# EXPERIENCES OF PARENTS OF CHILDREN WITH MENTAL DISABILITY REGARDING ACCESS TO MENTAL HEALTH CARE

**RACHEL COOMER**

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**Supervisor: Dr N. Roman**

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# ABSTRACT

Addressing mental health disabilities and disorders in children and adolescents should be an international priority (World Health Organization [WHO], 2001; 2005). However many countries do not allocate sufficient resources (WHO, 2003; 2008a). Namibia is one such country even though the government has recognised that mental health disabilities are a major cause of morbidity and mortality (Ministry of Health and Social Services, 2008). Unfortunately the concept of mental health disorders (healthcare problems that are less severe than disabilities) appears to be poorly recognised in Namibia and this means that there is a corresponding lack of service provision for such conditions. The purpose of this study was to explore the challenges parents of children with mental health disabilities and disorders in Namibia face when attempting to access mental healthcare resources. The study used a qualitative exploratory approach. Purposive sampling was used to include parents, caregivers and relatives of children with metal health disabilities and disorders. The sample also included key informants. Data was collected through focus group discussions with the participants and individual interviews with the key informants. Overall, a total of 41 people provided information for this study. Thematic data analysis was used to assess the data. The results suggest that parents/caregivers and relatives of children with mental health disabilities and disorders do experience barriers accessing mental health care. The challenges go beyond commonly-reported problems in the literature such as stigma and discrimination and include basic challenges such as a lack of transportation to healthcare services and a lack of acceptance of the mental health disorders by the parents. The study offers recommendations for how service provision can be improved and how parents of children with mental health challenges can have better access to services.

## DECLARATION

I declare that the thesis: *Experiences of parents of children with mental disability regarding access to mental health care* is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Rachel Coomer, May 2011

Signed: RCoomer

# ACKNOWLEDGEMENTS

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# CHAPTER ONE

# INTRODUCTION AND CONTEXTUAL INFORMATION

## 1.1 INTRODUCTION

Addressing mental health disorders in children and adolescents should be an international priority (WHO, 2001; WHO, 2005). The WHO estimates that 20% of children worldwide are affected by mental health disorders (WHO, 2005a) and almost half of all lifetime mental health disorders start by age fourteen (Kessler et al., 2005). Analysis of the global burden of mental health disorders suggests that "at any given time, about 10% of the adult population globally and about one in three adults attending a primary health center suffers from a mental disorder" (Patel, 2007; S87). With unipolar depression predicted to be the second most common disease in the world by 2030 (Mathers & Loncar, 2005), there is a need to address mental health disabilities and disorders at an early age. However, despite contributing to 12% of the global disease burden, only 1% of the world health budget is spent on mental health (WHO, 2003, WHO 2008a). There is also a discrepancy between the proportion of disability-adjusted life years attributed to mental health (11.48%) and the average amount of country healthcare budgets spent on mental health (3.76%; see Figure 1.1; WHO 2008a).

A further problem is that whilst countries may provide services for mental health disabilities, the concept of mental health disorders (healthcare problems that are less severe than disabilities) may be less well recognised and children and adolescents with such disorders may not receive the healthcare support they need. One reason is because budgetary provisions are often evidence-based. Children with mental health disorders are often much harder to access than children with mental health disabilities owing to the "hidden nature" of their conditions. Therefore, data available tends to focus on children with mental health disabilities. This study used the term *mental health disabilities and disorders* to ensure that the full range of conditions could be included in this study. A similar approach was taken by Fuller, Edwards, Procter and Moss (2000) who used the phrase *mental health problems* in their study.

The burden of mental health disorders is highest in developing countries where the greatest proportion of mental health sufferers but the lowest proportion of services are found (Patel, 2007). The treatment of mental health disorders in Africa is a particular problem because of additional factors such as inadequate care at childbirth, malnutrition, malaria and parasitic diseases, the impact of conflict and civil strife, the increasing impact of alcohol and drug abuse, poverty and natural disasters, and the prevalence of HIV/AIDS (Okasha, 2002). Mental healthcare is often sidelined owing to the overwhelming burden of diseases such as HIV/AIDS which take the bulk of healthcare budgets (WHO, 2005).

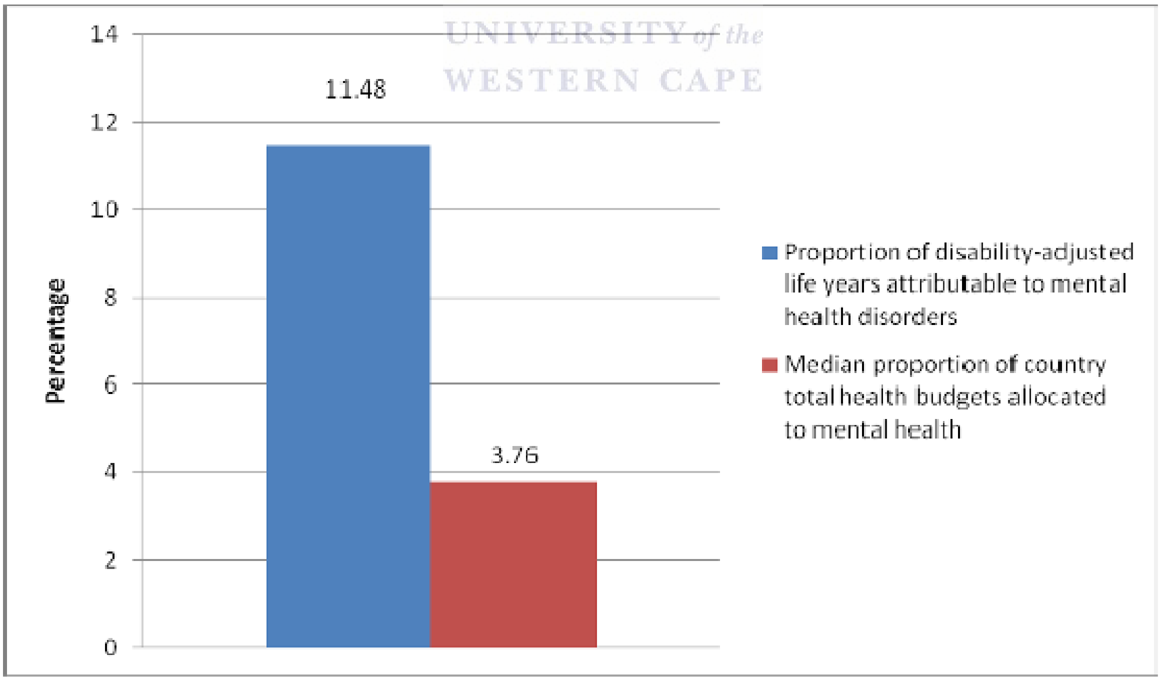

**Figure 1.1: Burden of mental health disorders and budget spent on mental health disorders** *(Reproduced from graph in WHO, 2008a; p 8).*

Some of the most recent data on the burden of mental health disorders in children originates from Israel (Mansbach-Kleinfeld et al., 2010) and the United States of America (Spears et al., 2010). The study conducted in Israel showed that of the 12% of the participants identified with a mental health disorder, approximately 60% had unmet health needs (Mansbach-Kleinfeld et al., 2010). The study conducted in America showed that even though America is the richest country in the world, almost one-fifth of children in America with mental health needs do not receive all the mental health services they require. The researchers identified stigma, discrimination and lack of information about mental health as barriers to healthcare (Spears et al., 2010).

Namibia is one of the many countries across the world struggling to address the needs of children with mental health disabilities and disorders (WHO, 2005). Mental health disorders are a major cause of morbidity and mortality in the country (Ministry of Health and Social Services, 2008). The 2001 Population and Housing Census and the 2006 Namibia Inter-Census Demographic Survey report that 5% of people in Namibia have a disability. Of this percentage 5.6% were defined as mentally disabled or mentally ill in 2001. According to the 2006 update, 11% are mentally disabled or mentally ill (National Planning Commission, 2001; 2010). The Survey does not cite separate data on the incidence of mental health disabilities in children and the figures differ from the global estimate of 10% incidence of adult and 20% incidence of child mental health disorders (Patel, 2007; WHO, 2005a).

The burden of people with disabilities having a mental disability ranges from 19.8% in the Omusati region to 1.1% in the Hardap region. The Survey does not explain why this regional difference exists and further studies have not been conducted to investigate the matter. There is a negligible difference in the incidence of mental health disorders between the genders (11.5% of men and 10.5% of women have a mental disability) but there is a large difference in rural and urban incidence. The report states that 82.9% of people with mental health disabilities live in rural areas. This is in line, but still higher, than general population figures which show that 64% of people live in rural areas.

The incidence of mental health disorders is also reported in the most recent Health and Social Services System Review. The Review reports that 42,124 people with a mental health diagnosis (2.34% of the population) were treated at outpatient clinics and 40,940 people who visited outpatient clinics were admitted owing to a mental health disorder between April 2007 and March 2008. The Review does not cite separate data on the incidence of mental health disabilities in children (Ministry of Health and Social Services, 2008).

The Census/Survey and System Review present different levels of incidence due to differing definitions used. The Census and Survey use a broad definition of disability, defining it as "a limitation in carrying out everyday activities at home, at work, or at school because of long-term (lasting more than six months) physical or mental condition" (National Planning Commission, 2010; p 16). The Inter-Census Survey does not provide a definition for the term mentally disabled or mentally ill. The term mentally disabled is defined in the Census: "persons who were mentally retarded and those who were mentally sick were classified under this category" (National Planning Commission, 2001; p 81). The Census does not make a distinction between mental illness and mental disability – this has been criticised in a recent policy review as in many countries across the world, the two terms are differentiated (Lang, 2008). The Health and Social Services System Review cites data for the number of people with a mental health diagnosis or who were admitted because of a mental health disorder. Despite the fact that the definition used in the Census is broader, and should capture a greater number of people, the System Review reports higher incidence statistics. In both measures the incidence of common mental health disorders is not captured by the definitions. The lack of robust data on the incidence of mental health disorders in Namibia has been criticised (Lang, 2008).

Further estimates of incidence are available in the 2005 National Policy for Mental Health. The incidence figures are similar to the statistics cited in the Healthcare System Review. The Policy estimates that 2-3% of adults in Namibia have serious mental health disorders and 10% have common mental health disorders, whilst 0.1-1% of children under the age of 15 have serious mental health disorders, with an additional 1% having learning or behavioural problems (Ministry of Health and Social Services, 2005). The Policy does not provide a definition for mental health disorder/disability but states that the incidence is calculated based on population projections. It is not clear from the policy what other factors were used to calculate these figures. Overall the statistics cited for the incidence of mental health disorders in adults are similar to the 10% global estimate, but again differ from the 20% global estimate for the incidence of mental health disorders in children (Patel, 2007; WHO, 2005a). One reason is because the data for children does not appear to include prevalence statistics for common mental health disorders.

Data from neighbouring South Africa suggests that the data in Namibia underestimates the true incidence of mental health disabilities and disorders. The South African Stress and Health (SASH) study, the first large-scale population-based study of common mental disorders conducted in South Africa, showed an adult prevalence of 30.3% (Herman et al., 2009). Diagnoses were made using the internationally accredited Diagnostic and Statistical Manual (DSM-IV) and the World Health Organization Composite International Diagnostic Interview (CIDI). Only 25.2% of the people with a mental health diagnosis had sought treatment within the previous 12 months. This suggests that there is a high level of unmet need in South Africa (Seedat et al., 2009). As Namibia and South Africa have many social and historical similarities, the data can be used to suggest that there is also a high level of unmet need for mental health services in Namibia.

There is sparse data available on the incidence of adult mental health disabilities and disorders in Namibia and there is even less information on the incidence of child mental health disabilities and disorders. A national representative study to assess the living conditions of people with disabilities, which assessed 2286 households with disabled members in Namibia, reported that almost half the respondents stated that the onset of their disability took place before the age of five (Eide, van Rooy & Loeb, 2003). Only three other studies have assessed the mental health needs of children in Namibia and these studies do not provide population-based data (Brown et al., 2009; Page & Hall, 2009; Ruiz-Casares, Thombs & Rousseau, 2009). The lack of information suggests that, as cited for the South African situation, the burden of mental illness in Namibia "has gone unrecognised because of scarce population-based data" (Lund, Stein, Bradshaw, Schneider & Flisher, 2008; 444). In light of the scarcity of information in this area, the purpose of this study was to explore the challenges parents/caregivers of children with mental health disabilities and disorders in Namibia face when attempting to access mental healthcare resources as a means to understand the better understand the reasons behind the lack of incidence figures for children with mental health disabilities and disorders.

## 1.2 THEORETICAL FRAMEWORK

The study primarily used a human rights framework to assess how the service provision in Namibia meets national and international standards. Article 24 (1) of the United Nations Convention on the Rights of the Child (CRC) requires State Parties to recognise "the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health." (United Nations, 1989). Article 23 of the CRC specifically refers to disability and requires State Parties to recognise "that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community".

Article 144 of the Namibian Constitution (Government of Namibia, 1990) provides for the automatic incorporation of international conventions into Namibian law. Therefore, the Convention on the Rights of the Child becomes part of Namibian legislation. However, it should be noted that despite this provision, international conventions often do not influence the Namibian situation until the provisions are domesticated into Namibian legislation or are tested in court (Dausab, 2010).

The Namibian Constitution also includes a provision for the "Promotion of the Welfare of the People" (Article 95) which requires the government to ensure the "enactment of legislation to ensure that the unemployed, **the incapacitated**, the indigent and the disadvantaged are accorded such social benefits and amenities as are determined by Parliament to be just and affordable with due regard to the resources of the State" (emphasis added). However, again this provision is a call-to-action rather than a definition of a right in itself.

The study also used a social construction framework to assess the data. This second framework is important as it allowed the researcher to analyse the impact of culture and social beliefs on access to mental health services as the way in which mental health is perceived helps to explain why parents of children with mental health disabilities and disorders are, or are not, accessing mental health services in Namibia. The use of this theoretical framework is supported by Earls, Raviola and Carlson (2009;295) who state "[t]he promotion of child mental health requires that children are viewed from their perspective in the social context in which they are developing".

## 1.3 PROBLEM STATEMENT

The need to address mental health disorders in children and adolescents is an international priority (WHO, 2001; WHO, 2005). Despite this call for action, many countries do not allocate sufficient resources to address the needs of children with mental health challenges. There is little data available regarding the specific challenges that Namibian children with mental health disorders face when accessing mental healthcare resources (Brown et al., 2009; Page & Hall, 2009) or a limited sample size (Ruiz-Casares, Thombs & Rousseau, 2009). This data is needed to support advocacy measures to increase service provision in this area. The purpose of this study was to explore the challenges of child mental health disabilities and disorders in Namibia through an assessment of the barriers parents, caregivers and relatives experience regarding access to mental health care for their children. The findings are used to develop recommendations for how service provision can be improved and how parents/caregivers of children with mental health disabilities and disorders can have better access to services.

## 1.4 RESEARCH QUESTION

1. What challenges do parents of children with mental health disabilities and disorders face when attempting to access mental health resources?

## 1.5 AIM OF THE STUDY

The aim of this study was to explore the experiences of parents or caregivers of children with mental health disabilities and disorders regarding access to mental healthcare.

## 1.6 OBJECTIVE OF THE STUDY

The objective of this study was to describe the problems that parents or caregivers of children with mental health disabilities and disorders experience when accessing healthcare resources for such children.

## 1.7 RESEARCH METHODOLOGY

This study used a qualitative exploratory design to identify the extent to which children with mental health disabilities and disorders are able to access healthcare resources. Whilst quantitative data can identify the incidence of children who face problems accessing mental health services, it is only through qualitative research that the meaning and diversity of perspectives of living with mental health disorders can be identified (Flick, 2006). The research paradigm for this study was human rights and social construction frameworks. These are utilised throughout the study.

## 1.8 SIGNIFICANCE OF THE STUDY

The information collected in this study has identified the problems and challenges experienced by children and their families when attempting to access mental health services. This has provided new information to a sparse research field. The participatory nature of the focus group discussions helped the participants to recognise the problems they are experiencing and to identify solutions to the barriers they experience. Through this study, dialogue about mental health disabilities and disorders in Namibia has increased and it is hoped that the study will promote further activity in this field. The findings have been used to develop recommendations for how service provision can be improved and how parents of children with mental health challenges can have better access to services. This information will be made available to decision-makers and the data can be used to inform change to service provision. It is hoped that through the removal of barriers, more parents/caregivers will be able to access mental health services for their children.

## 1.9 DEFINITION OF TERMS

### Child

According to the Convention on the Rights of the Child, the definition of a *child* is "every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier" (United Nations, 1989). It should be noted that the age of majority in Namibia is 21 (Age of Majority Act 57 of 1972).

### Disability

The term *disability* is defined in the 2006 Inter-Census Survey as "a limitation in carrying out everyday activities at home, at work, or at school because of long-term (lasting more than six months) physical or mental condition" (National Planning Commission, 2010; p 16). The Inter-Census Survey does not provide a definition for the term mentally disabled but the term is defined in the 2001 Census as: "persons who were mentally retarded and those who were mentally sick were classified under this category" (National Planning Commission, 2001; p 81).

### Mental health

*Mental health* is intellectual and emotional well-being as perceived through self-efficacy, autonomy and competence (WHO, 2001).

The definition of *mental health* in the National Policy on Mental Health is "a state of complete well-being that enables the fulfillment of one's full potential in occupational, social and relational functioning" (Ministry of Health and Social Services, 2005; p 23).

### Mental health disorders/mental health challenges

*Mental health disorders* are clinically significant conditions that present with symptoms of negative changes in thinking, mood, emotion, functioning and behaviour (WHO, 2001). Diagnosis of mental health conditions is usually made using either the ICD-10 Classification of Mental and Behavioral Disorders (ICD-10) (WHO 1992) or Diagnostic and Statistical Manual of Mental Disorders (DSM-IVTR) (American Psychiatric Association 2000).

*Serious mental health disorders* which can cause severe disability include depressive disorders, substance use disorders, schizophrenia, epilepsy, Alzheimer's disease, mental retardation, and disorders of childhood and adolescence (WHO, 2001).

*Common mental health disorders* which may not cause such severe disability include, amonst others, panic disorder, agoraphobia, specific phobias, social phobia, generalised anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder, separation anxiety disorder, mood disorders (major depressive disorder, dysthymia, bipolar I and II disorders), and substance use disorders (Kessler et al., 2005).

### Mental health legislation

In Namibia, the legislation on mental health is the Mental Health Act 18 of 1973.

### Mental health policy

In Namibia, the policy for mental health is the National Policy for Mental Health, 2005.

## 1.10 OUTLINE OF STUDY

This study consists of the following chapters:

**Chapter 1** contains the problem statement, the aim and objectives of the study and the significance of the study. The chapter also contains a brief overview of the theoretical framework and the methodology used.

**Chapter 2** describes the contextual framework for the study. The chapter reviews mental health from the theoretical frameworks of human rights and social construction. The chapter also reviews the status of mental healthcare in Namibia. Reference to regional studies is made where data from Namibia is lacking.

**Chapter 3** discusses the methodology used in the study. The data collection process and data analysis process are described and a review of the trustworthiness of the data and ethical considerations are given.

**Chapter 4** presents the results of the study and discusses the findings in the context of the relevant literature.

**Chapter 5** provides a summary of findings, methodological limitations and further research possibilities. The chapter makes recommendations for how service provision can be improved and how parents of children with mental health disabilities and disorders can have better access to services.

# CHAPTER 2

# CONCEPTUAL FRAMEWORK

## 2.1 INTRODUCTION

This chapter reviews mental health from the theoretical frameworks of human rights and social construction and reviews the status of mental healthcare in Namibia. Reference to regional studies is made where data from Namibia is lacking.

## 2.2 A HUMAN RIGHTS FRAMEWORK

Human rights are the basic fundamental rights that every person has such as the right to life, the right to dignity and the right to physical integrity. Human rights are defined in international treaties, in national Constitutions and in laws. As stated by Follesdal (2009; p 235) “human rights are claims that certain freedoms are very important, and that all have a moral obligation to consider what they should do to respect and protect these freedoms of everybody.” To analyse a situation through a human rights framework is to assess how the situation compares to agreed human rights standards as documented in international, national or local agreements.

