with disabilities have considerable challenges when using the public transportation system (\_\_\_\_2010). Although the City of Windhoek provides public transport free of charge for

persons with disabilities, a general observation noted this has not removed the challenges as most persons with disabilities report of having to pay transport costs and the service is still unreliable.

### **Social attitude**

Perceptions of disability are a pivotal role in how caregivers access health care services. These perceptions bring into existence the explanations of health and illness, and the choices made in health seeking behavior. This is essentially because perceptions serve a pivotal role in shaping beliefs, opinions, customs, norms and attitudes. The decision to utilize health service is in essence a social process where the child with disability together with the parent/caregiver and the social network label, explain, evaluate and respond to the disability (Hossain and Chatterjee 1998). The results from this review suggest that two belief systems influence the health seeking behaviors, that is, the biomedical and the cultural beliefs. The biomedical belief is the belief in medical interventions and the traditional belief is the belief in other alternatives such as traditional healers. These beliefs may occur concurrently and may lead to the use of multiple treatments.

As Hossain and Chatterjee (1998) discovered rural residents included all types of notions in their perceptions of what constituted a health care system. They postulate that the use of traditional healers is due to the lack of government services, their adoption of whatever seemed useful and their patience in dealing with the caregivers and it has been usually the unqualified who has reached out to persons in the rural areas. In many instances the preceding has been the picture with regards to children with disability in Namibia. These assertions corroborate the results from the review which showed that in Namibia persons with disability had utilized the services of a traditional healer at some point in their lives.

With regards to use of services offered by a traditional healer, Barrat and Penn (2009), elucidate that a generational difference in attitudes about health seeking behaviors is evident. Elder family members believed strongly in traditional healers and their counsel was sought before any intervention was sought with regards to the appropriate intervention for the child. This brings into focus the role of the extended family in shaping the choice of treatment. Children with disabilities in Namibia are often looked after by the grandparents as a form of informal social security mechanism (AHO undated). Thus the utilization of traditional services can be mirrored to the case of Namibia. Thus this substantiates the results of the

living conditions survey which showed that persons with disabilities in Namibia utilize services from a traditional healer.

Social inclusion must therefore be examined and developed first and foremost within the family unit since the family is essential for the care of the children with disabilities. However due to the economic weakness of some family units, the government, local authorities, associations and churches are called upon to create the necessary conditions to enable them to meet the needs of their disabled family member.

### **Concluding remarks on environmental barriers**

Data is essential in improving health outcomes. The overall goal for data collection is to inform policy-making, implementation protocols and program planning and ultimately leading to improvements in health outcome and health equity. The government of Namibia recognizes the importance of robust statistics and this is specifically mentioned in the National Policy on Disability and in the establishment of the disability council. However little action has been done to collect and distribute reliable statistics on persons with disability. This has several negative implications on the lives of persons with disability. The problem of inaccessible built environments has been linked to the incorrect or inaccurate number of persons with disabilities compared to the actual figures (Banda-Chalwe 2012). The Namibia Housing and Population Census estimate that persons with disability constitute 5% of the population (GRN 2003). The category for persons with disabilities used by the census has been criticized for not delineating between mentally ill and mentally disabled individuals and for its use of impairment of hands and impairment of legs which is superficial in nature (Lang 2008). Further there are no separate statistics on the number of children with disabilities. This raises concerns regarding validity and reliability of the estimates. The resulting low estimate contributes to governments not responding adequately to the needs of persons with disability. This means that serious challenges in achieving the health for all initiatives will be faced.

Innovative strategies to realize the right to health for children with disabilities are needed. These strategies to remove physical barriers to access include strengthening outreach services/mobile clinics, training of Community Health Workers, improved road networks and transport systems and strengthening the capacity of staff at the grass root health centers. Utilization of services was also dependent on the societal responses to children with

disabilities. Therefore community based initiatives in health care should acknowledge that the society will influence persons with disabilities responses to these initiatives.