A human rights framework for health does not provide for the right to health – something that is arguably impossible to achieve - but rather provides for the highest attainable standard of health. The difference between the right to [mental] health and the right to the highest attainable standard of mental health is explained by Gostin (2000; p 159; see also Gostin & Gable, 2004):

> States must ensure the conditions under which people can be mentally healthy. Governments can do a great deal to improve the mental health of individuals and

> populations, including providing decent economic conditions, social and welfare services, primary and secondary mental health care, community mental health services, and hospital-based treatment and services. Government obligations, then, go beyond the provision of discrete psychiatric medication to the assurance of a broad array of services that are necessary for populations to maintain mental health. The definition does not, however, ensure a minimal standard of mental health because, given widely disparate resource levels, a single international standard would be unworkable.

Therefore the human rights framework for mental health centres on the importance of *access* to mental health care services and *equal rights* for people with mental health disabilities. A human rights framework is relevant to this study as "a human rights approach, in conjunction with community engagement, can provide the structure and agency for promoting equity in health" – an important rights-based principle (Stuttaford, 2009; p 156).

## 2.3 THE HUMAN RIGHTS FRAMEWORK FOR THE MENTAL HEALTH OF CHILDREN

The mental healthcare needs of all people are broadly addressed in Article 12 (1) the 1966 International Covenant on Economic, Social and Cultural Rights and Articles 16 and 18 of the 1981 African Charter on Human and People's Rights. Namibia acceded to the Covenant in 1994 and it became effective in Namibia the following year. Namibia signed and ratified the Charter in 1999 and 2004.

Article 12 (1)

> 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

The African Charter specifically refers to mental health in Article 16 and refers to the needs of people with disabilities in Article 18:

Article 16

1. Every individual shall have the right to enjoy the best attainable state of physical and mental health.

2. States parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

Article 18

The aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs.

Namibia has signed three international conventions that specifically address the mental health needs of children. These are the 1989 Convention on the Rights of the Child, the 1990 African Charter on the Rights and Welfare of the Child (ACRWC) and the 2007 Convention on the Rights of Persons with Disabilities. Namibia signed and ratified the CRC in 1990, the ACRWC in 1999 and 2004, and the Convention on the Rights of Persons with Disabilities in 2007.

Article 24 of the CRC "recognises the right of a child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". Although the Article is silent on mental health as a specific category of healthcare, the Committee on the Rights of the Child addressed mental health in its General Comment No. 4, stating that Article 24 is applicable to mental health (footnotes from the excerpt not cited):

> Under article 24 of the Convention, States parties are urged to provide adequate treatment and rehabilitation for adolescents with mental disorders, to make the community aware of the early signs and symptoms and the seriousness of these conditions, and to protect adolescents from undue pressures, including psychosocial stress. States parties are also urged to combat discrimination and stigma surrounding mental disorders, in line with their obligations under article 2. Every adolescent with a mental disorder has the right to be treated and cared for, as far as possible, in the community in which he or she lives. Where hospitalization or placement in a psychiatric institution is necessary, this decision should be made in accordance with the principle of the best interests of the child. In the event of hospitalization or

> institutionalization, the patient should be given the maximum possible opportunity to enjoy all his or her rights as recognized under the Convention, including the rights to education and to have access to recreational activities. Where appropriate, adolescents should be separated from adults. States parties must ensure that adolescents have access to a personal representative other than a family member to represent their interests, when necessary and appropriate. In accordance with article 25 of the Convention, States parties should undertake periodic review of the placement of adolescents in hospitals or psychiatric institutions.
>
> United Nations, 2003; General Comment No. 4, paragraph 29

However, the Comment makes reference only to the needs of adolescents and is silent on the needs of younger children. Although data suggests that almost half of all lifetime disorders are diagnosed during adolescence (Kessler et al., 2005), this does not negate the importance of providing support for children who have mental health disorders from birth or who may develop disorders pre-adolescence.

Article 4 of the CRC reinforces the requirements of Article 24 through the requirement of State Parties to provide resources. Article 4 can be applied to the need for resources for mental health.

> Article 4
>
> **States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention.** With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation. (emphasis added)

The CRC also has a specific provision on disability (Article 23) – the first international treaty to do so. The Article requires State Parties to make special provisions for the needs of children with disabilities including the need to provide, wherever possible, free education, training, rehabilitation and health care services.

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development
4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

As discussed under section 2.2, the human rights framework for mental health centres on the importance of *access* to mental health. This is reflected in the CRC as the drafters specifically chose to use the wording “effective access” in Article 23 (3) to ensure that not only do services exist, but children with disabilities have access to them (Ang, 2007; United Nations, 1983).

Article 2 is also relevant to this study as it acknowledges the discrimination children with disabilities face by specifically prohibiting such discrimination.

Article 2 (1)

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language,

> religion, political or other opinion, national, ethnic or social origin, property, **disability**, birth or other status. (emphasis added)

In General Comment No. 4 the Committee stated that the term disability in Article 2 includes a mental health disability (United Nations, 2003). The Committee also addressed mental health in General Comment 6 which reviewed the rights of children with disabilities. The Committee stated:

> **"[t]his explicit mention of disability as a prohibited ground for discrimination in article 2 is unique and can be explained by the fact that children with disabilities belong to one of the most vulnerable groups of children.** In many cases forms of multiple discrimination - based on a combination of factors, i.e. indigenous girls with disabilities, children with disabilities living in rural areas and so on - increase the vulnerability of certain groups."
>
> United Nations, 2006; General Comment 9, paragraph 8 (emphasis added):

As noted by Combrink (2008; p 308), General Comment 9 is "potentially the most significant step taken by the Committee" to address the rights of children with disabilities. However, Article 23 and General Comments 4 and 6 are limited to a discussion of disability and do not sufficiently cover the concept of mental health disorders. Article 23 of the CRC has also been criticised for taking a welfare rather than rights-based approach (Jones & Basser Marks, 1997).

The ACRWC provides similar provisions for health (Article 14 (1)), albeit in less detail (Gose, 2002; Combrink, 2008). However, the provision on non-discrimination (Article 3) is weaker as it does not specifically prohibit discrimination on the basis of disability which is an unfortunate omission (Combrink, 2008).

Article 14 (1)
Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.

Article 3
Every child shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in this Charter irrespective of the child's or his/her parents' or legal guardians' race, ethnic group, colour, sex, language, religion, political or other opinion, national and social origin, fortune, birth or other status.

The Convention on the Rights of Persons with Disabilities addresses some of the criticisms of the CRC and the ACRWC by providing stronger mechanisms to overcome barriers and by taking a stronger rights-based approach to disability. However the Convention is again focused on the concept of disability rather than disabilities and disorders.

Article 7 of the Convention specifically focuses on children with disabilities:

Article 7:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

The United Nations describes the new Convention as bringing a “paradigm shift” in the approaches and attitudes toward disability, changing people with disabilities from objects to subjects (United Nations, 2010).

### 2.3.1. RECOMMENDATIONS ON MENTAL HEALTH MADE BY THE WORLD HEALTH ORGANIZATION

The WHO is the leading authority for health within the United Nations. The 2001 World Health Report, “*Mental Health: New Understanding, New Hope*” (WHO, 2001) was the start of a major focus to promote better service provision worldwide for mental health. For example, the 2003 *Mental Health Policy and Service Guidance Package* was developed to provide practical assistance for countries attempting to meet the recommendations made in the 2001 report (WHO, 2003a).

The WHO states that the starting point for intervention is to assess the mental health needs of the population (2003b; p 15, emphasis added):

> Countries encounter varying demands for services and unique cultural expressions of need. The economic context of a country frequently shapes the mental health resources that are available. For these reasons it is impossible to recommend a minimum level of care or a global norm, such as a minimum number of beds or staff..... **Countries should provide their own answers to these questions. This can be done with careful planning, based on a thorough assessment of local needs and existing services.**

This is because the WHO recognises the need to understand the social construction of mental health thus illustrating how the human rights and social construction frameworks are interlinked:

> The cultural context of mental health planning also has to be understood. How are mental health services perceived by the local community? What are the cultural or religious views of mental disorders? (WHO, 2003b; p 19).

Further details of the WHO recommendations on mental health are discussed in the context of the Namibian legislation on mental health.

There are also a number of other non-binding agreements which represent moral and political commitments to improving the standard of care and lack of discrimination against people with mental health disabilities and disorders. These commitments can be used to guide best practice or be used as reference points for policy or legislation development. Two examples are the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles) and the Standard Rules for Equalization of Opportunities for Persons with Disabilities (Standard Rules).

The MI Principles include a specific provision on minors, stating that “Special care should be given within the purposes of these Principles and within the context of domestic law relating to the protection of minors to protect the rights of minors, including, if necessary, the appointment of a personal representative other than a family member” (United Nations, 1991; Principle 2).

The Standard Rules do not have a specific rule for how minors should be treated but do provide for the appointment of a Special Rapporteur on Disability. The Rapporteur monitors the implementation of the Rules and provides another means for strengthening the human rights framework of mental health.

## 2.4 THE HUMAN RIGHTS FRAMEWORK ON MENTAL HEALTH IN NAMIBIA

The Constitution of Namibia includes provisions on respect for human dignity (Article 8) and freedom from discrimination (Article 10). These rights apply to all people although Article 10 does not specifically refer to freedom from discrimination against health disabilities or disorders, citing only sex, race, colour, ethnic origin, religion and social or economic status as specific grounds for non-discrimination.

International conventions have legislative applicability in Namibia as Article 144 of the Namibian Constitution provides for their automatic incorporation into Namibian law. Despite this provision, international conventions often do not influence the Namibian situation until the provisions are domesticated into Namibian legislation or are tested in court (Dausab, 2010). Furthermore, as the Namibian law on mental health has not been revised since 1973, the principles outlined in the conventions discussed under 2.3 – which were developed after this Act - have not yet been incorporated into Namibian law.

The Namibian Constitution also includes a provision for the "Promotion of the Welfare of the People" (Article 95) which requires the government to ensure the "enactment of legislation to ensure that the unemployed, the i**ncapacitated**, the indigent and the disadvantaged are accorded such social benefits and amenities as are determined by Parliament to be just and affordable with due regard to the resources of the State" (emphasis added). However again this provision is a call-to-action rather than a definition of a right in itself and it has not been tested in terms of the need for service provision for mental health.

Namibia also has a law and a policy on mental health (The Mental Health Act 18 of 1973; the National Mental Health Policy [Ministry of Health and Social Services, 2005]). The National Mental Health Policy is supplemented by a National Policy on Disability (Ministry of Lands and Resettlement, 1997). There is also a National Disability Council, as provided for by the National Disability Council Act 26 of 2004.

The WHO recommends a number of principles that should be included in mental health legislation. These include (1) the principles of the least restrictive alternative; (2) confidentiality; (3) free and informed consent; (4) involuntary admission as the exception; (4) automatic review of involuntary admission and treatment and (5) the appointment of guardians when a patient is not able to make decisions (WHO, 2003c). The 1973 Act meets some of these provisions, such as requiring consent for treatment where possible, requiring the automatic review of involuntary admissions and the appointment of a guardian. However, not all of the recommendations are met and none are met in sufficient detail.

The WHO has also made recommendations to meet the needs of children with mental health disorders. These include (1) suitable educational opportunities and facilities; (2) access to benefits; (3) promotion of mother-and-child bonding through provision of maternity leave;

(4) early detection and prevention of child abuse; (5) restricted access to drugs and alcohol; and (6) the establishment of mental health programmes in schools (WHO, 2003c). Again the recommendations have been met in part. Recommendation three has been met in the Labour Act 11 of 2007. Recommendations four and five will be met to some extent through the passing of the Namibian Child Care and Protection Bill (these issues are covered in the bill but direct linkages between the issues and children with mental health disorders are not made). Recommendation five is also addressed by the Liquor Act 6 of 1998 and the Abuse of Dependence-Producing Substances and Rehabilitation Centres Act 41 of 1971.

The Ministry of Health and Social Services acknowledges that the law on mental health is outdated and insufficient to meet national need and international best practice (Ministry of Health and Social Services, 2005; WHO, 2005a). The Ministry has discussed draft legislation to replace the Act and an eighth draft of a Mental Health Bill was circulated in 2011. However, the drafting process has been ongoing for many years and it is unknown whether a new law will be enacted in the near future. The consequences of insufficient protection for children with mental health illness have been seen in Namibia with the most recent example being an urgent application brought by the Legal Assistance Centre (a local non-governmental organisation) in 2010 to transfer a 15-year-old mentally ill boy from Windhoek Central Hospital following his alleged rape (Legal Assistance Centre, 2010).

The Mental Health Policy is also outdated as the health assessment used for the basis of the policy was conducted in 1996 - nine years before the policy was finally published. The policy is further weakened by the fact that Namibia does not have a separate policy for the mental health of children, despite this recommendation from the WHO (WHO, 2003d). An alternative option could be a separate section on children within a general policy on mental health. However, this is not the case in the current policy. The government recognises that the

Disability Policy is outdated (Ministry of Gender Equality and Child Welfare, undated) but unfortunately does not make a similar statement about the Mental Health Policy.

There are a number of structures aimed at addressing disability in Namibia but few structures that specifically focus on mental health disabilities and disorders. Government structures to address disability include a Disability Unit within the Office of the Prime Minister, a National Council on Disability and the Division of Disability Prevention and Rehabilitation within the Directorate of Primary Health Care Services in the Ministry of Health and Social Services. The government also signed the Continental Plan of Action which was developed as part of the African Decade of Persons with Disabilities (1999-2009). In its planning document Vision 2030, the government states that the steps taken by the government (including the signing of the United Nations Convention on the Rights of People with Disabilities) "reaffirm the country's commitment to autonomy, self-representation, full participation, empowerment and equality of people with disabilities." (Office of the President, 2007; p 243). Civil society lobbies for the rights of people with disabilities through the National Federation of People with Disabilities in Namibia.

Despite the existence of these structures, there appears to be limited action. For example, according to the most recent annual report from the Office of the Prime Minister (2008-2009), the Disability Unit conducted a survey on inclusive education, provided training on disability income-generating projects, assisted the University of Namibia in setting up a Disability Unit and conducted awareness-raising activities centred around the International Day of Persons with Disabilities (Office of the Prime Minister, 2009). Whilst these are positive actions, the magnitude is not sufficient to meet the demands of the relevant international conventions to which Namibia is a signatory. The Disability Unit did not appear to conduct any activities regarding accessing or improving access to healthcare services for children with disabilities. However, according to a regional disability policy review, the government through the Disability Unit is in the process of identifying disability focal points in all Ministries (Lang, 2008).

The functioning of the National Disability Council also appears to be problematic. The functions of the National Disability Council include a mandate to monitor the implementation of the National Policy on Disability, to identify areas for law and policy reform and comment on proposed legislation from the perspective of people with disabilities and to take all necessary steps to improve the situation of persons with disabilities in Namibia. Addressing the needs of children with disabilities should be included under these functions. However, there are no available reports documenting actions conducted by the Council as although government ministries are required to submit a report on the implementation of Disability Policy to the Council, such reports have not been submitted. Neither has the Council drafted annual reports which should be submitted to the Minister of Health and Social Services and then to the National Assembly as required by the National Disability Council Act.

### 2.4.1 THE HUMAN RIGHTS FRAMEWORK ON MENTAL HEALTH IN NAMIBIA– A REGIONAL PERSPECTIVE

The legislative and policy framework for the region is poor as the mental health framework for South Africa, Ghana, Uganda and Zambia has been described as weak, in draft form, non-existent and poorly implemented. Reasons for these problems include lack of political will and stigma, lack of resources, decentralisation of services and lack of consultation during policy development (Omar et al., 2010). Despite this low standard, the legislative and policy framework for Namibia still lags behind (see Table 2.1). Much of the information for the region has been documented by the Mental Health and Poverty Project (MHaPP), a consortium of researchers set up to evaluate mental health policy in poor countries in order to provide new knowledge regarding comprehensive multi-sectoral approaches to breaking the negative cycle of poverty and mental ill-health. Even where progress is being made, researchers have still identified a failure to effectively integrate mental health services into primary care or to recognise the specific needs of children with mental health challenges (Ssebunnya, Kigozi, Kizza, Ndyanabangi, & MHaPP Research Programme Consortium, 2010).

**Table 2.1: A comparison of mental health legislation, policy and plans across the region**

| | **Namibia** | **Ghana** | **South Africa** | **Uganda** | **Zambia** |
|---|---|---|---|---|---|
| **Mental health legislation** | 1973<br>(draft 2011) | 1972<br>(draft 2006) | 2002 | 1964 | 1951<br>(draft 2006) |
| **Provides for protection of minors[1]** | No<br>(common law does exist) | 1/6 | 1/6 | No | No |
| **Mental health policy** | 2005 | 1994 | 1997<br>(draft 2006) | (draft 2000) | 2005 |
| **National mental health plan** | No | 1976 | No | In Health Sector Strategic Plan, 2005 | No |
| **National child and adolescent mental health plan** | No | No | 2002 | No | No |

The 6 provisions for protection of the rights of minors in the WHO Legislation Checklist [*Adapted from Kleintjes, Lund, Flisher, and MHaPP Research Programme Consortium, 2010 (data for Namibia added)].*

## 2.5 SUMMARY OF THE HUMAN RIGHTS FRAMEWORK FOR MENTAL HEALTH

The international human rights framework for children with mental health disorders is based on international agreements and information about best practice from the World Health Organisation. Namibia is a signatory to three conventions that promote the human rights of children with mental health disorders. However, service provision for mental health in

Namibia does not meet international standards and significant change is needed to improve the status of mental health in Namibia.

The next section reviews the impact of mental health challenges from a social construction perspective.

## 2.6 A SOCIAL CONSTRUCTIONIST PERSPECTIVE

A social construction is “an invention or artefact of a particular culture or society”; social constructionism is “a theory of knowledge that considers how social phenomena develop in particular social contexts” (Gilbert, 2008; p 514). The term social construction has also been described as “a tradition of scholarship that traces the origin of knowledge, meaning or understanding to human relationships” (Gergen & Gergen, 2007; p 461, 462). This means that “what we take to be true as opposed to false, objectives as opposed to subjective, scientific as opposed to mythological, rational as opposed to irrational, moral as opposed to immoral, is brought into being through historically and culturally situated social processes”. To view a situation from this perspective is to assess a situation from the context within which it is assessed, according to a group understanding of “convention, human perception and social experience” (Gilbert, 2008; p 506).

One of the earliest contributors to the social constructionalist theory was Emile Durkenheim (1858-1917). In his pivotal work on suicide, Durkenheim showed that the incidence of suicides was related to social integration. Durkenheim used this relationship to argue that contextual information is needed to accompany facts to explain why a situation occurs (Babbie & Mouton, 2009). Whilst researchers have subsequently criticised Durkenheim’s work, the principle holds true that the context of a situation is often critical to explaining the “why” and “how” of an occurrence. As a result, following Durkenheim’s seminal work, a theory of research has developed which states that there is never one single reality but instead many interpretations of a situation.

The use of the social construction lens to view barriers to mental healthcare is relevant to this study as "people living with mental illness have always faced difficulties in participating in society because of pressure to conform to normal social and legal standards" (Dhanda & Narayan, 2007). Earls, Raviola and Carlson (2009; p 295) also state that "[t]he promotion of child mental health requires that children are viewed from their perspective in the social context in which they are developing". Finally, as Gergen and Gergen explain, whilst scientists and social scientists would both agree "that while Western medical science does succeed in generating what might commonly be called 'cures' for that which is termed 'illness', these advances are dependent upon culturally and historically specific constructions of what constitutes an impairment, health and illness, life and death, the boundaries of the body, the nature of pain, and so on... The constuctionist does not abandon medical science but attempts to understand it as a powerful cultural tradition" (p 463).

## 2.7 THE SOCIAL CONSTRUCTION OF MENTAL HEALTH

The social construction of mental health includes the impact of stigma and discrimination, poverty, the economics of mental health care, the impact of HIV/AIDS and the role of traditional healers. Each of these factors impacts on access to services. Research pertaining to these factors is reviewed below.