## **5.2 Structural barriers: Health care financing**

### **Catastrophic out-of -pocket payments**

Out-of-pocket payments have severe consequences for health care access and are especially catastrophic for the vulnerable social groups in the society this includes children with disabilities. Generally in Namibia health care fees vary between different health care centers and range from N\$4 at health clinic to N\$30 at national referral hospitals for state out-patient, inclusive of all services rendered (AHO undated). As small as these amounts may be, coupled with the low economic status of most households who have children with disabilities the amount still poses as a constrain to accessing health care services. This un-affordability of health service can be attributed to the poor implementation of policies that remove financial barriers to accessing health care services (ibid). Namibia is one of the few African countries to administer social safety nets for persons with disabilities and also includes a variety of grants for vulnerable children. This grant is administered by the Ministry of Gender Equality and Child Welfare. However figures have shown that only a small portion of eligible recipients are receiving the disability grant (Eide *et al.* 2003a) with pervasive regional asymmetry (Subbarao 1999). The findings further assert that even those who have registered to receive the disability grant seem to be experiencing challenges in actually receiving the grant. This is due to two main reasons; the complexity of the pay procedures and the procedures for registration and payment are not known to most of the eligible persons (ibid).

The review further reveal that poverty is a cross-cutting issue within the discussion of disability and access to health services because the majority people with disabilities form the poorest in the community. This in turn has wide ranging implications. Poverty means that persons with disability are unable to pay for health care services. However it should be noted that the government of Namibia has adopted a waiver fee policy for the vulnerable groups in the societies this includes children under the age of 6 years, persons with disability, pregnant woman and the elderly people over the age of 60 years. Cost however still plays a major role in access to service since the exemption from paying for the services is unevenly applied and the implementation of the waiver is cumbersome (AHO undated). Ultimately the choice of utilizing health services is made on a cost-benefit ratio. Grut and colleagues (2012) offer valuable insights into the complexity of the barriers which affect utilization. They assert that

looking at each factor as a single entity without understanding the interconnectedness of them limits our understanding of the barriers. An acknowledgement that different combinations of factors create barriers to accessing health care services and these maybe too challenging to overcome even in instances where the service is accessible is required.

### **Concluding remarks on structural barriers**

The results from the review bring into question the poverty alleviation strategies which the government has put into place to ensure that persons with disabilities have a decent life. It also puts into question the policies and legislation which are formulated on the principle of empowerment and inclusion. Not enough is being done to ensure the implementation of these initiatives.

In view of the above, the values underpinning human rights such as equality, autonomy, dignity and social justice need to be promoted. A reformulation of the policies is needed to include the needs of children with disabilities. In addition reformulation is imperative since National Policy of disability (1997) and the National Disability Council Act (2004) both predate the UN CRPD therefore as Namibia as a signatory to this convention is required to align its national provisions to the international law.

## **5.3 Process barriers: Accountability and good governance**

### **Health worker shortages**

Many health care initiatives are devoting interest to the quality of health care which is administered to the end service users. Quality of health services is affected by many complex interactions among which are the staff compliment at a given center, shortage of staff, inadequate supply of medication and health professionals' knowledge and attitude. In view of the analysis above, poor quality in service delivery acts as barrier to accessing health care services.

Ensuring the availability of an adequate number of health workers is essential in the delivering of quality health services to the population. According to estimates from WHO in 2006 there was a 4 million shortage of health care works with sub-Saharan Africa being the hardest hit the crisis (OECD, 2010). This shortage has been attributed to inadequacies at local training institutions to produce the required number of health workers, immigration by health professionals to third world countries, career changes among health workers, early retirement,

morbidity and premature mortality (Kinfu *et al.* 2009). The push and pull factors have been hypothesized to influence migration. Push factors include; underfunding of health services; lack of career advancements; poor remuneration and lack of established posts. Pull factors include; opportunities for further training and career advancement; greater financial security; improved working conditions and availability of post (Naicker 2009, OECD 2010).

This situation mirrors the Namibian human resource crisis in the public sector. In Namibia health sector reviews have shown that there are fewer than two health workers per 1,000 population which falls short of the benchmark provided by WHO which is 2.5 health workers per 1,000 population. There is a gross staff shortage and staff turnover in the public health system, as of 2010 specific health worker and user ratio include 1:2,952 for doctors; 1:704 for registered nurses; 1:10,039 for pharmacists; 1:13,519 for social workers, and 1:28,562 for health inspectors (AHO undated, MOHSS and Macro International 2008). (Note that image 1 provide 2001 health worker and user ratio, these ratios have not changed significantly over the ten year period). These ratios are due in part to the limited training capacities of the health institutions as current numbers of trained workers do not meet the demand, resulting in Namibia relying on foreign trained health personnel (*ibid*). Health worker retention is another impeding challenge as there are a high number of health worker migrations from the public service into the private sector. There is a further rural and urban disparity in terms of staff compliment with the rural centers at a disadvantage (MOHSS and Macro International Inc 2008). According to the public expenditure tracking survey the shortage of health workers, pharmacists in particular has also resulted in the erratic supply of medicines to the health clinics and districts. Consequently this corroborates the literature review which has shown that the shortage of health workers at established health centers acts as a barrier to accessing health care services for children with disabilities.

### **Lack of knowledge by health professionals**

Another important aspect which came out in the review was that health workers are not competent in the management of children with disabilities. This can be due to the fact that most training programs in low and middle income countries still concentrate on the growth aspects of children's health neglecting the neuro-developmental and disability dimension (Scherzer, 2012). This lack of training has been attributed to multiple factors including physician attitude, insufficient training, uncertainty about where to refer and the referral process, time limitations of a consultation and cost factors. Cost factors arise when the health

worker does not want to alarm the parent/caregiver about the condition of the child rather to wait until limitations are obvious before they refer to other professionals (ibid). However due to scope and time constraints this could not be verified for the case of Namibia.

### **Health worker attitude**

The central and regional hospitals which have specialist services could be of benefit to children with disabilities, but these facilities are too far to reach for the poor. As shown by the review those children and caregivers that eventually use the services are often discouraged by the bad attitudes and discriminatory practices they experience and in the worst scenario they may discontinue treatment. This negative attitude may be due to patient overload or to staff burnout. For the case of Namibia, if we look at the high ratios of health worker and service user as presented above, it can be one factor that reduces the quality of service provided to the users. Furthermore it should be noted that although more than two-thirds of the Namibian population resides in rural areas, this area is usually the least staffed creating patient overload (Obeid 2001).

### **Concluding remarks on process barriers**

Process barriers are to a large extent the result of inefficient and inequitable use of resources. According to the World Health report (2010), a conservative estimate of about 20-40 percent of health care resources is being wasted. While it is imperative that African countries strive to increase their health care spending to the agreed 15% of the Abuja Declaration. It is also just as important to find ways to minimize wastage. This inefficient use of resources can be due fragmented service provision or mismanagement of human resources. The MOHSS in 2008 conducted a Health and Social Services System Review which noted that the delivery of social welfare services to persons with disability is administered by two different ministries (MOHSS and the Ministry of Social Services) resulting in fragmentation, duplication and confusion regarding roles and responsibilities. Combining the directorates involved in management of disability issues will ultimately lead to reduction in inefficiencies and ineffectiveness in meeting the needs of the service user.

Furthermore the effectiveness of the offices in charge of the ensuring that persons with disabilities are accorded the same opportunities as non-disabled persons have been criticized for not doing enough. According to a report the “Alternative report to Namibia’s first, second and third periodic reports on the implementation” the Disability Unit which is

responsible for working towards removal of access barriers for children with disabilities appear to be not doing anything to rectify these problems. This is evidenced by the absence of their report from the recently published 2008-2009 annual report from the Office of the Prime minister. The council has also not been submitting annual reports as per requirement to the Ministry of Health and Social Services. Therefore the council has been inadequate in removing the access barriers for children with disabilities (Gender Research and Advocacy Project Legal Assistance Center 2012).

## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

While the provision of health services improves the life chances of children with disabilities, achieving access for most is a considerable challenge for most southern African countries and specifically Namibia which was the center of this thesis. For many children with disabilities health care is unavailable, inaccessible or not affordable and this presents challenges to maintain a decent quality of life. Quality of care and lack of disability cultural awareness by health care providers also increase the likelihood of persons with disability not utilizing health care services. Other pervasive barriers to care include previous negative experiences and self-esteem issues which are a result of years of experiencing stigma and discrimination. At the same time there is interplay between social, economical and political factors such as poverty, inadequate implementation and monitoring of laws and policies and fragmented health services which further hinder access to health services by children with disabilities.

Given the extent of the challenges that children with disabilities face when accessing health care service, it is becoming increasingly essential to influence health agencies and health care practitioners to go beyond reducing infant and child morbidity and mortality. Early identification and management of disability is essential in ensuring an improvement in the quality of life for many children. Early child development programs are designed to ascertain the survival, growth, prevent the occurrence of risks and minimize the effects of risks if they occurred. These programs have greater success rates in children from disadvantaged background. Early evaluation and intervention includes not only management and treatment for the individual child, but also provision of appropriate family and community- based support mechanisms. It is but a first step on the long road to ensuring the needed services that will enable every child to reach their best potential and to assume a productive role in society.