### 2.7.1 STIGMA AND DISCRIMINATION

Many people with mental health disorders face stigma and discrimination (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Kakuma et al., 2010). Ssebunnya, Kigozi, Lund, Kizza & Okello (2009) conducted focus group discussions and semi-structured interviews with mental health stakeholders in Uganda to assess barriers to mental health services. The study showed that there is a relationship between stigma, poverty and mental illness, particularly due to local belief systems. Similar assessments have been conducted in Ghana, where words such as social isolation, abnormal and antisocial behaviour, dishevelled and dirty dress, nakedness, talking to oneself, and aggression have been reported as associated with mental health disorders (MHPPP, 2008).

In Zambia stigma and discrimination was found to be “ubiquitous and insidious” across all levels of society from the family of the person with mental illness to service providers and policy makers (Kapungwe et al., 2010 p.200). Kapungwe et al. (2010) noted that some healthcare professionals have negative attitudes towards mental illness, although this behaviour was often more subtle than that exhibited by community members. The researchers also noted the belief that people with mental health disorders are HIV positive is widespread and people suffer from stigma about both conditions. Reasons behind the stigma identified by the participants included fear of disease transmission and fears that the person may be dangerous. A study conducted in Nigeria also reported that mental health patients are often described as dangerous and of low intelligence (Gureje, Lasebikan, Ephraim-Oluwanuga,, Olley, & Kola, 2005).

A paper summarising the regional pattern of stigma and discrimination concludes that stigma is often a barrier to services because people do not want to admit to a mental health disorder, or they fear a negative reception from service providers and the community if they ask for help. This problem affects both the patient and family members (Kleintjes, Lund, Flisher, & MHaPP Research Programme Consortium, 2010).

The only peer-reviewed information on mental health and stigma in Namibia is the acknowledgement in a small qualitative study that patients are affected by stigma (Shifiona, Poggenpoei, & Myburgh, 2006). More information on the impact of stigma and discrimination on mental health in Namibia is needed.

The government recognises the problem of stigma and disability in its planning document Vision 2030, stating that:

> many in Namibia, in the Southern African Development Community, in Africa and internationally still view disability as a health and rehabilitation issue. The medical mode of disability casts people with disabilities in a subordinate role in their encounters with doctors, rehabilitation professionals, governmental bureaucrats and social workers, who often aimed to help the disabled to adjust to a society structured around them at the convenience and interest of those without disabilities.
>
> Traditionally, society has viewed and treated individuals with disabilities as needing assistance to participate in mainstream community activities. The underlying social ethos behind such a response has been one that segregated and excluded people with disabilities from mainstream society, sometimes providing them with special schools, sheltered workshops and separate projects, such as income generating projects for people with disabilities. The philosophy was justified by the pervasive belief that people with disabilities are incapable of coping with either society at large or most major life events/activities. It is acknowledged that people with disabilities are experiencing a broad range of barriers to their full participation in their communities.
>
> Office of the President, 2007; p 242

The government also recognises the problem of negative attitudes of the community towards people with disabilities in its most recent periodic report on the implementation of CRC (Ministry of Gender Equality and Child Welfare, undated). There does not appear to be any information on the recognition by the government of a link between stigma and mental health disorders.

### 2.7.2 POVERTY

A link between poverty and mental health disorders in low-middle income countries is acknowledged in the literature. Poverty can exacerbate the impact of mental health challenges and mental health challenges can exacerbate poverty (Patel & Kleinman, 2003). An inverse correlation between prevalence of mental health illness and income has been identified globally and regionally (Pickett, James, & Wilkinson, 2006; Fryers, Melzer, Jenkins & Brugha, 2005). In a study of the distribution of common mental health disorders correlated with social inequality in Europe, the authors gave a rough estimate that disadvantaged groups have a 1.5-2 times greater risk of common mental disorders compared with the least disadvantaged groups (Fryers, Melzer, Jenkins & Brugha, 2005).

The difference between accessibility to services for rural and urban children with mental health challenges has been studied in Australia (Aisbett, Boyd, Francis, Newnham & Newnham, 2007; Kurtin, Barton, Winefeld & Edwards, 2009). Through the use of focus groups and interviews with service providers, the researchers found that children living in rural areas had poorer access to healthcare services. Aisbett, Boyd, Francis, Newnham and Newnham (2007) divided the barriers into three main themes, namely (1) accessibility issues; (2) stigma and social exclusion, and (3) characteristics of rural communities. Kurtin, Barton, Winefeld and Edwards (2009) identified five themes; (1) community and society factors; (2) youth issues; (3) indigeneity; (4) service delivery and utilisation; and (5) occupational factors (see Table 2.2). They concluded that to improve the service provision for adolescents with mental health needs in rural areas, there should be increased engagement with young people, youth-friendly facilities and increased collaboration between service providers.

**Table 2.2: Themes and codes identified in an assessment of the extent to which the mental health needs of adolescents living in rural areas are met in rural Australia (Kurtin, Barton, Winefeld & Edwards, 2009)**

| Theme | Codes |
|---|---|
| community and society factors<br>*(aspects of local communities and society which work to affect the mental health of adolescents.)* | rural lifestyle<br>boredom<br>homogeneity<br>isolation<br>financial factors<br>farming<br>stigma |
| youth issues<br>*(mental health and behavioural problems including social, gender and youth issues which impact upon the mental health of adolescents.)* | drugs & alcohol<br>risky behaviour<br>mental health problems<br>depression<br>anxiety<br>suicide<br>school problems<br>bullying<br>relationships |
| indigeneity<br>*(aspects of indigenous culture impacting on the mental health of adolescents, and their access/use of existing services)* | cultural differences<br>indigenous issues<br>shame<br>grief & loss<br>barriers to services<br>staff & training |
| service delivery and utilisation<br>*(factors which impede the appropriate delivery of mental health services to adolescents)* | access to system<br>financial barriers<br>bureaucracy<br>distance & travel<br>waiting times<br>future needs<br>staff/services<br>training<br>youth-friendliness<br>funding<br>resource usage |
| occupational factors<br>*(factors related to the vocation of human service which impact on the successful delivery of mental health service and influence the individual experience of service providers)* | collaboration<br>confidentiality<br>time constraints<br>GP burden<br>competence<br>psychiatric training |

The relationship between poverty and mental health in Namibia is complicated by the fact that a substantial proportion of healthcare in Namibia is administered through private healthcare providers (Sekhri & Savedoff, 2005). Currently it is estimated that 28% of people in Namibia have private health insurance; a finding that is considered high for Sub-Saharan African countries (Gustafsson-Wright, Asfawb, and van der Gaag (2009). This finding is supported by a regional study which shows that individuals in Namibia spend a relatively low amount on out-of-pocket healthcare (6%) compared with countries such as Chad (62.2%); Zimbabwe (34.3%); and Zambia (29.1%); (Leivea & Xu, 2008). This suggests that access to good-quality healthcare services in Namibia may be possible for more people in Namibia compared with people in neighbouring countries.

However, this data may be misleading as Namibia has one of the highest Gini Co-efficients in the world (United Nations Development Project, 2009). A local study which sampled data from households in the greater Windhoek area in 2006 reported that in the poorest consumption quintile, only 5.27% of people were enrolled in a medical aid fund compared with to 69.14% in the wealthiest quintile (MRCC/AIID/PharmAccess Foundation, 2007).

The data from the regional studies also differ from the data shown in table 2.3 which shows out-of-pocket expenditure at 15.7% in Namibia in 2006 (WHO, 2008). By itself table 2.3 suggests that the level of healthcare service provision in comparison to other countries in the region is fairly good. However the data is for all healthcare services and does not give specific information on access to mental health services.

**Table 2.3: Statistics on healthcare service provision (World Health Organization World Health Statistics 2009)**

| Country | Total expenditure on health as % of gross domestic product | | General government expenditure on health as % of total expenditure on health | | Private expenditure on health as % of total expenditure on health | | General government expenditure on health as % of total government expenditure | | External resources for health as % of total expenditure on health | | Out-of-pocket expenditure as % of private expenditure on health | | Private prepaid plans as % of private expenditure on health | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Year | 2000 | 2006 | 2000 | 2006 | 2000 | 2006 | 2000 | 2006 | 2000 | 2006 | 2000 | 2006 | 2000 | 2006 |
| Namibia | 7.0 | 5.4 | 68.9 | 66.7 | 31.1 | 33.3 | 13.1 | 10.5 | 3.8 | 21.1 | 18.2 | 15.7 | 77.3 | 79.1 |
| Zambia | 5.7 | 6.2 | 51.3 | 60.7 | 48.7 | 39.3 | 9.4 | 16.4 | 17.8 | 38.1 | 80.5 | 67.2 | 0.7 | 3.7 |
| Ghana | 7.2 | 5.1 | 41.4 | 34.2 | 58.6 | 65.8 | 10.8 | 4.4 | 9.5 | 22.6 | 79.6 | 77.8 | 6.1 | 6.0 |
| Uganda | 6.6 | 7.0 | 26.8 | 25.4 | 73.2 | 74.6 | 7.3 | 8.9 | 28.3 | 31.2 | 56.7 | 51.0 | 0.1 | 0.2 |
| South Africa | 8.1 | 8.0 | 42.4 | 37.7 | 57.6 | 62.3 | 10.9 | 9.1 | 0.3 | 0.9 | 18.9 | 17.5 | 75.6 | 77.7 |

Therefore overall, whilst funding for healthcare services may not be as low as in neighbouring countries, poverty is still likely to be a barrier towards accessing healthcare in Namibia. The high proportion of private healthcare services may also mean that public pressure to achieve the highest-attainable quality of government healthcare services is reduced, thus meaning that the quality of services that poorer economic groups are able to access remains low.

A further problem with the provision of private healthcare is that private healthcare systems can themselves be a barrier to mental health care. This is because medical aid funds often provide fewer services for mental health conditions compared to physical illnesses (Barry & Ridgely, 2008; Busch & Barry, 2007; Busch & Barry, 2009; Oosthuizen et al., 2004; Zuvekas

& Meyerhoefer, 2006). This is arguably discriminatory (Busch & Barry, 2007). Unfortunately there is no information available in Namibia to show what barriers or positive effects private insurance has on access to mental health services, although South African data is available and suggests medical aid schemes can be discriminatory between physical and mental illness (Oosthuizen et al., 2004).

### 2.7.3 MENTAL HEALTH AND HIV/AIDS

Stein, Seedat and Emsley (2005;167) state that "the biggest mental health challenge in Africa, now and in the foreseeable future, is HIV/AIDS". This is because mental health problems can increase the risk of HIV infection due to increased risk-taking behaviour or reduced ability to prevent abuse and because mental health problems can occur both as a result of HIV infection – both as a neuropsychiatric manifestation of the disease and as a psycho-social impact of the disease (Cournos, McKinnon, & Wainberg, 2005). The combination of mental illness and HIV infection may also result in duel stigmatisation (Kapungwe et al., 2010).

Children orphaned by HIV/AIDS have also been shown to be at greater risk of psychological problems compared to the general population (Cluver & Gardener, 2007; Cluver, Gardner, & Operario, 2008; Cluver & Orchin, 2009). Harms, Kizza, Sebunnya and Jack (2009) assessed the psycho-social impact of HIV and mental health challenges in Uganda. They found that the Lugandan language does not have a word for mental health and that youths were confused by the terminology. This lack of recognition of the problem can be one of the reasons why there is little support for mental health problems associated with HIV/AIDS. The researchers stated that the data collected suggests that Western methods of addressing mental health, including the terminology used and pharmacological treatment, are not sufficient to address the mental health needs of children in Africa.

However, more information is required to understand the relationship between HIV/AIDS and mental health as recent reviews suggest that whilst some studies show a significant correlation between HIV infection and mental health, others do not show such a connection (Brandt, 2009; Earls, Raviola & Carlson, 2009; Harms, Kizza, Sebunnya & Jack, 2009).

A situational analysis of HIV and disability in Namibia has been conducted by the Secretariat of the African Decade of Persons with Disabilities. The report identified problems between integrating policy objectives to reduce problems related to HIV and disability with concrete actions (Secretariat of the African Decade of Persons with Disabilities, 2008). Some examples of particular challenges are:

- "People with disabilities are still extremely poor and struggle with basic needs like food, shelter, education and employment. All these take precedence over the dangers of HIV/AIDS. In general if a person has two dollars, he or she will spend this on bread and not on condoms" (p 25);*
- "People with disabilities are still often seen as people who don't have sexual needs and therefore no need for HIV education" (p 26);
- "A certain group of people with mental disabilities is sexually very active and extremely vulnerable... Some parents deny their children access to sexual education, because they want to protect them, while other communities actively strive to sterilize young adults with mental disabilities (Omaheke Region), but forget to inform them on the dangers of HIV/AIDS ( p 31)".

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* It should be noted that the government has made efforts to provide free condoms - the government distributed 30, 314, 800 condoms and 1, 162, 000 femidoms during the 2008-

2009 financial year - however these may not be accessible to all (Directorate of Special Programmes, 2009)

### 2.7.4 MENTAL HEALTH AND TRADITIONAL HEALERS

The WHO acknowledges that many people with mental health disorders experience social and financial barriers that prevent them from accessing healthcare services (WHO, 2001). The prevalence of traditional healers in Africa provides an alternative option of healthcare but whilst some mental health patients may choose to access this form of healthcare, others may be forced to seek help from traditional healers because of barriers experienced elsewhere. An important concern is that traditional healers may not be equipped to deal with the neurological needs of the patient.

The results of a study conducted in Ghana shows that 6% of people with mental health disorders had seen a traditional healer (Appiah-Poku, Laugharne, Mensah, Osei & Burns, 2004) and the Mental Health and Poverty Project report for Ghana states that traditional healers fill a "'yawning gap' in mental health service provision, particularly in providing psychosocial and spiritual support" (2008; pp 40). In Tanzania twice the number of patients with mental health disorders visited traditional healing centres (centres managed by herbalists, diviners, herbalists and faith healers) compared to primary care centres (Ngoma, Prince & Mann, 2003).

There is no information on the use of traditional healers for mental health illness in Namibia.

## 2.8 MENTAL HEALTH SERVICES IN NAMIBIA

According to Namibia's Mental Health Policy, a total of 211 psychiatric beds provide for the mental health needs of 1.8 million people in Namibia. One hundred and twelve beds are provided at the Windhoek Central Hospital and 90 beds are provided at the Oshakati Psychiatric Unit. There is also a mental health unit in Rundu State Hospital, which is managed under the auspices of the mental health unit at the Windhoek Central Hospital. Emergency mental health services are available at district hospitals (MHSS, 2005). Private facilities are provided by the Okonguarri Psychotherapeutic Centre in Otjiwarongo and the organisation Leonard Cheshire has two residential facilities in Namibia offering services for children with disabilities.

As of 2005 there were 1.5 psychiatric beds and 0 psychiatric nurses per 10 000 population and 0.2 psychiatrists, 6 psychologists, and 6 social workers per 100 000 population in Namibia (WHO, 2005a). In 2011 the Health Professions Council of Namibia reports that there are now 90 registered psychologists which is the equivalent of 4 psychologists per 100 000 of the population. The Council was not able to provide data on the number of registered psychiatric nurses but stated that as psychiatry is one of the major subjects in the nursing diploma/degree most of the 5600 registered nurses in Namibia are trained in psychiatry (Health Professions Council of Namibia, personal communication, 31 March 2011).

Published information on mental health resources for children is not available as Namibia did not provide data for the WHO Child and Adolescent Mental Health Resources assessment (WHO, 2005). Neither is information on the number of mental health care professionals working with children recorded by the Health Professions Council.

The current level of service provision is lower than government projections. The second National Development Plan (effective 2001/2002 - 2005/2006) recommended that 80% of health facilities should have personnel trained in mental health. However, the third National

Development Plan (effective 2007/2008 - 2011/2012) reports that this has been achieved in only 10% of health facilities (National Planning Commission, 2008). The report does not assess the quality of service delivery in the 10% of health facilities now equipped. As Vision 2030 has a broad-based commitment of “eliminating the main causes of physical ill health, as well as mental and social ailments” before 2030 (Office of the President, 2004; page 23), Namibia has a substantial way to go to meet these commitments.

Educational services for children with disabilities or disorders are provided through a total of nine special schools – seven in the Khomas region: NISE (National Institute for Special Education), NISE Visual impairments, NISE Hearing impairments, Môreson (a State school for learners with intellectual impairments), Dagbreek (a private school for learners with intellectual impairments) Pionier Boys (learners with learning disorders) and Eros Girls (learners with learning disorders), one in the Hardap region: Klein Aub (learners with learning disorders) and one in Ohangwena: Eluwa Visual impairments and Hearing impairments Outapi (learners with learning disorders). Mainstream schools also accept learners with mental health disabilities and disorders but often do not have special facilities to assist these learners.

Statistical data from the Ministry of Education reports that 32,169 learners with disabilities were enrolled in the education system in 2009. Of these learners, 17,346 have a mental health problem (see table 2.4). When broken down by region, the majority of learners with disabilities live in the Khomas, Ohangwena and Kavango regions (EMIS, 2009, table 61). This may be due to proximity to the main hospitals providing mental health services (the Central Hospital in Windhoek- Khomas region, the Oshakati State Hospital in the Oshakati region (next to Ohangwena) and the Rundu State Hospital in the Kavango region) and because the two specialist schools are found in the Khomas region The lack of robust data for children with disabilities in the education system has been criticised (Lang, 2008).

**Table 2.4: Total number of children with disabilities enrolled in the education system and type of disability**

| Total | Both Visual and Hearing | Partially blind | Totally blind | Hard of Hearing | Deaf | Epileptic | **Behavioural Disorder** | **Mild Intellectual** | **Severe Intellectual** | Physical | **Learning Disorder** | **Autistic** | Other |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **32 169** | **919** | **4 309** | **196** | **4 929** | **614** | **1 331** | **5 308** | **3 596** | **1 039** | **1 376** | **7 057** | **316** | 1 179 |

Although service provision for mental health in Namibia is low, from a regional perspective service provision is better than neighbouring countries. For example, whilst Namibia has 12.2 mental health professionals per 100 000, Ghana has 2.15, Zambia 5.1 and Uganda 7.6 (Table 2.5; WHO 2008).

**Table 2.5: A regional comparison of health services**

| Country* | Income category | Gross national income per capita (US$) - 2006 | Population in thousands (2002) | MNS disorders DALYs** (per 1000) | MNS disorders DALYs (per 100 000) | Mental health Professionals*** (per 100 000) | Health providers (per 1000) |
|---|---|---|---|---|---|---|---|
| **Namibia** | **Low-middle** | **3230** | **1 961** | **34** | **1743.2** | **12.2** | **3.35** |
| Zambia | Low | 630 | 10 698 | 172 | 1604.7 | 5.1 | 2.13 |
| Ghana* | Low | 520 | 20 471 | 372 | 1818.0 | 2.15 | 1.07 |
| Uganda | Low | 300 | 25 004 | 377 | 1508.5 | 7.6 | 0.81 |

* Countries selected because they have a low or low-middle income status. Namibia has a far higher gross national income per capita, but a sparse population. The small size of the population in relation to the size of the country presents problems of its own.

** MNS = Mental, neurological, and substance use (MNS) disorders; DALYS = Disability adjusted life years

*** Definition of mental health professional not provided

## 2.9 THE MENTAL HEALTH OF CHILDREN IN NAMIBIA

Limited data is available on the number of children with mental health disabilities and disorders in Namibia. The published data that is available is combined in multi-country studies (Brown et al., 2009; Page & Hall, 2009) or of limited sample size (Ruiz-Casares, Thombs & Rousseau, 2009).