As with any other minority group whose basic needs for health care is not being met, there is no easy solution. The following recommendations address the most relevant issues;

1. **Reforming policies-** The policies and legislations are formulated on the principle of empowerment and inclusion but there is no clear overview of how these principles can be extended to children with disabilities. Traditionally children are to be seen and not heard, making them invisible in the adult world. This is even more so for children with disabilities. It is therefore not sufficient to assume that their rights and needs will be adequately realized without their consultation. Therefore there is a need to develop policies that challenge the social systems and the cultural beliefs and these will enable social inclusion of children with disabilities. Furthermore the National Policy of disability and the National Disability act both predate the UN CRPD therefore as Namibia is a signatory to this convention it is required to align its national provisions to the international law.
2. **Moving towards universal health coverage-**The international organizations have issued innovative ways to ensure that countries establish a Social Protection Floor for its citizens. These options include charging user fees to the non-poor, developing risk sharing mechanisms to protect the population from catastrophic out of pocket payments, decentralization of services and the coordination of providing services between NGO's, churches and for-profit organisations.
3. **Investing in specif programs which benefit children with disabilities** – Ordinarily the needs of persons with disability should be met in mainsteram activities. However they also require specialised servicess which are specific to their disability. Persons with disabilities require rehabilitation services such as orthopedic and medical rehabilaion to improve independence and quality of life. Where services are available there is need for a better, more accessible, flexible and well coordinated multi-disciplinary services. Reviewing of existing programs is essential to improve their coverage, effectiveness and efficiency.
4. **Expanding research and evidence based practice-**Disability research should be inclusive of all sectors involved including persons with disability, and their caretakers. Reports of the research should ultimately be communicated to relevant ministries and agencies so that findings can be acted upon systematically and efficiently to reduce the burden of childhood disability.

**5. Improving implementation, monitoring and accountability-**The government of Namibia has excellent plans on paper but flawed implementation of these plans. The plans are often not implemented because of insufficient budget allocations indicating both a lack of financial planning and a lack of commitment to the principles contained in these tools. The development, implementation and monitoring of disability programs should involve a wide range of stakeholders including children with disabilities, government ministries, civil society, the general public and the private sector.

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## Appendices

### Appendix 1: Data analysis table

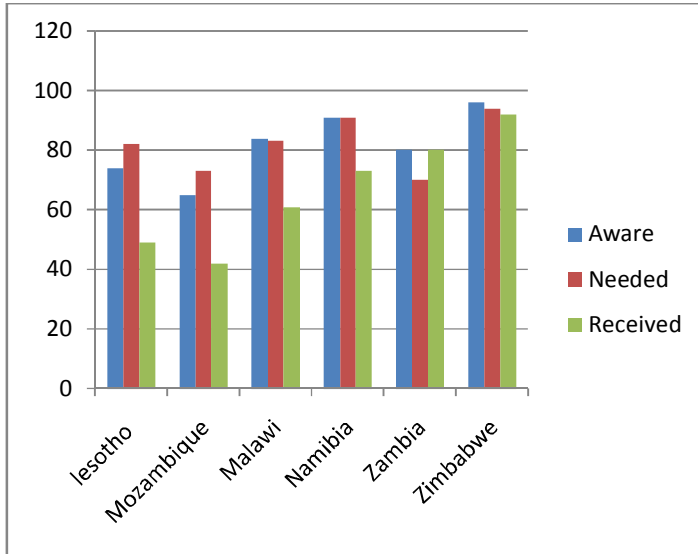
<b>AUTHOR AND YEAR</b>	<b>LOCATION AND SETTING</b>	<b>METHODOLOGY</b>	<b>STUDY FOCUS</b>
Barratt J. and Claire Penn.	Mpumalanga, South Africa	Ethnographic study. Interview and observation methods also used. 27 participants were interviewed in Siswati and these interviews were recorded and later transcribed.	Aim was to explore the daily challenges of caring for a child with cerebral palsy
<b>Coomer R.A. 2012</b>	Namibia, Windhoek	Qualitative study- 3 focus group discussions were carried out using open-ended semi structured questions.	Aim was to describe the problems faced by parents of children with mental illness in accessing healthcare services
<b>Eide et al, 2001.</b>	Namibia	National representative study undertaken in 2002. A stratified single-cluster sampling was used and the target population was all households in Namibia.	Household survey of the living conditions of persons with disabilities compared to those who are non-disabled. It focused on issues such as education, employment, household income, service provisions and accessibility
<b>Eide et al, 2003</b>	Zimbabwe	National representative study carried out in 2001-2003. The study had the same design as all other "Living conditions studies" of persons with disability	Household survey of the living conditions of persons with disabilities compared to those who are non-disabled. It focused on issues such as education, employment, household income, service provisions and accessibility
<b>Eide and Loeb, 2006</b>	Zambia	National representative study carried out in 2005-2006. A master sampling strategy was used and the units of analysis was households and individuals. 350 enumeration areas were used in the 9 provinces covering rural and urban Zambia.	Household survey of the living conditions of persons with disabilities compared to those who are non-disabled. It focused on issues such as education, employment, household income, service provisions and accessibility
<b>Eide and Kamaleri, 2009.</b>	Mozambique	National representative study carried out in 2007-2008. The study had the same design as all other "Living conditions studies" of persons with disability. A master sampling strategy was used and the units of analysis was households and individuals.	Household survey of the living conditions of persons with activity limitations compared to those who are non-disabled. It focused on issues such as education, employment, household income, service provisions and accessibility.

<b>AUTHOR AND YEAR</b>	<b>LOCATION AND SETTING</b>	<b>METHODOLOGY</b>	<b>STUDY FOCUS</b>
<b>Eide Arne and Lobe Mitchell, 2004</b>	Malawi	Enumeration sampling was used to select the case and the control for each household and a questionnaire was administered to each household. 1574 persons with disability responded to the survey questions	Comparison of living conditions between individuals with and without a disability and between households with and without persons with disability
<b>Grut et al, 2012</b>	Eastern Cape, South Africa	Qualitative in-depth interviews were used to obtain information from 24 participants, 7 of which were children with various types of disabilities. Caretakers were used as informants in the case of the 7 children and adults who had language problems.	The study aimed to assess how poverty influences access to and utilization of health services and how poverty renders services out of reach of services even when they are available.
<b>Kamaleri and Eide 2011</b>	Lesotho	National representative study carried out in 2009-2010. Same design as the "living conditions studies".	Comparison of living conditions between individuals with and without a disability and between households with and without persons with disability. The information would be used to inform policies and programs that are inclusive for all persons with disability.
<b>Maart et al, 2007</b>	Eastern and Western cape Province, South Africa	A descriptive, analytical cross-sectional study.	An ICF checklist of environmental barriers was used with people living with disabilities in rural and urban South Africa
<b>Maart and Jelsma. 2013</b>	Cape Town, South Africa	Descriptive cross-sectional study using randomized stratified cluster sampling was used to identify 1083 households in the Cape Town metropolitan area and within these a person with disability. The mean age of respondents was 46.5 years with standard deviation 20.5 and range 4-87 years.	The study sought to explore the access barriers preventing persons with disabilities in with low income settings from accessing healthcare services disaggregated by age, sex, and associated health condition.
<b>Munthali et al, 2013</b>	Balaka, Karonga, Lilongwe and Nsanje districts, Malawi	Qualitative study. 43 in-depth interviews with children with disabilities, 40 in-depth interviews with parents who had children with disabilities, 40 in-depth interviews with parents who had disabilities and 29 interviews with children of parents with disabilities and 14 focus groups with children with disabilities.	A situational analysis of children with disabilities in Malawi. It focused on the availability of data on children with disability, the challenges and interventions to address challenges being faced by children with disabilities and the relevancy of national policies and legislation in implementing changes to issues affecting children with disabilities.