Data from the multi-country studies (Brown et al., 2009; Page & Hall, 2009) is taken from the Global School-based Student Health Survey conducted by the WHO (2010). Brown et al., and Page and Hall analysed data from all five Southern African countries assessed (n=22 656; Namibia n=6367; 28%). Using the total dataset, Brown et al. (2009) reported that of the children exposed to physical and/or sexual violence, 29% had planned suicide in the twelve months preceding the survey (standard error 0.93). Assessing the Namibian data alone 41.9% of children had attempted suicide one or more times in the past 12 months (n=4554) and 21.3% had seriously considering attempting suicide (n=5991), with 35.9% making a plan for how they would commit suicide (n=6130; Ministry of Health and Social Services, 2008). This finding is supported by a comment in the Namibian Mental Health Policy which also reports suicide and suicide ideation to be a concern (Ministry of Health and Social Services, 2005). However, the only other published information for Namibia on suicide is a narrative report (Feinstein, 2002).

A retrospective assessment of medical autopsy reports between 1993-2003 in Transkei, South Africa, shows a similarly high incidence of suicides. The data shows that of the 10 340 reports assessed, 3.84% of the suicides were caused by hanging. Of this data, 23% of the incidents occurred in people under the age of 20 (Meel, 2009).

Page and Hall (2009) assessed the relationship between sexual behaviour, alcohol use and indicators of psychosocial distress in adolescents. The data showed that adolescents who reported psychosocial distress and alcohol use were at higher risk of having sex (the correlation to sex was used as an example of risk-taking behaviour). The Namibian Mental Health Policy conducted in 1996 reports that alcohol, tobacco and drug abuse are problems and that “drug induced mental disorders are therefore a major concern” (Ministry of Health and Social Services, 2005; p 3).

In a smaller study of 157 children in Namibia, Ruiz-Casares et al. (2009) reported that double orphans (children who have lost both parents) were significantly more likely to be rated as depressed compared to non-orphans (p=0.037). The difference for single orphans (children who have one parent still living) was higher than for non-orphans but was not significant. The researchers concluded that high levels of psychological distress are present in approximately one in six children in Namibia. Calculated as a percentage (17%), this correlates with the world estimate of a 20% burden of mental health disorders in children and adolescents (WHO, 2005). However, one might expect that the burden of mental health disorders in this specific subpopulation of at–risk children should be higher than the general global incidence of mental health disorders. These three studies indicate that there may be a high prevalence of mental health disorders in Namibia. Further research in this area is needed.

National reports provide little further data and all focus on disability. A situational analysis of children and adolescents in Namibia includes reports from 28 children with disabilities who participated in focus group discussions for the study. The children reported feeling sad and angry about their lives due to the attitude of people who care for them. School carers reported challenges with the provision of education services, stating that some parents of children with disabilities are unwilling to pay school fees as they do not see the children receiving any benefit from their education (National Planning Commission, 2010).

Similar findings were published by a researcher who conducted a small qualitative study in rural Namibia (emphasis added):

> Obtaining data about the inclusive practices of the rural and remote schools we visited in northern Namibia became a moot issue, as **I learned that children with any type of severe or visible disability simply are not sent to school**. Allusions were made to schools in urban areas for children with disabilities, but no one could offer specific information. Two representative responses are provided. Sch-4/T-1 held that “there are no children with disabilities at this school. It is possible to send children with disabilities to special schools in the urban areas. Whether or not they go depends upon the parents. Parents are not required to send the children to special schools. Parents may keep the children at home. Children are definitely not sent to a regular school.” Sch-6/PT-1 disclosed “there is no such school here. The [disabled] child sits in the house; stays at home and … [relating the case of one deaf child who came to school, but was unable to learn] … no one knew how to teach him, so then he stayed at home.” (Lopez Levers, 2002; page 120)

The only other national data available is information about disability grants dispersed to children by the Ministry of Gender Equality and Child Welfare. In 2010 the Ministry provided disability grants to 1821 children (Ministry of Gender Equality and Child Welfare, 2010). The data is not broken down into physical and mental disabilities. Even combined, the number of recipients is clearly lower than the number of children with disabilities enrolled in the education system – a number that is itself likely to be an underestimate of the true incidence of children with disabilities.

A similar situation is seen with the disbursement of the disability grant to adults. According to Vision 2030, disbursement is currently only achieved to 40.8% of people who should be receiving the grant. The government has set a target of 95% disbursement. Despite the current low level of disbursement, the government describes the provision of basic state grants to the elderly and people living with disabilities as one of its five flagship programmes (Office of the President, 2007). Critics however have described the disability grant as “grossly inadequate” (Lang, 2008; p 14). The allocation of the grant largely on the basis of medical diagnosis was another criticism of the grant in the same report. This is a valid point given that a medical diagnosis may preclude many children and adults from receiving the grant if their condition is not clinically significant but is dishabilitating.

Given the paucity of data on the mental health needs of children in Namibia, the best indication comes from South Africa. In a study to assess the prevalence of mental disorders among children, adolescents and adults in the Western Cape of South Africa, Kleinjkies et al., (2006) found that 17% of children and adolescents have a mental health disorder. This is within the estimated global prevalence of 10-20% (WHO, 2001). The South African Stress and Health (SASH) study also showed that 12.8% of participants were diagnosed with a common mental disorder before the age of 18 (Myer et al., 2009).

## 2.10 BARRIERS ACCESSING MENTAL HEALTH SERVICES IN NAMIBIA

The majority of children access healthcare services through the assistance of parents or caregivers. Therefore, general barriers to accessing healthcare as experienced by adults are relevant to this study.

The 2006-2007 Demographic and Health Survey reports that 70.4% of women report at least one of seven specified problems accessing healthcare services. The problems are (1) concern that there is no service provider available (43.7%); (2) problems with transport (41.7%); (3) distance to the health facility (41.5%); (4) getting money for treatment (38.9%); (5) not wanting to go alone (25.9%); (6) concern that there is no female service provider available (16,5%); and (7) needing to get permission to go for treatment (10.1%)(Ministry of Health and Social Services, 2008a).

The National Policy for Mental Health identifies the following barriers to accessing mental health services in Namibia (Ministry of Health and Social Services, 2005; p 7):

- Lack of skilled health care professionals
- Inability to accurately diagnose mental disorders
- Inaccessibility of available services
- Ill-informed belief systems about the causes, as well as the treatment of mental disorders
- Lack of follow up and after care
- Lack of rehabilitation programmes and facilities
- Lack of knowledge regarding mental health among key decision-makers
- Lack of regional level management representation for mental health
- Lack of up-to-date legislation.

The policy also criticises the referral system for mental health and states that “services are not community-based and inadequately integrated into primary health care” (page 7).

Barriers that prevent access to mental health services have also been reported in the 2008 Health and Social Services System Review. These include lack of personnel, lack of facilities and equipment and distance from services, particularly for the rural population (Ministry of Health and Social Services, 2008).

Further problems with service provision in Namibia have been noted in the literature. Ikealumba (2006) assessed the prevalence rate of suicide in a single hospital in Namibia and concluded that “the lack of a clear, coordinated, multidisciplinary management approach to the survivors of a suicide attempt appeared to be a serious gap in management”. Shifiona, Poggenpoei,and Myburgh (2006; p 6) describe problems with mental health services in the Ondangwa region (where the Oshikati Psychiatric Unit is located) as “characterised by inadequate mental health facilities, insufficient mental health personnel like psychiatrists, psychiatric nurses, social workers and clinical psychologists, as well as a lack of interest and a negative attitude towards mental illness among some of the health personnel".

A visiting Canadian psychiatrist in 2003 stated in his report that: "[i]n Namibia, mental health and physical health are very separate in the health care structure," (Sibbald, 2003; p 463). He further stated that "addressing mental health issues is seen as almost a luxury" and commentator Feinstein (2002) notes that the healthcare system is overwhelmed by the burden of care for patients with mental health disorders. A review of the healthcare services in Namibia (McCourt & Awases, 2007:3) provides a useful summary of the situation. Whilst the Namibian healthcare system has "done well in providing basic public health facilities and managing its staff.... the relatively sound healthcare infrastructure" is "creaking under the weight of these problems".

However, it should be noted that a 2008 regional disability policy review which assessed the situation in Namibia did find that "large majority of disabled people were able to access health services, with over two-thirds of respondents actually doing so" (Lang, 2008; p 10). Furthermore, in a national representative study to assess the living conditions of people with disabilities, which assessed 2286 households with disabled members in Namibia, the authors reported that health services were generally available for the large majority of people with disabilities, with two thirds of those who needed services receiving them. The report stated that primary healthcare clinics and hospitals were among the most accessible facilities (Eide, van Rooy & Loeb, 2003).

Similar problems have been noted within the continent. In Ghana researchers reported that barriers to the implementation of the national mental health policy include lack of political will, limited resources, lack of multi-sector integration, insufficient dissemination of policy provisions and insufficient information to inform decisions (Awenva et al., 2010). In Uganda the researchers noted challenges in service provision and concluded that there needs to be a deliberate strategy in place to scale up activities for integration into primary care (Ssebunnya, Kigozi, Kizza, Ndyanabangi, & MHaPP Research Programme Consortium, 2010). In a summary paper reviewing literature from the continent, the Mental Health and Poverty Project identified three major themes that affect mental health service provision for children and adolescents in the region, namely (1) stigma; (2) the low priority of mental health; and (3) lack of attention to the link between poverty and mental ill-health (Kleintjes, Lund, Flisher, & MHaPP Research Programme Consortium, 2010).

## 2.11 CONCLUSION

This chapter has reviewed the human rights and social construction framework for mental health in Namibia. Whilst an assessment of the human rights framework in Namibia can be made, less information on the social construction of mental health in Namibia is available. This indicates that there is a clear need for more research in this area. The next chapter reports the methodology used to collect the data for this study.

# CHAPTER 3

# METHODOLOGY

## 3.1 INTRODUCTION

This chapter focuses on the methodology used in the study. The data collection process and data analysis process are discussed and a review of the trustworthiness of the data and ethical considerations is given.

## 3.2 A QUALITATIVE APPROACH

This study used a qualitative exploratory design to identify the extent to which children with mental health challenges are able to access healthcare resources. Qualitative research helps to identify values and motives that affect healthcare decisions and to identify barriers or incentives to action (Correil, 1997).

A qualitative research design is relevant to this study as it allows the researcher to assess the experiences of individuals and groups, seeking to "unpick how people construct the world around them, what they are doing or what is happening to them in terms that are meaningful and that offer rich insight" (Gibbs, 2007; p. x). Qualitative data allows the researcher to capture in-depth information about the cultural context of an issue and to assess patterns in behaviour. Using the data collected, "qualitative data analysis seeks to organize and reduce the data gathered into themes or essences, which, in turn, can be fed into descriptions, models, or theories" (Walker & Myrick, 2006; p 549). Qualitative research is also important to influence change - as stated by Risk (2003); p626 "qualitative research is highly relevant to the information needs at this stage [policy formulation] in the policy cycle".

Whilst there is a clear need for both quantitative and qualitative research in the field of mental health (Tew et al., 2006) and a number of studies have used quantitative methods to assess unmet mental health needs (Borges, 2008; DeRigne, 2010; Kurtin, Barton, Winefeld & Edwards, 2009), it is only through qualitative research that the meaning and diversity of perspectives of living with a mental health disorders can be identified (Flick, 2006). Harms, Kizza, Sebunnya and Jack (2009) conducted a qualitative study to assess the impact of HIV infection on mental health, justifying the use of this research methodology as follows: "[q]ualitative research findings can provide insight into why individuals engage in specific behaviours and so allow us to identify the contextual and cultural factors influencing behavioural processes".

The research paradigm for this study was a human rights and social construction framework. The human rights framework was used to compare how mental health service provision in Namibia compares to human rights standards as documented in international, national or local agreements. The social construction framework was used to assess the data collected from the context within which it was collected as there is never one single reality but instead many interpretations of a situation.

## 3.3 PARTICIPANTS

The majority of participants were parents and caregivers of children who have mental health disabilities and disorders. Some teachers and support staff from the schools where the focus group discussions were held also participated in the discussions. These additional participants were included in the study because, as stated by Tew et al., (2006; p 33) "users of services and their carers [in this instance the teachers and support staff] are experts in their own situation, and research should recognise and build on their expertise".

Purposive sampling was used to recruit participants to the study. Contact was made with two schools for children with mental health disabilities and disorders in Windhoek and permission was requested to conduct the research. The Principals granted permission and assisted with the identification of participants. Contact was also made with a volunteer from the organisation "Special Needs Network" who granted permission for the Network to assist the researcher and helped to identify participants whose children do not attend the special schools. The ability to speak English to a fair standard was a requirement to participate in the study.

The focus group discussions were supplemented by interviews with key informants. Two interviews were conducted with parents of children with a mental health disability or disorder. One parent was sourced through referrals made through a chain of people contacted to help identify participants for this study. The other parent was known to the researcher and was a relevant key informant for this study. The Principals of the two schools where the focus group discussions were held also agreed to be interviewed. To protect confidentiality, the key informants are described as key informant 1-4 and of female gender although they were of both sexes.

The participants were from a range of cultural groups. The participants were not requested to identify their cultural group as no responses indicated this information was relevant to the research. Overall, a total of 41 people provided information for this study.

## 3.4 DATA COLLECTION PROCESS

Data was collected through focus group discussions. Focus group discussions provide a different dimension to interviews as they allow for participant interaction and the development of group opinion (Wong, 2008). Group discussions are particularly useful to identify common experiences or to access a range of viewpoints about a situation (Gilbert, 2008). Through group discussions, the conscious understanding of the researcher and the participants is developed. As stated by Berg (2007; p.146), “when focus groups are administered properly, they are extremely dynamic”.

The use of focus groups as a means of data collection is a common methodology in the field of mental health research. Focus group discussions have been frequently used by the Mental Health and Poverty Project (MHaPP) to collect data (Ofori-Atta1, Read, Lund, & MHaPP Research Programme Consortium, 2010; Akpalu et al., 2010; Harms, Kizza, Ssebunnya & Jack, 2009; Kleintjes, Lund, Flisher, & MHaPP Research Programme Consortium, 2010; Ssebunnya, Kigozi, Kizza, Ndyanabangi, & MHaPP Research Programme Consortium, 2010). Focus group discussions have also been used by other researchers to assess mental health needs in a variety of contexts (Barrio et al., 2009; Gibbs, Brown & Muir 2008; Palinkas et al., 2007; Schulze & Angermeyer, 2003; Shattell, Hamilton, Starr, Jenkins, & Hinderliter, 2008; Wong, Sands & Solomon, 2010).

The focus groups were conducted in an environment which was familiar to the participants. This helped them to feel comfortable. The setting of the focus group discussions was informal and relaxed. At the start of the discussion the participants were informed about the confidential nature of the discussions, that there was no harm associated with the study, and that they could leave the discussion at any time. Further details about the ethics of the study are discussed below.

Each focus group followed the same structure. Open-ended semi-structured questions were used to collected data. The order of the discussion and the number of questions discussed was dependant on the dynamics within the group and the time available. In general, the majority of questions were discussed by all groups. The questions were developed with reference to information in the literature (Barrio et al., 2009; Gibbs, Brown & Muir 2008; Palinkas et al., 2007; Peterson et al., 2009; Schulze & Angermeyer, 2003; Shattell, Hamilton, Starr, Jenkins, & Hinderliter, 2008; Wong, Sands & Solomon, 2010).

The questions used to guide the discussion were as follows:

1. What do you understand to be the meaning of the terms "mental health" and "mental illness"?

2. What mental health services have you accessed for your child? What services were provided by the government? What services were provided through private healthcare? To what extent were the services provided in primary care? Has your child been admitted into hospital for treatment? Why was this?

3. Have you experienced problems regarding the service you have received for your child (based on the mental health needs only)? Can you describe positive aspects of the service provision that you have received?

4. Have you experienced any problems relating to stigma and/or discrimination? If so, from whom? (Community members? service providers?)

5. Have you experienced any barriers regarding access to services? What type of barriers did you experience?

6. Can you explain how a person may access help regarding the barriers you have experienced? Are there any places that you would not go for help? Why?

7. What services should be offered to children with mental health challenges? Who should offer these services? What other suggestions do you have that might solve the problems we have talked about today?

8. What five things do you think are most needed to improve services regarding mental health needs? Why are these services needed?

9. Are there any issues relating to mental health that we didn't talk about today but you would like to discuss?

The use of open-ended semi-structured questions was appropriate for the study. This is because this style of questioning allows the participant to fully supply an answer without prompts or options. This meets the objective that exploratory studies must use an “open and flexible research strategy” to collect data (Babbie & Mouton, 2009: 81).

Time was limited in the second and third focus group discussions as the meetings were part of pre-arranged parent-teacher meetings. In light of the greater flexibility in the first focus group discussion, the participants were also asked to perform a role play to illustrate how health services are provided to children with mental health disorders in Namibia. As stated by Colluchi (2007; p 1427) “there are circumstances in which participants might not be able to describe verbally how they would behave or react in a situation, solve a problem, or deal with a difficulty as it is requested, for instance, in the storytelling exercise but can demonstrate it in action. In those cases (but potentially also in others), role-playing is the perfect technique”.

The participants in the first and second focus group discussions also drew diagrams to illustrate the availability of service provision in Namibia. Diagrams were not drawn in the third focus group discussion as time was most limited in this meeting. The size of this group also limited the feasibility of conducting participatory activities within the context of the meeting setup.

## 3.5 DATA ANALYSIS

The steps in analysing the data were as follows: (1) transcription of the data (2) coding of the data; (3) thematic analysis of the data; (4) grouping of the themes according to the weight and extent of the problems identified; (5) writing a report about the findings.

The researcher took detailed notes during the focus group discussion and transcribed the notes following the workshop. As far as possible the notes were transcribed verbatim. The transcripts were then coded and themes identified. Coding is described as “conceptualizing data by constant comparison of incident with incident, and incident with concept” (Glaser, 1992). As explained by Gibbs, “codes form a focus for thinking about the text and its interpretation” (2007; p 40). Open coding was used to examine the data. “This is the type of coding where you examine the text by making comparisons and asking questions” (Gibbs, 2007; p 50). Grounded theory was used to develop the codes. The process of grounded theory allows the research to develop ideas or hypotheses from the data rather than testing pre-conceived theories (Gibbs, 2007). Guidance on the identification of codes was taken from a review of the literature (Kurtin, Barton, Winefeld & Edwards, 2009; MHPP Ghana Country Report, 2008). The codes were then examined for relationships and patterns, resulting in a reduction of the initial number of codes and integration of similar concepts.

The codes were then considered in the context of the available literature and themes identified. Thematic analysis is the identification of subjects that repeatedly occur during the discussions. The use of thematic analysis permits the management of the data and allows the researcher to compare the results from the different focus group discussions (Flick, 2006). This form of analysis allows outputs from the different focus group discussions to be compared but at the same time “the procedure remains sensitive and open to the specific contents of each individual case and the social group with regard to the issue under study” (Flick, 2006; 311). Therefore a rich understanding of the totality of the issue was obtained as well as identification of singular issues identified at individual discussions. Based on the comparisons between the focus groups, final themes for the data were identified and reported.

## 3.6 TRUSTWORTHINESS

Babbie and Mouton (2001) refer to trustworthiness as the need for dependable, credible and transferable data.

*Dependable* data is data that “if it were to be repeated with the same or similar respondents (or subjects) in the same (or a similar) context, its findings would be similar” (Babbie & Mouton, 2001, p 278).

*Credibility* is the collection of data that is compatible with the “constructed realities that exists in the minds of the respondents” (Babbie & Mouton, 2001, p 277). To ensure c*redibility,* member checking was used. At relevant points in the discussions the researcher summarised the discussion to check that the interpretation was correct. The data collected was also compared with other research in the field and was peer-reviewed. Comments from the peer review are reflected in the write-up.

*Transferability* is the “extent to which the findings can be applied in other contexts or with other respondents” (Babbie & Mouton, 2001, p 277). The use of purposive sampling helped to ensure *transferability* as the considered selection of participants helped to ensure that appropriate participants were included in the study so that the findings can be applied in other contexts or with other respondents.

*Self-reflexivity* was also important for this study. This is where the researcher must reflect and review the assumptions made in the study, including analysis of the data, interpretation of the literature and knowledge about the situation. The study was peer reviewed by the supervisor and an additional person working in the field to gain feedback and to promote the process of self-reflexivity.