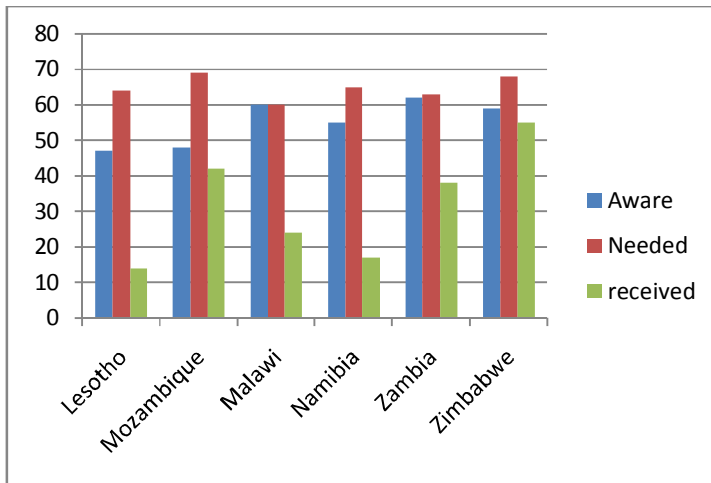


<b>AUTHOR AND YEAR</b>	<b>LOCATION AND SETTING</b>	<b>METHODOLOGY</b>	<b>STUDY FOCUS</b>
<b>Munthali et al, 2013b</b>	Mangochi district, Malawi	A qualitative study using interviews to gather data. A snowball method was used to identify persons with disability. 63 interviews were conducted and of these 8 were with persons suffering from epilepsy.	The research sort to explore the health seeking behaviors of people suffering from epilepsy in the rural southern parts of Malawi. And the impact of epilepsy on household productivity.
<b>Saloojee et al, 2006</b>	Orange Farm township, Johannesburg, South Africa	An interview with a semi-structured questionnaire was used to gather information from 156 key informants who had been recruited using a snowballing method. Interviews were conducted in Sotho or Zulu and later translated to English.	The study aimed to investigate unmet health needs, educational needs and social welfare need by children with disabilities in one of the impoverished townships in South Africa. with the health needs it especially focused in rehabilitation services
<b>Ravim and Handicap International, 2010.</b>	Maputo and Matola, Mozambique	Quantitative/qualitative questionnaires	Situational analysis of people with disabilities in the suburban areas of Maputo and Matola.

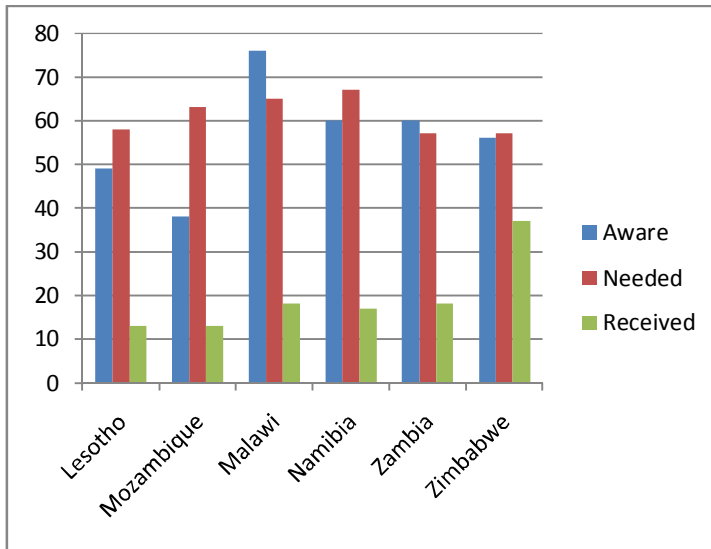
**Appendix 2: Percentage of types of services that are persons with disability are aware of, need and have received.**



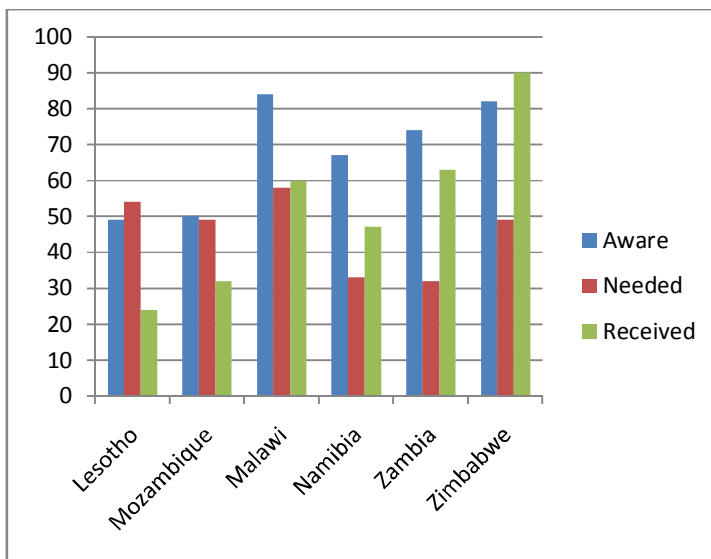
**Figure 2: Health services**



**Figure 3: Rehabilitation services**



**Figure 5: Assistive devices**



**Figure 6: Traditional services**

Sourced from : Namibia (Eide *et al*, 2003a); Zimbabwe (Eide *et al*, 2003b); Zambia (Loeb and Eide, 2006); Malawi (Eide and Loeb, 2004); Mozambique (Eide and Kamaleri, 2009),and Lesotho(Kamaleri and Eide, 2011).