## 3.7 ETHICAL CONSIDERATIONS

The World Medical Association’s Declaration of Helsinki states that “some research populations are vulnerable and need special protection” (World Medical Association, 2002). The participants of this study were vulnerable because the literature reports that people with mental health disorders face a number of barriers accessing healthcare services. Even though the participants were parents/caregivers and not the people with the disorders, their engagement in the care of the children means that they are a vulnerable population and in need of special protection during data collection.

Therefore, in addition to the standard ethical procedures outlined below, further measures as described by Stevens, Lord, Proctor, Nagy and O'Riordan (2010) were used to provide special protection to the participants. Sufficient time was built into the study timeline to engage and prepare the participants; regular contact was made during the recruitment phase; care was taken to establish and maintain a rapport with the participants; a range of discussion techniques was used to put the participants at ease and to allow the participants to contribute when they were at ease; breaks were included in the focus group discussions as needed. In light of the sensitive nature of the topic, a balance was maintained between the need for the participants to discuss personal issues and the need to focus the research. Following the focus group discussions, contact was made with the focal points who recruited the participants to check whether any participants wished to discuss further any of the issue identified in the focus group discussions, or if they needed help being referred to an appropriate counselling source. The participants also received the contact details of the researcher and were informed that they could contact the researcher at any time.

Standard ethical procedures were also applied to the study. All participation was voluntary. The participants were informed about the nature and intent of the study. The participants were informed that there were no harmful procedures involved. All participants received the consent letter shown in Appendix C prior to the discussion. Participants were able to leave the focus group discussion at any time. Participation was confidential and anonymous. The participants were warned that confidentiality by their fellow participants cannot be guaranteed and the participants were encouraged only to discuss general issues. The researcher provided opportunities for individual discussions for participants who wished to provide information they did not want to share with the group. Debriefing and support after the focus group discussions was made available to the participants.

## 3.8 CONCLUSION

This chapter has discussed the methodology of the study and the process of data collection and analysis. The chapter has also reviewed the trustworthiness of the data and the ethical considerations that were applied to the study.

The results of this study are discussed in Chapter 4.

# CHAPTER FOUR

# RESULTS AND DISCUSSION

## 4.1. INTRODUCTION

The purpose of this study was to explore and describe the experiences of parents/caregivers of children with mental disabilities and disorders when accessing mental healthcare. This chapter discusses the results of the study and discusses the findings in the context of the literature available in the field.

## 4.2 PARTICIPANTS

Three focus groups were conducted. The majority of participants were parents and caregivers of children who have mental health disabilities and disorders. Some teachers and support staff from the schools where the focus group discussions were held also participated in the discussions.

Twelve participants (11 females and 1 male) attended the first focus group, eight participants (7 females and 1 male) attended the second focus group and seventeen participants (13 females and 4 males) attended the third focus group. Although the third focus group was unexpectedly larger than planned (focus groups usually consist of six-ten people (Gilbert, 2008)), the first and second groups met the criteria of an optimal-sized focus group and it was still possible to conduct a successful discussion with the third group.

The first focus group discussion was held in Katutura, the township of Windhoek. The participants were sourced through the volunteer from the Special Needs Network. The participants were parents of children with mental health disabilities and disorders and support staff who provide special needs services to the families invited.

The second and third focus group discussions were held at two special schools in Windhoek. The principals of the schools arranged for the meetings to be held. The majority of participants were parents or relatives of children attending the school. The Principals and some of the teaching staff also attended.

The focus group discussions were supplemented by interviews with four key informants. Two key informants were parents of children with mental health disabilities/disorders. The other two key informants were the principals of the schools where the focus group discussions were held.

## 4.3 OVERVIEW OF THE TOPICS DISCUSSED AND THEMES IDENTIFIED

A summary of the topics discussed is shown below:

1. Understanding the concept of mental health, mental illness and associated stigma and discrimination
2. Access to services
3. Barriers to services
4. Principles of service provision such as confidentiality and informed consent
5. Recommendations for service provision

The main themes identified were:

1. Transport
2. Money
3. The importance of educational services

4. Poor service provision, in particular
    a. Language barriers and need for therapeutic services
5. Lack of appropriate parental involvement

## 4.4 UNDERSTANDING THE CONCEPT OF MENTAL HEALTH AND MENTAL ILLNESS

The participants in the first and second focus groups discussions were asked to define mental health and mental illness. Because of a lack of time , this question was not discussed with the participants in the third focus group.

The definition of mental health in the Namibian policy on mental health is "a state of complete well-being that enables the fulfillment of one's full potential in occupational, social and relational functioning" (2001; p 23) According to the WHO (2001), mental health is intellectual and emotional well-being as perceived through self-efficacy, autonomy and competence. Mental health disorders are clinically significant conditions that present with symptoms of negative changes in thinking, mood, emotion, functioning and behaviour (WHO, 2001).

The definitions provided by the participants were much simpler than the ones cited in the literature. For example, participants said that mental health is:

- *to be good without sickness (focus group 1)*
- *to have and maintain a reasonable mental condition (focus group 2)*

Examples of the definitions of mental health disorders given by the participants were:

- *you must always take your medicine (focus group 1)*
- *when the brain does not function in the proper sense (focus group 2)*

The responses differed between the first and second focus groups. In the first focus group discussion, responses centred around concepts of whether or not medication was needed and whether the person was good or not; for example the definition "*to be good.... to be accepted in other social groups"* was given by a participant in the first focus group.

The responses from the second focus group discussion were generally more detailed, suggesting a deeper level of understanding of mental health conditions. For example, one participant in the second group explained that mental illness is *a condition having an impact on your mental health, such as depression, bi-polar disorder etc. Thus it can be psychological, psychiatric or neurological diseases such as down's syndrome, cerebral palsy etc.*

The responses from the second focus group indicated a greater sense of acceptance of mental health illness, with participants describing a mental health disorder as something that a child may have or be born with, saying for example "o*ne has a mental challenge but you must care for the person with his/her mental challenge individually. It is not necessarily an illness, but he/she is in need of others for help".* In contrast, the participants in the first focus group used simpler explanations such as it is when "*you must always take your medicine*".

One reason for the different responses is likely to be the social context. The participants in the first focus group discussion have less access to support services for mental health as the children are not enrolled in the special schools. Therefore, they are likely to have less access to information about the causes and disease trajectories of the conditions their children are suffering from. In contrast, the children of the participants in the second focus group are all enrolled at the special school and through this link receive more information and guidance on how to manage and understand their child's illness.

The data collected on the understanding of the concepts of mental health and mental illness in Namibia suggests that people lack information about mental health conditions. This finding is similar to data collected in South Africa which has shown that mental health literacy is also low. This study found that low literacy about mental health is a barrier to accessing care (Ganasen, Parker, Hugo, Stein, Emsley, & Seedat, 2008, Trump & Hugo, 2006).

## 4.5 INSTANCES OF STIGMA AND DISCRIMINATION

### 4.5.1 STIGMA AND DISCRIMINATION FROM COMMUNITY MEMBERS

The participants identified a range of situations where stigma and discrimination occur. The participants in the first and third focus groups explained that many people think that children with mental health disabilities and disorders have been cursed by witchcraft. The participants in the first focus group discussion described the myth that if a person with a mental health problem hits you, you must hit the person back if you do not you will also get sick.

The participants in the second focus group mainly felt that stigma in the community is based on people being surprised about the behaviour of the child because they do not know about the condition. For example, people may not want a child with Down’s Syndrome to sit next to them. One participant suggested that there is not enough integration of children with mental health challenges in society and this is why community members do not know how to react. The participants in the third focus group made similar comments, stating that community members can stigmatise the children because “*they are not informed about mental health conditions*”. One of the participants described a situation where her brother who has a mental health disability/disorder wanted to play with younger children aged 3-4 years. Because he was so much older than these children, people in the community told the 3-4 year old children to beat him up. Similarly, when he wanted to play with children living at the neighbouring house, the family chased him away. The participants in the third focus group were proactive in suggesting remedies, stating that "*we should do more and often [to promote public understanding about mental health challenges]. We should go to the radio to talk about it.*"

Children with mental health disorders may also experience "labeling". One participant said that the children are sometimes called "vertraag" in Afrikaans, which is a derogatory term meaning abnormal. The word is commonly used to say there has been an abnormality that has caused a delay (a "vertraggen"). The participants explained that to use the word in the context of labelling a child is offensive. Key informant three also stated that learners with mental health disabilities are often described as retarded.

Key informant one was aware only of minor discrimination. She cited discrimination in a church where the congregation was not sensitive to the special needs of a child. This experience differs to the discussion in the first focus group where the participants cited the church as a place for support.

Key informant two said that people were surprised when the parents of a child with a mental health disorder speak openly about a child's mental health problem. She stated that although people were surprised when their family spoke out about their child's illness, the openness helped to reduce stigma from friends and acquaintances. The family in question also experienced discrimination from their medical aid provider through capped provisions for hospitalisation for a psychiatric disorder compared to hospitalisation for another reason (N$10 000 versus N$1 million) and by the attitudes of the staff at the medical aid fund. The informant stated that one staff member told the family that "*people who attempt suicide have just brought their problems upon themselves*".

Key informant four said that people in the community are afraid to be touched by a child with Down's Syndrome. She called on the Ministry of Health and Social Services to provide more information about mental health to the community to help alleviate this problem in the long-term. Key informant four described community opinion as "*so negative*" and stressed that the parents are also negative, as they perceive a child who has a mental health disorder to be pathetic, sick and hopeless.

Overall the parents and caregivers described more problems with ignorance rather than stigma whereas the key informants described problems about negative responses. This suggests that acceptance of mental health conditions varies between communities and that in communities where awareness is high, stigma is lower.

Stigma and discrimination in the community has also been noted in other countries such as Ghana and Nigeria (Gureje, Lasebikan, Ephraim-Oluwanuga, Olley & Kola, 2005; MHaPP 2010). However, the studies in the literature often present a more intense level of stigma and discrimination than was identified in this study. Explanations for the differences cannot be made from the data collected. It could be that sensitisation campaigns held in Namibia about other illnesses such as HIV/AIDs or tuberculosis have led to a more positive culture of acceptance for all illnesses compared with some other countries. Alternatively it may be that the participants in this study mixed with a limited number of people and have not been exposed to more intensive stigma. It should also be noted that the sample of participants in this study was small and that a larger study might reveal that stigma and discrimination about mental health are a problem in Namibia.

### 4.5.2 STIGMA AND DISCRIMINATION FROM SERVICE PROVIDERS

The participants in the first focus group discussion gave examples of stigma from service providers. For example, some hospital security guards are afraid to help people with mental illnesses. The participants in the second focus group also cited stigma from service providers, saying that even with conditions such as dyslexia where "*we know so much*", doctors still do not want to help and that "*there are only barriers"*. The participants felt that doctors do not know how to help, and sometimes do not try to help even when they do have the knowledge. The participants in the second and third focus group discussion stated that service providers may be unwilling to speak in the local language to the parents, even when they are able to do so. Furthermore, Namibian hospitals have many Cuban doctors who are only able to speak English or Spanish and this can be a problem for the patients. These finding are similar to the results presented by Kapungwe et al. (2010) who also noted that some healthcare professionals were reported to have negative attitudes towards mental illness in Zambia.

### 4.5.3 STIGMA AND DISCRIMINATION FROM FAMILY MEMBERS

The problem of discrimination from parents was also noted. A participant in the second focus group discussion said that the parents may even abuse the child because they are frustrated and do not know how to deal with the child's behaviour. Some parents are ashamed of children with mental health disabilities and disorders and keep them hidden on family farms. One participant gave the example of a 19-year-old girl in the Omaheke region who had never received help because the mother did not know what to do and was embarrassed to ask for help. The participant described the mother as being "*careless"* at getting help for the child.

Another participant cited a situation where an authority figure visited a mother of a child with mental health challenges but the mother did not want to accept help because she was afraid that the child would be taken away. The participant explained that the mother was frightened to accept help because it would reveal the poor way she was caring for the child.

The participants in the third focus group discussion also discussed discrimination from parents. One participant stated "*I don't know how my brother is affected. I just know something is wrong. My mother doesn't want to explain.*" Again the participants in the third focus group discussion were proactive in making recommendations, stating that the parents of children need counselling. This would have positive effects as "*after the counselling the parents will come back and start to love their child*". One of the recommendations for better services made by the participants in the first focus group (discussed below) was for more support for parents. Only one participant stated that she did not experience any stigma or discrimination about her child.

It should be noted that the participants did not discuss problems of acceptance of their own children and based on the general discussions, it did not appear that the parents who participated in this study stigmatise their children.

Key informant four summarised the problems by saying that some children with mental health disabilities/disorders never really get any love. Some parents take their children to the special school and hand over all responsibility because of the stigma the family experiences or feels. The informant was concerned about this for many reasons; one practical problem being that hostel staff do not have special training to manage learners with mental health disabilities and disorders and should not be left with such a burden.

The problem of a lack of parental involvement has been noted in the recent situational analysis of the status of children in Namibia, albeit in a different way. Key informants for the study (school carers), stated that some parents of children with disabilities are unwilling to pay school fees as they do not see the children receiving any benefit from the education (National Planning Commission, 2010).

## 4.6 ACCESS TO SERVICES

The participants were only able to list a small number of healthcare services that are available for children with mental health disorders. As data from the WHO reports that there are only 0.2 psychiatrists, 6 psychologists, and 6 social workers per 100 000 population, the fact that the participants could not identify many services is not surprising (WHO, 2005a).

In the first and second focus group discussions a diagram was drawn to illustrate current access to services by the participants. There was insufficient time to draw a diagram in the third focus group discussion. Figures 4.1 and 4.2 are reproductions of these diagrams.

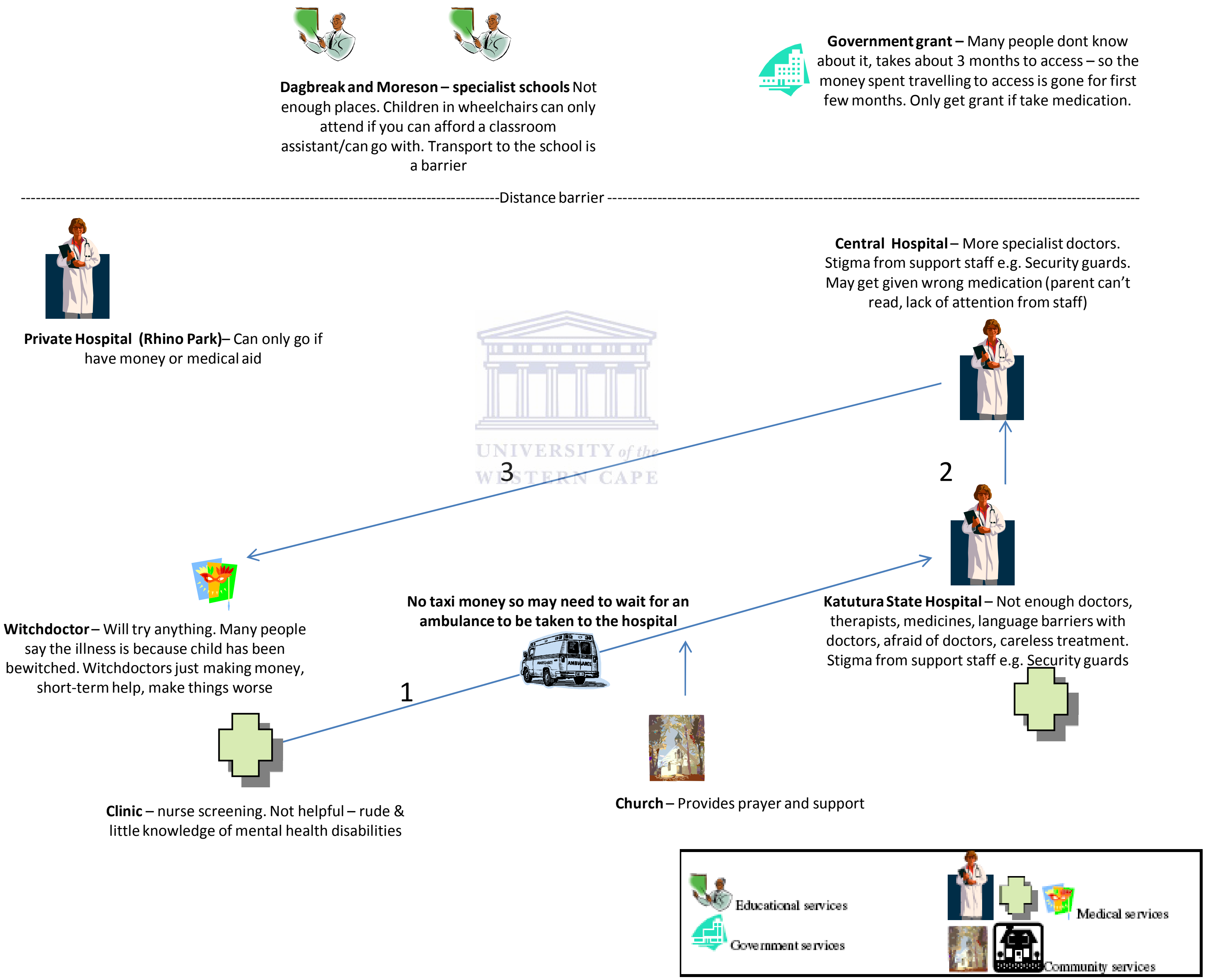
Figure 4.1 was created by the participants from the first focus group discussion and shows that the participants visit their local clinic and are then referred to the hospital. The parents in the third focus group described a similar process for accessing healthcare services.

Figure 4.2 was created by the participants from the second focus group discussion and shows that the participants are more aware of the range of educational options and support services from community groups. The participants described a healthcare referral process that is less fraught with challenges than the process experienced by the parents in the first focus group discussion.

Distance to services was a significant barrier for the participants in the first group but was not mentioned as a problem by the second group. Distance from healthcare services was one of the barriers investigated in the 2006-2007 Demographic and Health Survey and identified as a problem by 41.5% of the respondents (Ministry of Health and Social Services, 2008a).

The participants in the second focus group discussion seemed to be the most aware of the support services that are available for parents of children with mental health disabilities and disorders, whereas the participants in the first focus group discussion were the most aware of informal support services, such as churches and witchdoctors. The participants in the first focus group discussions barely named services such as therapists and support groups, and this suggests that these services are not available or accessible to them. In contrast, the participants in the second and third focus group discussions, who all had children attending the special schools, discussed a range of therapeutic services.

Figure 4.1: Diagram of services accessed by participants in the first focus group discussion



**Dagbreak and Moreson – specialist schools** Not enough places. Children in wheelchairs can only attend if you can afford a classroom assistant/can go with. Transport to the school is a barrier

**Government grant –** Many people dont know about it, takes about 3 months to access – so the money spent travelling to access is gone for first few months. Only get grant if take medication.

**Private Hospital (Rhino Park)**– Can only go if have money or medical aid

**Central Hospital** – More specialist doctors. Stigma from support staff e.g. Security guards. May get given wrong medication (parent can't read, lack of attention from staff)

**Witchdoctor** – Will try anything. Many people say the illness is because child has been bewitched. Witchdoctors just making money, short-term help, make things worse

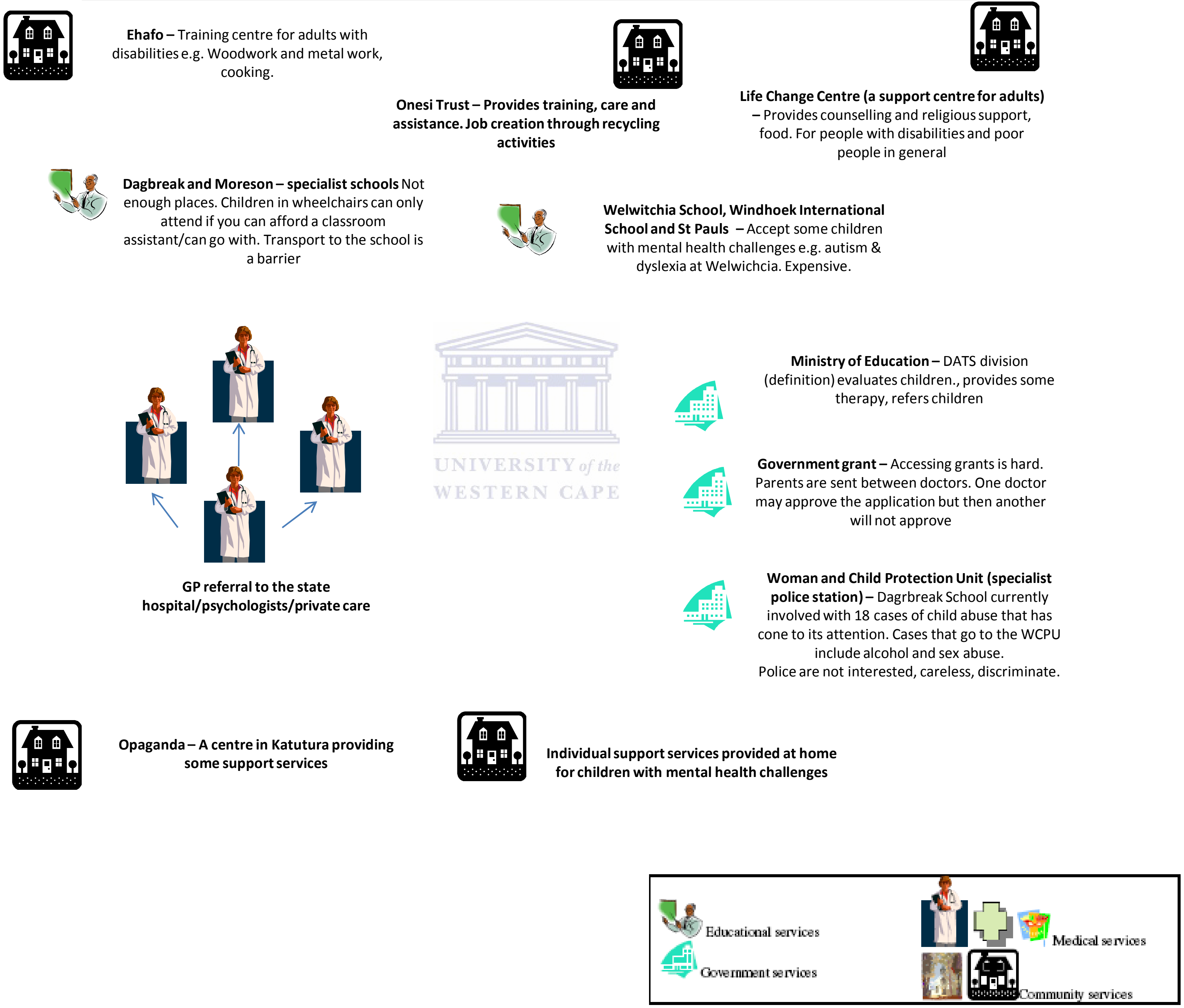
**No taxi money so may need to wait for an ambulance to be taken to the hospital**

**Katutura State Hospital** – Not enough doctors, therapists, medicines, language barriers with doctors, afraid of doctors, careless treatment. Stigma from support staff e.g. Security guards

**Clinic** – nurse screening. Not helpful – rude & little knowledge of mental health disabilities

**Church** – Provides prayer and support

Figure 4.2: Diagram of services available/accessed by participants in the second focus



**Ehafo –** Training centre for adults with disabilities e.g. Woodwork and metal work, cooking.

**Onesi Trust – Provides training, care and assistance. Job creation through recycling activities**

**Life Change Centre (a support centre for adults)** – Provides counselling and religious support, food. For people with disabilities and poor people in general

**Dagbreak and Moreson – specialist schools** Not enough places. Children in wheelchairs can only attend if you can afford a classroom assistant/can go with. Transport to the school is a barrier

**Welwitchia School, Windhoek International School and St Pauls** – Accept some children with mental health challenges e.g. autism & dyslexia at Welwichcia. Expensive.

**GP referral to the state hospital/psychologists/private care**

**Ministry of Education –** DATS division (definition) evaluates children., provides some therapy, refers children

**Government grant –** Accessing grants is hard. Parents are sent between doctors. One doctor may approve the application but then another will not approve

**Woman and Child Protection Unit (specialist police station) –** Dagrbreak School currently involved with 18 cases of child abuse that has cone to its attention. Cases that go to the WCPU include alcohol and sex abuse.
Police are not interested, careless, discriminate.

**Opaganda – A centre in Katutura providing some support services**

**Individual support services provided at home for children with mental health challenges**

Even though the researcher used a range of questioning probes to obtain details on healthcare services with the groups, the participants had less information to share about healthcare services compared to other services, such as education. Key informant two also stated that the school provided the best support for the child and the family. This suggests that for many of the participants, access to education is a greater priority than access to healthcare. One of the reasons appears to be because the schools help to facilitate access to healthcare services. The interviews with the two principals showed that the schools are dedicated to trying to ensure that the children receive the healthcare services they need. The principals also cited a number of examples where they had to intervene on behalf of the parents to ensure that the correct care was provided (discussed in more detail below)

All of the participants stated that parents will access private care if possible, although they noted that for most people this is not an option owing to lack of money. This explanation is in line with data which shows that only 5.27% of people in the poorest consumption quintile in Windhoek are enrolled in a medical aid fund compared with to 69.14% in the wealthiest quintile (MRCC/AIID/PharmAccess Foundation, 2007).

Key informant one voiced a similar opinion, stating that "*a person is likely to go to private not to state services where possible*". Key informant four explained that the state hospitals cannot always provide the medical care that is required. For example, scans are only available at the private hospitals. One of the key informants was forced to access healthcare services in South Africa and America because the necessary medical care was not available in Namibia. The medical aid provider refused to cover the costs, resulting in a huge financial burden for the family.

Another barrier was that some children may be cared for by a relative other than the parents and even if the caregiver has medical aid, the child may not be permitted to be registered on the scheme. This may be due to a workplace policy, rules of the medical aid fund or because the caregiver is unwilling to pay for the additional member to be added. This is a problem that is not unique to mental healthcare but is a problem that is particularly relevant to the African continent where the fluidity of family relationships is common and children are often not cared for by their parents.

One participant recommended that where patients have medical aid, the medical aid service should advise on the services available/possible to access. The participant also suggested that the medical aid provider could provide a co-ordinating service, for example if the provider is aware that there are two children with the same mental health condition they could be given the option to contact each other. This recommendation is very specific to Namibia as because of the low population density, there may only be one or two children with specific conditions in the entire country. In other countries such a co-ordinating service would more likely be provided by a non-governmental organisation.

The participants in the first focus group discussion performed role plays to illustrate parents accessing healthcare services. Role plays were not conducted in the second and third focus group discussions owing to a lack of time. In the role plays the participants showed the parents seeing unknown doctors for illnesses such as influenza. The participants stated that "*there are few doctors, [we] don't get help in time. Doctors also have to deal with emergencies or do operations. If have to go from 5pm at night, only one doctor.*" The doctors and nurses in the role plays shouted at the patients for not have their medical cards showing a lack of respect from the service providers.

The National Mental Health Policy recognises that there is a lack of skilled health care professionals and an inability to accurately diagnose mental disorders in Namibia, but does not specifically recognise the problem of lack of respect from service providers (Ministry of Health and Social Services, 2005).

The participants in the first focus group stated that they do not see the same healthcare specialists on a regular basis – as one participant said, "*there is too much change with doctors, you have to keep restarting to tell your story*". This is likely to be a general problem with the healthcare system in Namibia but one that is particularly problematic for people with long-term conditions.

The participants in the third focus group discussion had similar complaints, noting that they should be permitted to see the same healthcare specialist on a regular basis. Key informant four stated that she "*tries*" to stick to the same doctor at the Central Hospital. The use of the word 'tries' indicates that seeing the same doctor on a regular basis is not the norm. The National Policy recognises the problem of lack of follow-up and aftercare but does not mention the specific problem that patients see a different doctor each time (Ministry of Health and Social Services, 2005).

One of the participants described the experience at the hospital as "stressful" as the doctors are not always available and the parents have to make repeated trips in order to have a consultation. This means that the child has to keep missing school and the parent has to get sick notes each time to explain the absence of the child. Another participant stated that "*my experience every* *time is that service at the clinic and hospital is very poor. It is the same for the elderly and the very sick*". These problems are likely to be general problems with the healthcare system in Namibia rather than specific to mental healthcare provision, although the low number of mental healthcare providers does mean that it may be exacerbated in this sector (WHO, 2005a).

The participants in the second focus group discussion also criticised healthcare services for not providing enough support or advice on treatment options. The participants complained that the doctors "*do not have knowledge*" and "*do not know what might be in the best interests of the child, such as whether swimming will help, or occupational therapy*". The participants complained that there is a "*lack of expertise*" and that as soon a doctor makes a diagnosis, he/she will give a prescription and end the consultation rather than providing any further support or information.

The participants in the third focus group discussion made similar points stating that the doctors are not "*treating the cause of the sickness*". One participant said the doctors are just "*prescribing pills and not giving other treatments*". The participants also complained that they are often only prescribed painkillers or medication to make the child sleepy rather than being provided with specific medication for the condition. Another problem was that the children may be seen by student nurses, who again only prescribe painkillers. One of the participants complained about the lack of counselling services, explaining that counselling would be much more helpful than taking painkillers. The repeated reference to the prescription of painkillers, which was discussed in all groups, suggests that the problem is commonly experienced. This suggests that some doctors and nurses do not engage with the patient's condition and seem to give broad treatments for symptoms rather than dealing with the core problems. This may be caused by insufficient training on mental health conditions or the fact that the doctor is only seeing the patient for a single visit and is not experienced with the clinical history of the child.

The participants also gave examples of what appear to be medical negligence. One participant cited the example of a girl who was pregnant. The mother did not know what was wrong with her and took her to the hospital. The staff thought that the child had malaria and gave her anti-malarials which are generally proscribed during pregnancy. On a visit two months later, she was given further treatment for malaria. The participant stated that healthcare providers make assumptions rather than doing proper tests and investigations.

Key informant four explained that it was only through persistence from the school that the children received the correct treatment. One example was a child given painkillers even though she had meningitis; another example was of a child who had an infected cut but was not given antibiotics to prevent the spread of infection. The key informant explained that nurses do not have respect for children with mental health disabilities/disorders and if the parents go by themselves with the child (e.g. without a representative from the school), the nurses do not help them properly. One person stated that in Namibia people "*care more for animals than these children*".

A participant in the first focus group discussion discussed the challenge she faced accessing physiotherapy services. At the hospital the nurses told her she must have a referral letter before the child could receive physiotherapy and they would not assist her without a letter. The participant explained that to get the letter she would have to go through a series of consultations, which as discussed above, can be difficult to access. The parent felt that the process was too bureaucratic because many people may not be able to get access to the services they need due to a lack of referral letter.

Although many of the problems discussed by the participants were about general barriers to healthcare, the fact that mental health disabilities/disorders are long-term conditions means the parents may experience a greater number of general barriers than people who have other conditions.

### 4.6.1 ACCESS TO GRANTS

The government disability grant was discussed in two groups. The participants in both groups stated that it is hard to access. The participants in the first focus group discussion were positive about the help the grant provides but noted that the amount paid was small. One of the participants explained that it can take approximately three months to access the grant, and with the time and transport required to access it, it can mean that when the grant is finally released, the first few payments may be used to pay back money borrowed to access the grant. The participants in the second focus group discussion were more negative about the grant and felt that it was difficult to access.

Key informant one stated that accessing the grant is so difficult and time-consuming that she had not attempted the process. Key informant three said that the specialist schools will often do the majority of the application process for the parents including getting the forms, semi-completing them and helping them to open bank accounts as the parents may be unable or unwilling to persevere through the process without this assistance. As data from the Ministry of Gender Equality and Child Welfare shows that only 1821 disability grants were dispersed in 2010

(Ministry of Gender Equality and Child Welfare, 2010)., the complaints from the participants provide an explanation as to why access may be so low

The low disbursement of grants is a problem as research in Namibia has shown that even though grant amounts are small, they can play an important role in alleviating poverty (Levine, van der Berg, & Yu, 2011). Although the researchers did not assess the impact of the child disability grant, they did assess the adult disability grant and stated that the grant plays a significant role in reducing poverty at the upper-bound poverty line. This finding suggests that poorer people are not benefiting from the grant – as access is currently estimated at 40% this finding is not surprising (National Planning Commission, 2008). Although the government has set a target of 95% of recipients to receive the disability grant, the report did not differentiate between the child and adult grant and is not sufficiently clear on how this goal will be achieved (National Planning Commission, 2008). However, the Ministry of Gender Equality and Child Welfare did produce a pamphlet on the available grants for children in 2010 which is a start towards awareness-raising about the disability grant for children.

## 4.7 BARRIERS TO SERVICES

The participants in the first focus group drew a diagram to illustrate barriers to services (Figure 4.3). Diagrams were not drawn in the second and third focus group discussions because of time constraints. The figure shows that the participants experienced barriers in the form of the attitude of service providers, lack of resources, stigma and transport, all of which have been discussed above. Although the problem of stigma from medical staff was discussed by this group, the participants did not list this in the diagram.

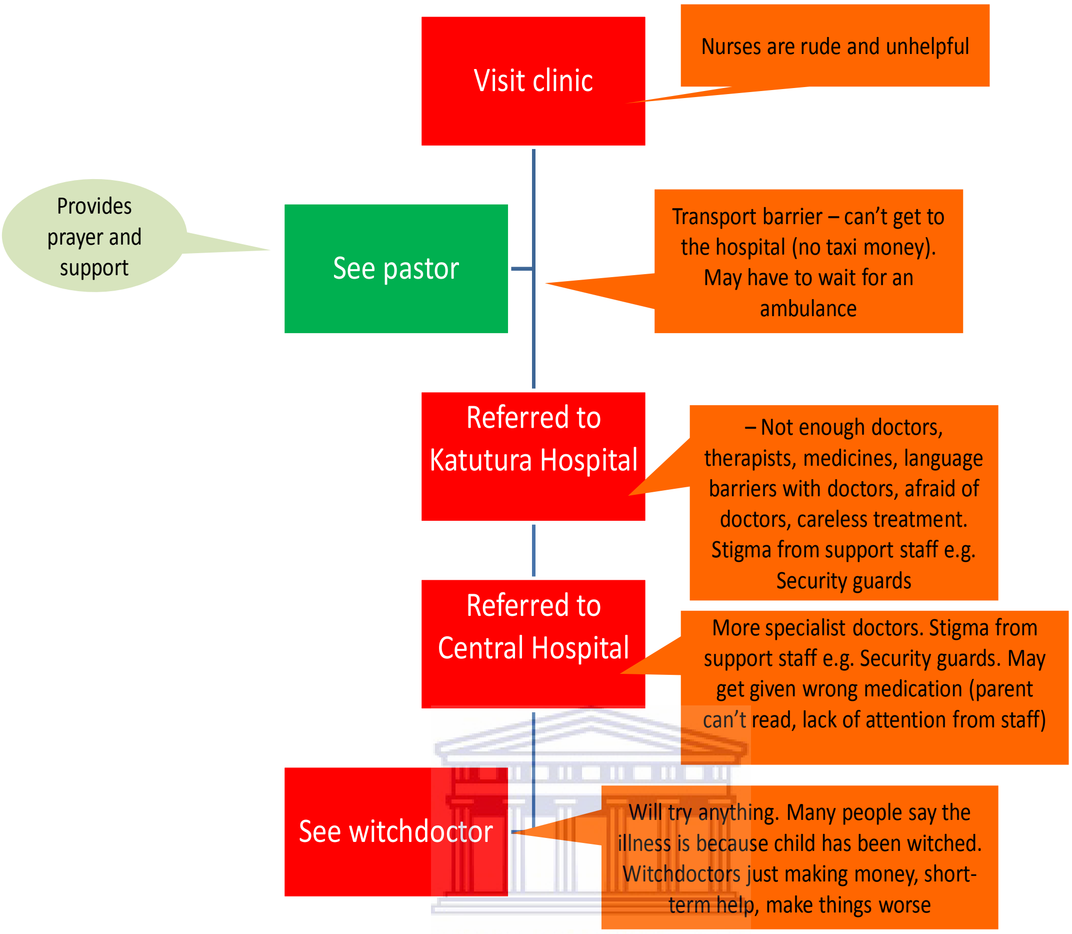


**Figure 4.3: Process and barriers participants in focus group one experienced in attempting to access services**

The participants in all focus groups stated that transport to the hospitals is a problem. The participants in the first focus group discussion explained that they sometimes do not have the money to pay for a taxi between the clinic and the hospital and have to wait for an ambulance to take them there. This means that there is a delay in the parents accessing services for their children, and also that emergency services are being reallocated from their designated function, which can also cause problems in emergency situations. Transport was another one of the barriers investigated in the 2006-2007 Demographic and Health Survey. It was identified as a problem by 41.7% of the respondents (Ministry of Health and Social Services, 2008). Distance travelled is also reported as a barrier in the 2008 Review of Health and Social Services Systems (Ministry of Health and Social Services, 2008a).

The problem of transport has not been commonly reported as a barrier to mental healthcare in the literature, although the problem has been recognised in rural Australia (Kurtin, Barton, Winefeld & Edwards, 2009). However, in this study the participants were living in urban areas in relatively close proximity to the hospital but still found transport to be a barrier, mainly as a result of poverty.

Although not related to accessing healthcare services, the participants in the third focus group discussed the problem of transport to and from school. It appears that many children usually travel to school alone by taxi or by bus. Some come to school on the back of bakkies (pick-up trucks). Key informant four told the story of a child with mental health problems who travelled on the back of a bakkie and would get squashed and injured by the other child because she was not able to communicate that she was being hurt. The participants in the first focus group discussion cited transport by bus as being a problem because other travellers may be unwilling to travel with children who are behaving differently. One of the participants in the third focus group had arranged for his child to come to school on a combi (a minibus) and offered to find out more information about space available and cost so that other parents could utilise this option. This is an example of how the participatory nature of the discussions helped the participants to develop their own solutions to some of the problems experienced.

Key informant three stated that the children are also vulnerable to abuse on journeys to and from school because they may be unable to understand or resist what happens to them. She gave the example of a child who took one of the municipal buses but because of his unusual behaviour was forced off the bus. The child could not get home that night but slept along the side of the road.

Although the participants stated that they experienced problems travelling in Windhoek, the City of Windhoek does make provision for people with disabilities to travel for free on municipal buses. To do this, the parent/disabled person must register with the Economic Development and Community Services Department. The City of Windhoek will then issue a card which entitles the recipient to one free return trip per day. On questioning, the Municipality did not report receiving complaints from people with disabilities about the service.

The discrepancy between the experience of the parents and the service provided by the City of Windhoek suggests that there is a lack of awareness about the transport option and the City of Windhoek should do more to ensure that people are aware of this service. There is also a need to involve private organisations such as Namibia Bus and Taxi Association to increase awareness about mental health disabilities and disorders amongst private transport services providers.

The participants in the second and third focus group discussion also stated that cost was a barrier to services. The participants stated that they are required to pay N$15 for a hospital consultation (the standard fee in Namibia) even though children with disabilities should be exempt from these fees. The participants did not know how to get an exemption, or what information was required. The participants recommended that they should be given a card that entitles them to an exemption.

Key informant four made similar comments, saying that money can be a problem as parents may not be able to afford the consultation fee or cannot afford to take a child for any follow-up appointments that are needed. She also felt that some parents do not understand certain conditions and this is a barrier, explaining that in some circumstances parents "*think the child can't feel pain because the child does not express pain*" and so the child does not receive treatment even for basic problems such as toothache.

Decisions about fees are prescribed in the regulations for the Hospitals and Health Facilities Act of 1994 as published in Government Gazette 4459. The regulations state the following:

> 9 (1) (a) a person may not be refused admission to a state hospital for treatment in, at or from that hospital on the grounds that he or she is not able to afford the payment of the prescribed fees for treatment;

and also specifically refer to exemptions for people receiving a disability grant:

> 9 (1) (h) a person who is receiving a basic state pension, a blind person's pension or a disability pension under the National Pensions Act, 19 92 (Act No. 10 of 1992), and who is not entitled to any of the benefits referred to in paragraph (a) or (b) of regulation 4(1), must receive free treatment;*

**(4 (1) (a) and (b) refer to people registered under medical aid schemes including the Public Service Employees Medical Aid Scheme, or payments made through the Employees Compensation Act or Motor Vehicle Accident Fund.*

Therefore, if the parents have registered their children for the disability grant, they should be able to access free treatment. As discussed above, many of the parents/caregivers experience problems accessing the grant. Knowing that accessing the grant is also beneficial to accessing healthcare services may provide a motivation to access it. However, the grant is limited to children with "disabilities" and some children with mental health disorders may be unable to access the grant. This is a problem that should be considered by the Ministry of Gender Equality and Child Welfare in its rules of how the grant is to be disbursed. Despite this, even without the grant, parents who are not able to pay the hospital administration fees should be able to access healthcare, as per point 9 (1) (a) although this may be harder to prove. There is a need to ensure that more people are aware of these exemptions – including both service-seekers and service providers - and that parents are empowered to access this right.

The participants also cited paying for private treatment and the lack of specialists as a burden. For example, the participants stated that there is no specialist for Down's Syndrome in Namibia. This is a problem for many medical conditions in light of the small population size of Namibia.

Money was also a barrier to accessing education for their children. For example, the parents in the first focus group said they would like to send their children to the specialist schools but there are limited places. Some private schools will accept children with mental health disabilities/disorders but the parents may struggle to afford the fees. The participants also explained that even if they can find a place for a child to attend a good school and can pay the fees, the child may still not be able to attend if he/she needs dedicated class assistant to help the child. Even if the parents are given exemptions from the school fees, there are still costs associated with living in the hostel and these costs can be a barrier.

Key informant three said that although the Ministry of Education is trying to promote inclusive education this can be problematic as children often tease learners with special needs. Furthermore she stated that mainstream teachers are currently not always sufficiently trained to work with children with special needs. This problem was also discussed in the third focus group, where one of the parents had transferred her child out of mainstream schooling because of bullying.

## 4.8 CONFIDENTIALITY AND INFORMED CONSENT

The participants in the focus group discussions did not cite concerns about confidentiality and informed consent. However, it seems that this was because they experience larger preliminary problems, such as transport barriers or poor service provision, which are so problematic that issues such as confidentiality and consent may be secondary problems not yet experienced.

The participants in the first focus group discussion did report that parents/caregivers may receive the wrong medication because they are not able to read or understand the instructions they are given. The participants in the second focus group discussion also stated that sometimes the parent may not understand the treatment that is prescribed. They complained that consultations are often rushed, and as discussed above, they have to see a different doctor each time and explain the situation from the beginning. The participants stated that even when the parent asks for assistance the doctor does not explain or does not know enough about the child's condition to provide the information the parent needs. For example, a participant in the third focus group discussion stated that her child is receiving medication for epilepsy but is hungry all the time and gets angry if she asks him to stop eating. She did not know what to do about this. The example suggests that some parents do not receive sufficient information about the side-effects of medication or how to deal with them. Another example was given by a teacher. The teacher stated that many children are hyperactive at the school. When the parents take the children to the doctor, the medication the children receive just makes them sleepy. Three participants added their comments; "*They try to kill the energy, but the kid becomes dumb. They don't care"; "They give tablets to make the child quiet";* and *"The child is sleeping the whole day in class"*. The participants also complained about a lack of follow-up. Again these problems are not specific to mental health disorders but the impact of them may be greater than for other conditions as there is little supplementary information about mental health care in Namibia unlike long-term conditions such as HIV/AIDs or tuberculosis.

## 4.9 BARRIERS NOT IDENTIFIED IN THIS STUDY

### 4.9.1 HIV

This study did not identify a relationship between HIV infection and mental health and did not identify problems with or a notable usage of traditional leaders for the treatment of mental health disabilities and disorders.

The only mention of HIV in this study was made by one of the school principals. The principal noted that some of the learners are HIV positive and this can place additional challenges upon the child and the school.

The lack of association between HIV and mental health disorders may seem surprising given that Namibia has an HIV prevalence rate of 18.8% and a documented association between orphanhood and psychosocial problems (Ministry of Health and Social Services, 2010, Ruiz-Casares, Thombs, & Rousseau, 2009). However, the lack of recognition is likely to be due to the sample of participants selected. Studies that have assessed the linkage between AIDS orphans and psychological problems have specifically selected participants from this cohort (Cluver & Gardener, 2007; Cluver, Gardner, & Operario, 2008; Cluver and Orchin, 2009). In contrast HIV status was not a relevant selection factor for this study and was not discussed with the groups. Therefore, it is likely that the relevant participants who would identify these problems were not captured in the sample.

However the data collected in this study has shown that parents of children with diagnosed mental health disabilities and disorders face a number of barriers accessing healthcare services. It is likely that caregivers of AIDS orphans (or the children themselves if they live in child-headed households), who may often have undiagnosed conditions, face even greater challenges accessing mental healthcare services. Research is needed in this area.

### 4.9.2 TRADITIONAL HEALERS

There was little discussion about the use of traditional healers in this study even though such practice has been reported in the international literature (Appiah-Poku, Laugharne, Mensah, Osei & Burns, 2004; Ngoma, Prince & Mann, 2003). This may have been due to the location of the study in the capital city where access to formal healthcare services is likely to be greatest. If this study is repeated in rural areas, the use of traditional healers may be identified. Research into this area is needed

## 4.10 SEXUAL ABUSE

The identification of sexual abuse amongst children with some mental health disabilities and disorders was not part of the objectives of this study but the problem was highlighted in discussions. The issue was discussed in particular detail by both principals of the special schools in Windhoek. One of the problems, abuse when accessing public transport, has been discussed above. Another example was of a child with mental health challenges who was raped by a friend of the family. The man was buying food for the family and the mother allowed her child to have sex with him in return for the food. The child was not able to understand the situation and did not know how to get help. The acknowledgement of sexual abuse as a problem is so serious that the topic warrants further discussion. Recent data from Sweden confirms that children with chronic conditions, including disabilities, are at greater risk of physical abuse. The researchers found that the risk of abuse was higher for children living in poorer socio-economic conditions (Svensson, Bornehag & Janson, 2010).

Data from Namibia suggests that sexual abuse by caretakers of children in general is a problem (UNICEF, 2006). The data shows that one in four respondents between the age of 10-14 in a Knowledge, Attitudes and Practices Study on HIV/AIDS had experienced one or more forms of sexual abuse. Approximately 15% had been forced to have sex with a parent or caregiver at least one time. Therefore, there is a critical need to ensure that children with mental health disabilities and disorders, who are a vulnerable subgroup of children, are protected.

Data collected in Namibia between 2000-2005 also shows that in 3% of rape cases, the rape survivor had a disability. Of the cases the most frequent form of disability was mental disability, accounting for 86% of the disability cases. The report states that this is likely to be an underestimate as people with disabilities may experience greater barriers to reporting compared with a non-disabled person who has been raped. Barriers include not being able to communicate or not being able to understand the severity of the situation (Legal Assistance Centre, 2006).

People with disabilities appear to be at greater risk of rape from strangers compared with rape from someone they know. This is because the perpetrator was not known to the rape survivor in 50% of the disability cases whereas when all rape cases were assessed, the perpetrator was not known to the rape survivor in 33% of cases. In the cases where the perpetrator was known to a rape survivor who had a disability, the relationship included step-parents and landlords (Legal

Assistance Centre, 2006). However, the sample of cases was very small and the data should be viewed with this in mind.

The data also suggests that the successful conviction of a rape case involving a rape survivor who has a disability is lower than for rape cases in general. During the time period assessed, a conviction against the accused person in a disability rape case occurred in only 14% of the cases compared with 21.7% for all rape cases. Just as barriers in communicating evidence are likely to lower the reporting of such rape cases, barriers in communicating evidence are also cited as one of the reasons for the lower conviction rate (Legal Assistance Centre, 2006).

The only other available literature on the problem in Namibia is a thesis to assess prevention strategies in combating sexual abuse also amongst hearing-impaired learners (Philander, 2006).

One participant in this study recommended that there should be a dedicated place to report cases of abuse of people with disabilities. It is unlikely that this recommendation is practical as the Woman and Child Protection Units (specialist police centres to set up to deal with abuse cases) are already designed to receive complaints of abuse and the Units should be able to deal with such reports. However the Woman and Child Protection Units are not operating optimally and problems with dealing with cases affecting children with disabilities have been reported (Legal Assistance Centre, 2006). The researchers recommended that the handling of cases involving children with disabilities should be improved and that community members and institutions be provided with more information on how to identify signs of abuse in people with mental health disabilities. The Legal Assistance Centre also stated that there is also a need to better record data on the incidence of abuse to people with disabilities for better monitoring of the problem. Given the unexpected identification of this problem in this study, there is a need to conduct further research into this area.

## 4.11 PARTICIPANT'S RECOMMENDATIONS FOR SERVICE PROVISION

The participants in the first focus group discussion cited the following five recommendations for the improvement of healthcare services. The participants were asked to list recommendations for healthcare services but in all cases gave a more holistic list of needs. The points are listed in the order in which the participants said them:

1. *Better service delivery*
2. *Better education services*
3. *Support for parents*
4. *Need for afterschool services*
5. *Transport to schools*

The participants explained that better service delivery was something that could be applied to all patients, not just those with mental health disabilities and disorders. Service providers should be polite, courteous and should treat the needs of the patients seriously.

The participants in the second focus group discussion cited the following five recommendations for the improvement of healthcare services:

1. *More information on where, how and who can provide help for children with mental health disabilities and disorders*
2. *More therapeutic and social services (should be provided by government)*
3. *Long-term support (e.g. for when the parents are no longer alive, services for young adults post-school)*
4. *Activities to integrate the children into society*

5. *Additional services for children with serious mental health disabilities and disorders*

Again the participants did not specifically mention healthcare services, although they did highlight the need for therapeutic services. Points three and four address long-term needs by trying to promote the inclusion of children and adults with mental health disabilities into society. The participants advocated for an integrated service centre where doctors, therapists and other support services are in one place. The participants in the third focus group discussion also made this request.

The Central Hospital does have a Mental Health Unit but it appears that the participants do not always have access to this unit, instead seeing doctors at the Katutura hospital. As one participant explained, "*the Central Hospital is a referral hospital*" (meaning that the patient must first be seen by a non-specialist before having access to specialist help at the Central Hospital). International standards advocate for the provision of mental health services in primary care. However, the parents highlight the need for additional specialist services as well, something that is sometimes overlooked in broad discussions about the provision of mental healthcare services.

The participants in the third focus group discussion cited the following four recommendations for the improvement of healthcare services:

1. *Access to physiotherapy*
2. *Better access to existing support services that are provided by a range of government Ministries (e.g. Ministry of Youth, National Service, Sport and Culture)*
3. *The provision of disability identification cards to ensure that the hospital does not charge fees*
4. *More support from private sector health services when the state does not have the facilities, or when there is an emergency*

The participants in the third focus group recommended that there should be a doctor or nurse on site at the school. They felt that this would help promote long-term care needs and reduce the problems that are currently experienced when accessing healthcare with the rest of the general public at clinics and hospitals. The Principal of Môreson school said that the school will soon have an on-site physiotherapist. It could also be feasible for the school to arrange for a doctor or psychiatrist to visit on a regular basis.

The need for disability identification cards, which has been referred to in the discussion above, was mentioned throughout the third focus group discussion, showing that this was an important point of concern for the participants and one that they felt could be easily addressed.

As listed by the second focus group, the participants in the third focus group also wanted more therapeutic services, in this instance in the form of physiotherapy.

Point two about better access to existing services was slightly confused. The participant who made the recommendation cited the Ministry of Youth, National Service, Sport and Culture as a key Ministry. However, it was not clear, despite further questioning, what services the Ministry was expected to provide, the group however did specify the need for better access to social services from the Ministry of Gender Equality and Child Welfare and better access to grants from the Ministry of Health and Social Services.

Key informant one cited the following five recommendations for the improvement of healthcare services:

1. *Training of social workers*
2. *Training of parents*

3. *Provision of therapists*
4. *Translating of information*
5. *Use of media to get information out*

As with the list made by the participants in the first focus group discussion, key informant one highlighted the need for support for parents, and as with the list made by the participants in the second and third focus group discussion, she recognised the need for more support services including social workers and therapists.

Key informant two cited the following three recommendations for the improvement of healthcare services:

1. *Specialised counselling and psychiatric services for children and teenagers (both state and private)*
2. *More state and private residential facilities in Namibia*
3. *More discussion of mental health generally in school curriculum and at community level to reduce stigma, to alert people to signs of mental illness, and to inform children and community where to get help*

The lists show that both key informants one and two identified the importance of ensuring that communities and parents have sufficient information about mental health disabilities and disorders.

Key informant three cited the following eight recommendations for the improvement of healthcare services:

1. *Transport*

2. *Dedicated place to report abuse & immediate access to legal assistance*
3. *Provision of therapists*
4. *Health care*
5. *Schooling*
6. *Counselling*
7. *Integration into society post school*
    a. *Need for work opportunities*
8. *After school centre*

As with the list made by the participants in the first focus group, key informant three recommended after-school services, transport and education. Key informant three also concured with the recommendations made the participants in the second and third focus groups and by key informants one and two for more therapeutic and counselling services.

Key informant four cited the following four recommendations for the improvement of healthcare services:

1. *Having a doctor at the specialist school*
2. *Mechanisms in place to help deal with the fact that some of the children are sexually active and may be HIV positive*
3. *More funding allocated for mental health from the government*
4. *Better access for children with mental health challenges to be sterilised, if needed*

In common with the lists given above, key informant four cited the need for more resources through the need for the allocation of more funding. However the list also differs in focus as key informant four is the only person to have identified sexual activity as a serious concern.

Table 4.1 below collates the lists from the seven sources. Figure 4.4 summarises the recommendations which were made by more than one person/group. The most frequently recommended suggestion was for more therapeutic and counselling services. Most recommendations received support from two groups, suggesting that whilst the participants experience similar problems, the most important needs to address vary in priority according to circumstances.

**Table 4.1: Recommendations for the improvement of healthcare services made by the focus group participants and key informants**

| 1st focus group discussion | 2nd focus group discussion | 3rd focus group discussion |
|---|---|---|
| 1. Better service delivery<br>2. Better education services<br>3. Support for parents<br>4. Need afterschool services<br>5. Transport to schools | 1. More information on where, how and who can provide help for children with mental health challenges<br>2. More therapeutic and social services (should be provided by government)<br>3. Long-term support (e.g. for when the parents are no longer alive, services for young adults post-school)<br>4. Activities to integrate the children into society<br>5. Additional services for children with serious mental health challenges | 1. Access to physiotherapy<br>2. Better access to existing support services that are provided by a range of government Ministries (e.g. Ministry of Youth)<br>3. The provision of disability identification cards to ensure that the hospital does not charge fees<br>4. 4. More support from private sector health services when the state does not have the facilities, or when there is an emergency |

| Key informant 1 | Key informant 2 | Key informant 3 | Key informant 4 |
|---|---|---|---|
| 1. Training of social workers<br>2. Training of parents<br>3. Therapists<br>4. Translate information<br>5. Use media to get information out | 1. Specialised counselling and psychiatric services for children and teens (both state and private)<br>2. More state and private residential facilities in Namibia<br>3. More discussion of mental health generally in school curriculum and at community level to reduce stigma, to alert people to signs of mental illness, and to inform children and community where to get help | 1. Transport<br>2. Dedicated place to report abuse and immediate access to legal assistance<br>3. Therapists<br>4. Health care<br>5. Schooling<br>6. Counselling<br>7. Integration into society post school<br>8. Need work opportunities<br>9. After school centre | 1. Having a doctor at the specialist school<br>2. Mechanisms in place to help deal with the fact that some of the children are sexually active and may be HIV positive<br>3. More funding allocated for mental health from the government<br>4. Better access for children with mental health challenges to be sterilised, if needed |

*Five recommendations*

1. More therapeutic and social services

*Three recommendations*

1. More information for parents and communities

*Two recommendations*

1. Better healthcare services
2. Better service delivery
3. Afterschool services
4. Better transport services
5. Better education services
6. Support for parents
7. Long-term support and better integration into society (e.g. for when the parents are no longer alive, services for young adults post-school)
8. Better reporting facilities for situations where children have been abused

**Figure 4.4: Summary of the most frequently made recommendations**

## 4.12. SUMMARY OF THE THEMES IDENTIFIED

### 4.12.1 TRANSPORT

The problem of lack of **transport** was frequently discussed by the participants. The participants complained that they did not have the money to pay for the taxi fares to get to the hospital for an initial consultation or to return for follow-up visits. Although the families live relatively close to the hospital (for example within 5 kms), the participants explained that travelling on foot with a child with a mental health disability can be extremely difficult even over a short distance. When the child also has a physical disability, travelling on foot can be impossible.

The problem of transport is recognised in Article 9 of the Convention on the Rights of Persons with Disabilities (emphasis added):

> To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, **to transportation**, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas...."

The Convention on the Rights of Persons with Disabilities Handbook for Parliamentarians also recognises that bus travel can be a problem, stating (Office of the High Commissioner for Human Rights, 2007; page 13):

> The Convention's approach to disability also emphasizes the significant impact that attitudinal and environmental barriers in society may have on the enjoyment of the human rights of persons with disabilities. In other words, a person in a wheelchair might have difficulties taking public transport or gaining employment, not because of his/her condition, but because there are environmental obstacles, **such as inaccessible buses** or staircases in the workplace, that impede his/her access.

The report also recognises that transportation can be a barrier for children accessing educational services but does not specifically recognise transport as a barrier to accessing healthcare services (page 83):

> Access to education is not only about the education system. Even if a school allows a child with disabilities to enrol, a lack of accessible transport may make getting to school difficult or impossible. Sometimes the school itself is inaccessible. Changing the physical infrastructure may seem daunting, but it need not be. Over time, as buildings need to be refurbished, they could be retrofitted to include accessible design features.

Provision 9 2b of the Convention requires States Parties to take appropriate measures to "Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities", and under 9 2c that State parties should "Provide training for stakeholders on accessibility issues facing persons with disabilities". The government must do more to meet this goal. A good starting point would be for municipal bus drivers to receive training on mental illness to increase their awareness and social responsibility when children travel on these services. Another practical solution could be the allocation of dedicated seats for people with disabilities at the front of the buses. In the longer-term the entire bus system needs to be upgraded (there are few routes and buses often do not run to time) and dedicated transportation to the hospitals considered (such initiatives are being piloted in Namibia in other areas, such as maternal health; Synergos, n.d.).

Article 23 of the CRC is also relevant as it states that children with mental health disorders should have "effective access" to healthcare services. Currently this provision is not being met in Namibia. The government recognises that it is not meeting this need in its most recent periodic report on the implementation of CRC (Ministry of Gender Equality and Child Welfare, undated).

The problem statement, however, is brief indicating a possible lack of political concern about the issue:

> Problems include the delayed establishment of the National Disability Council; the outdated Disability Policy; limited access for people with disabilities to public buildings, public transport, information, education, employment, healthcare, counselling services and other services due to environmental barriers (including the lack of brailed materials and sign language interpreters and the inaccessibility of physical environment); and negative attitudes of the community towards people with disabilities.
>
> Ministry of Gender Equality and Child Welfare, undated, page 62.

### 4.12.2 MONEY

The problem of **money** was frequently discussed by the participants. Many participants said that they are charged a N$15 administration fee for consultations. Article 24 of the CRC "recognises the right of a child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". This right is not being realised as the administrative fee is a barrier against accessing potential healthcare services that are attainable in Namibia. Children with disabilities should be exempt from this fee but it appears that often this exemption is not applied. This is another example of a discrepancy between the experiences of the parents and a service provided by the State. The government should do more to ensure that the public is aware of the exemption and that service providers pro-actively assist people to access it. It is likely that the public will also need support in empowerment to ensure that they have the confidence to access an exemption even when they face barriers.

Money is also a barrier from accessing better quality healthcare, as the participants and key informants agreed that private healthcare is preferable to treatment available from the State. Furthermore, although a disability grant is available, few people access this service as noted by the results of this study and by data from the government (Ministry of Gender Equality and Child Welfare, 2010).

Money is also a barrier in accessing information about mental health conditions. There is little information freely available in Namibia, meaning the parents must resort to buying books or accessing information on the internet. For many this is not possible when there are more pressing needs, such as transport or food. There is a need for the government and civil society to provide better access to information about mental health conditions. In General Comment No 4 by the Committee on the Rights of the Child, the Committee urged State Parties to make the community aware of the early signs and symptoms and the seriousness of these conditions [mental disorders] (United Nations, 2003). The government is not meeting this recommendation. One solution would be for better partnering between existing civil society organisations working in the field of mental health in South Africa and new or existing civil society organisations in Namibia.

The impact of poverty on mental health is well known and the link between poverty and the exacerbation of mental health disorders has been reported (Lund et al., 2010; Patel & Kleinman, 2003). This study provides evidence of this linkage in Namibia as many participants in the study reported being unable to pay to access healthcare services owing to a lack of money to pay for both transport to the hospital and for the hospital administration costs. More must be done to address the problem of poverty and mental health in Namibia.

### 4.12.3 EDUCATIONAL SERVICES

The study identified the importance of **educational services** in accessing healthcare services. However, this relationship appears to be limited to cases where children are able to access specialist schools and only applies to a subset of children with mental health disabilities – children with mental health disorders will remain in mainstream schools but may not receive the support they need. Despite this statement, some mainstream schools do provide support. Key informant two, who does not send her child to a specialist school, still noted that the education system provided the best support for her child. The participants reported that the special schools provide educational support and address a number of holistic needs. Unfortunately there is considerable competition for places at these schools and parents who are unable to pay fees or cannot pay to support their child's living costs at the school are often not able to access the support in this system. As a result, this may also mean that children with mental health disabilities who are not able to access these schools have exposure to a much narrower range of healthcare services.

Having only nine specialist schools in the country is insufficient to meet the needs of all the children with disabilities in Namibia and the government must do more to promote inclusive education and the provision of special services in mainstream schools as mandated by Article 23 of the CRC (a disabled child should have effective access to education) and Article 7 of the Disability Convention (States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children).

The fact that money was a constantly recurring theme shows how mental health challenges in Namibia are considered the responsibility of the family and receive little support from the government. The isolation of families in Namibia has been previously noted as shown by the comment made by Levers Lopez (2002, page 120) who stated "I learned that children with any type of severe or visible disability simply are not sent to school". This statement is corroborated by a report in a regional review of disability policies that 38.6% of people living in disabled households have never attended school compared with 16.2% of non-disabled households, and that over 50% of disabled children over the age of 5 do not receive primary education (Lang, 2008). Under the Education Act 16 of 2001, school attendance is compulsory for children from age 7-16. The Act states that parents who fail to send their children to schools should be issued with a notice in writing to comply. However, given that many schools do not have the facilities to support children with special needs, it is unlikely that this provision is enforced for children with disabilities.

### 4.12.4 POOR SERVICE PROVISION

**Poor service provision** was another recurring theme in this study. However, it must be noted that this is a general barrier to healthcare services in Namibia rather than a specific barrier to mental health issues. In this study nurses were commonly cited as providing poor service and being rude or difficult when dealing with children with mental health disorders. Problems with service delivery have been noted by the government (Ministry of Health and Social Services, 2005; Ministry of Health and Social Services, 2008). The incidence of stigma and discrimination is against the Namibian Constitution, Article 2 of the CRC (children should not receive discrimination on the basis of disability) and the principles in the Disability Convention.

**Language barriers** were identified as a sub-theme of poor service provision. The participants explained that the doctors may be unwilling to speak to the parents/caregivers in their indigenous language, even if they are able to speak the language. The problem of language as a barrier in Namibia has not been reported as a general barrier to healthcare. However, it is unlikely that it is a problem that is specific to the treatment of mental health conditions. Further research in this area is needed.

It should be noted that participants in this study had very negative opinions about service delivery. However a Sister working at the Central Hospital Mental Health Unit, briefly interviewed by telephone for this study, stated that the Unit conducts outreach visits to clinics in Katutura and others areas of Windhoek to see mental health patients on a weekly basis. It is likely that the patients who receive help through these means experience better service delivery. Yet it is clear that the need for these services is much greater than the resources available and this explains why the parents in this study have not experienced the outreach visits from the Unit. Although the outreach programme attempts to meet the CRC principle of "effective access", the level of service provision is not sufficient.

Another sub-theme identified was the need for **therapeutic services.** The government has acknowledged that there is a lack of social workers in Namibia (Republic of Namibia, 2009). Although the government is making efforts to increase the number of social workers, progress reports do not recognise the need to ensure that social workers are equipped to assist with children who have mental health disabilities and disorders (Republic of Namibia, 2009). The government does not appear to have recognised the need for other service providers.

The question of whether **private health insurance** provide sufficient support was not identified as a key concern in this study. This was because the majority of participants did not have access to medical aid schemes rather than because there are no problems. Information from other countries, including South Africa, suggests that whilst private healthcare providers often provide better healthcare services, patients may experience discriminatory service provision for private mental health needs compared with private physical health needs (Oosthuizen et al., 2004).

One of the key informants did identify problems with service provision from a medical aid provider. These problems include stigma and discriminatory financial aid (the medical aid provider was unwilling to provide equivalent financial support for a mental health condition compared with a physical condition). Article 7 of the Disability Convention says that “States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children”. The potentially discriminatory nature of funds provision by medical aid providers may be in violation of this principle. The WHO also states that “[h]ealth insurance schemes should not discriminate against persons with mental disorders, in order to give wider access to treatment and to reduce burdens of care” (2001; xii). Further research in this area is needed to assess the extent to which discrimination by medical aid providers occurs.

### 4.12.5 LACK OF APPROPRIATE PARENTAL INVOLVEMENT

A **lack of parental involvement** was reported by the participants. The participants cited anecdotes of parents of children with mental health disorders were get frustrated with their children or want to disown them. This is problem that is also likely to occur with children who have physical disabilities. Some of the participants stated that the parents need support to help them learn to love and care for their children.

In light of the reported incidence of lack of parental responsibility, there is a need for social workers to be equipped to deal with such situations. The Child Care and Protection Bill provides for prevention and intervention services (Ministry of Gender Equality and Child Welfare, 2009). Such services could include the need for support for parents of children with mental health challenges. Non-governmental organisations should also consider how they can assist in meeting the needs of parents of children with mental health disabilities and disorders. These actions would be in line with Article 7 of the Disability Convention which requires State Parties to "take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children".

## 4.13 CONCLUSION

This chapter has presented data obtained from the focus group discussions and interviews conducted with the key informants. The next chapter makes conclusions and recommendations.

# CHAPTER FIVE

# CONCLUSION AND RECOMMENDATIONS

## 5.1 INTRODUCTION

This chapter provides a summary of findings, methodological limitations and further research possibilities. The chapter makes recommendations for how service provision can be improved and how parents of children with mental health disabilities and disorders can have better access to services.

## 5.2 SUMMARY OF THE FINDINGS

The data shows that parents of children with mental health disabilities and disorders experience a number of barriers that hinder access to healthcare services. The challenges go beyond commonly-reported problems such as sub-optimal service provision and include basic challenges such as lack of transportation to healthcare services. The World Health Organisation report on mental health lists ten main goals to improve mental health service provision (WHO, 2001). The findings from this study have been reviewed in light of the extent to which Namibia is meeting each of these objectives.

*(1) Provide treatment in primary care:* The WHO (2001; xi) states that "[t]he management and treatment of mental disorders in primary care is a fundamental step which enables the largest number of people to get easier and faster access to services". This study has highlighted the fact that parents are rarely able to access mental health care in primary care. The lack of mental

health care in primary care has also been recognised by the government (Ministry of Health and Social Services, 2008).

The Namibian National Policy for Mental Health recognises the need for primary healthcare mental health service provision, stating that the guiding principle for healthcare reform in Namibia is “equity, accessibility, affordability, community involvement and participation through the Primary Health Care (PHC) approach” (Ministry of Health and Social Services, 2005; page 2) but insufficient steps have been taken to make this a reality. As recommended by Kapungwe et al. (2010) regarding service provision in Zambia, there is a need for “greater commitment from governments and policy-makers in African countries to start prioritizing mental illness stigma as a major public health and development issue” (page 192).

The problem of integrating mental healthcare services into primary care is not unique to Namibia. Mwape et al. (2010) conducted a study in Zambia with primary healthcare providers to assess the barriers and opportunities for providing better mental healthcare services in primary care. Whilst service providers supported the integration of mental health services into primary care, many people interviewed suggested that patients with a mental illness should be treated separately, indicating that despite a willingness to incorporate mental health into the primary care remit, service providers still consider mental health orders to be specialist conditions that require separate treatment.

This study also identified transport as a barrier to accessing services. If better mental health services (and better healthcare services in general) were provided in primary care, it is likely that the problem of transport would be less of an issue and more children, including the children of the parents who participated in this study, would receive better mental healthcare provision.

*(2) Make psychotropic drugs available:* The main areas discussed in the focus groups did not centre on the availability of psychotropic medication. However, the participants did discuss some associated issues. For example, the participants complained of being prescribed painkillers rather than more effective medication. The participants also cited examples of misdiagnosis such as a pregnant girl being misdiagnosed with malaria and a case where meningitis infection was missed. Clinical research is needed to investigate problems in this area to assess the extent of the problems and to evaluate whether the problems are part of general failures in the healthcare system or are more specific to mental healthcare.

*(3) Give care in the community:* The concept of care in the community is intended to reduce the need to commit mental health patients to institutions. Fortunately care in the community does seem to be practised in Namibia as none of the participants reported problems with institutionalisation. However, key informant four stated that some parents will register their children at the special schools and then abandon the children to the care of the school, handing over future responsibility. This is a type of institutionalisation. As discussed under 5.3, more support for parents is needed to help them meet the challenges of living with a child with a mental health disability or disorder.

It should also be noted that although institutionalisation is recommended as a last resort by the WHO, there is still a need for such facilities. Key informant three noted the insufficient number of residential mental health facilities in Namibia and recommended the provision of more facilities as there are instances when children do need this type of care. Such a point illustrates the basic level of service provision available in Namibia. For some countries, decentralisation of services is the goal. In Namibia the goal is both to increase the total range of services provided and ensure that key services are provided in primary care.

*(4) Educate the public:* The importance of educating the public about mental health was noted by all participants involved in this study. There is no information from Namibia on the current level of mental health literacy. However, research from South Africa suggests that low mental health literacy is a barrier to healthcare (Ganasen, Parker, Hugo, Stein, Emsley, & Seedat, 2008; Trump & Hugo, 2006). The government and civil society could partner with organisations in South Africa to better disseminate information about mental health disorders and disabilities.

(5) *Involve communities, families and consumers:* The WHO recommends that "Communities, families and consumers should be included in the development and decision-making of policies, programmes and services.... In addition, interventions should take account of age, sex, culture and social conditions, so as to meet the needs of people with mental disorders and their families" (WHO, 2001; page 111).

One of the most striking findings in this study was the challenges parents living in Windhoek face accessing healthcare services even though the actual distance to the hospital is relatively small. This problem is an example of how the social context must be considered when developing policies, programmes and services. The government should include communities, families and consumers in policy debates.

*(6) Establish national policies, programmes and legislation:* The WHO states that "mental health policy, programmes and legislation are necessary steps for significant and sustained action" (WHO, 2001; xii). Namibia has a law and policy on mental health but these are outdated and

insufficient to meet national need or international agreements (Ministry of Health and Social Services, 2005; WHO, 2005a). Namibia does not have a specific policy on child mental health, despite this being a WHO recommendation (WHO, 2001a). Although the participants did not specifically discuss the legal or policy framework for mental health in Namibia, they did identify the need for more programmes and support for children with mental health disabilities and disorders.

Consequently there is a need to update policy and legislation in Namibia, with a particular need to either develop a separate policy for children or to include a specific chapter on children in a broader mental health policy. As noted under point 5, the community, families and consumers should be involved in policy development.

*(7) Develop human resources*: This study identified problems with mental health service provision in Namibia, particularly in the form of therapeutic and social services. Indeed the most common recommendation made in this study was for more therapeutic and social services. This finding is collaborated by data which confirms that the number of trained mental healthcare providers is insufficient to meet the needs (WHO, 2005a).

*(8) Link with other sectors:* This study has shown that linkages between sectors are very important as the relationship between educational services and access to healthcare was very clear. The government has made limited progress in developing multi-sectoral approaches in the disability sector as illustrated by the limited number of government interventions discussed in Chapter 2.

Some progress is being made. The National Gender Policy contains a provision on education which includes reference to the promotion of access to education for children with disabilities. But the policy does not confirm that this includes physical and mental disabilities, nor does it recognise the concept of mental health disorders (Ministry of Gender Equality and Child Welfare, 2009a). The accompanying plan of action for the policy has not yet been drafted. It is hoped that the plan will include mechanisms for inter-sectoral involvement. The Ministry of Education is also in the process of drafting a policy on inclusive education. Again it is hoped that this policy will recognise physical and mental disabilities, as well as mental health disorders. The benefit of school-based programmes has been discussed in the literature (Kutash & Duchnowski, 2004; Swartz et al., 2007) and it is hoped that linkages between education and health can be strengthened in Namibia.

The WHO also recommends that civil societies should be more active in promoting multi-sectoral involvement and there is a clear need for this in Namibia. There are very few organisations in Namibia that provide support services for people with mental health services. Where they do exist they are often of a small scale or localised intervention. There is a need to scale-up current activities and increase the number of NGOs in this field.

*(9) Monitor community mental health*: The participants did not discuss the proactive identification of mental health challenges in the community as the discussions centred on barriers in their personal situations and there was insufficient time to broaden the discussions. Yet the proactive investigation of mental health challenges is very important, particularly in light of the known linkages between HIV and psychological problems and the high prevalence of HIV in

Namibia ((Brandt, 2009; Earls, Raviola & Carlson, 2009; Harms, Kizza, Sebunnya & Jack, 2009; Ministry of Health and Social Services, 2010).

*(10) Support more research:* This study was conducted in Windhoek. Similar focus group discussions are needed in all regions of Namibia to assess how the experiences of parents differ across the country particularly as data shows that the majority of people with disabilities live in rural areas (National Planning Commission, 2001). As mental health care services in Namibia are currently centralised, it is likely that findings will be very different and show that children with mental health disabilities and disorders living in rural areas experience even greater problems accessing healthcare services. Further research will help to identify these issues, and help shape policy decisions about service provision (Lang, 2008).

As discussed in Chapter 2, there are large regional variations in the number of children with disabilities. Priority should be given to conducting studies in the Kavango and Ohangwena regions as these are the regions where most children with disabilities are living (EMIS, 2009). There is also a need to formally assess the national legislation, policies and programmes from a rights-based perspective in order to make recommendations for reform.

## 5.3 RESEARCH LIMITATIONS

This study was conducted with a small pool of participants and key informants in Windhoek. As discussed above, there is a need to expand this study to allow a greater number of participants from all areas of the country to be accessed.

The study is also limited by the fact that it was conducted by one researcher. This means that the data analysis was conducted from the perspective of one person only. If this study was scaled up a greater number of people would likely be involved in the data collection and analysis and this would improve the checking and validation of the codes and themes identified.

## 5.4 RECOMMENDATIONS FOR FURTHER RESEARCH

This study has identified a number of areas for further research. These are summarised below:

- Conduct research to assess the needs of children with mental health disabilities and disorders in all regions of Namibia, starting with the Kavango and Ohangwena regions.
- Conduct a rights-based analysis of current legislation and policy.
- Assess the incidence of discriminatory mental health care service provision by medical aid funds.
- Assess the association between HIV infection/orphanhood and mental health.
- Conduct clinical research into the adequacy of the medicines provided for mental healthcare.
- Research linkages between sexual abuse and mental health disabilities/disorders.

## 5.5 RECOMMENDATIONS FOR THE IMPROVEMENT OF SERVICE DELIVERY

The participants made a number of recommendations about how service provision can be improved. The list below organises these recommendations according to responsibility. Recommendations made by the researcher have also been included in the list.

*Recommendations for the Ministry of Health and Social Services*

- Update the Mental Health Act and National Mental Health Policy.
    - Develop a separate policy on child mental health.
    - Involve mental healthcare users in the reform process.
- Promote the decentralisation of mental healthcare services into primary care.
- Provide more therapeutic services including occupational therapy, speech therapy and physiotherapy.
- Provide more psychologists, psychiatrists and other relevant specialists.
- Ensure that basic training in mental health is included at the new medical school at the University of Namibia.
- Educate healthcare professionals about mental health conditions with specific focus on reducing the incidence of stigma and discrimination within service provision.
- Address the problem of language as a barrier during consultations.
- Provide dedicated transport systems to and from clinics and hospitals.
- Provide more information about mental health illnesses for community members in all Namibian languages.

- Ensure that the public is aware of administration fee exemptions. Encourage service providers to assist the public with administration fee exemptions where possible.

*Ministry of Gender Equality and Child Welfare*

- Increase the number of social workers.
- Train social workers on how to address the needs of parents of children with mental health disorders.
- Conduct research to assess the needs of children with mental health disabilities and disorders in all regions of Namibia.
- Increase awareness about the disability grant.
- Ensure that the national plan of action for the National Gender Policy includes mechanisms for multi-sectoral involvement to address the needs of children with mental health disabilities and disorders.

*Ministry of Education*

- Finalise and implement the draft policy on inclusive education. Ensure that the policy includes mechanisms for multi-sectoral approaches to address the needs of children with mental health disabilities and disorders.
- Provide more specialist education services for children with mental health disabilities and disorders.

- Collaborate with the Ministry of Health and Social Services to facilitate access to healthcare services through the education system.
- Provide training for staff on the identification of mental health disabilities and disorders.

*Ministry of Safety and Security*

- Implement recommendations made by the Legal Assistance Centre to improve the management of rape cases and reports of abuse to children with mental health challenges:
    - Rape cases involving persons with disabilities should be recorded and tracked as part of the standard record-keeping system of police and Woman and Child Protection Units, with information on this category of cases incorporated into regular reporting of crime statistics (Legal Assistance Centre, 2006; p 566).
    - Requests for the withdrawal of cases involving complainants with mental disabilities should be treated with strict caution (in co-ordination with the Office of the Prosecutor Genera; Legal Assistance Centre, 2006; p 581).

*Law Reform and Development Commission*

- Implement proposals for law reform in the Combating of Rape Act that will improve service provision for children with mental health challenges:
    - Make rape of persons with physical or mental disabilities a basis for imposing the highest category of minimum sentence (Legal Assistance Centre, 2006; p 577).

*Municipal services*

- Increase public awareness about the option for free bus travel for people with disabilities.
- Provide municipal bus drivers with training on mental illness to increase their awareness and social responsibility when children with mental health disabilities and disorders utilise their services.

*Non-governmental organisations*

- Increase the number of outreach activities conducted by existing organisations, and encourage more organisations to operate in this field.
    - Co-ordinate with South African organizations to facilitate this and to avoid duplication of initiatives.
- Provide information about mental illness for community members.
    - Media outlets can be key partners in increasing the availability of information about mental health disabilities and disorders.
- Provide social and support services for families who have children with mental health disabilities and disorders.
- Conduct training to empower people with disabilities and disorders and their families to combat barriers that they may experience.

- Provide training for transport companies e.g. through the Namibian Bus and Taxi Association.

## 5.6 CONCLUSION

This chapter has discussed the findings of this study and has made recommendations for how service provision can be improved and how parents of children with mental health disabilities and disorders can have better access to services. Many of the barriers identified in this study have been related to general problems with the healthcare system in Namibia, such as lack of transport and poor-service provision. The study has clearly identified that there insufficient mental health services available in Namibia, including both health and education services. A positive finding has been that the incidence of stigma and discrimination appears to be lower than has been identified than some neighbouring countries. An unexpected finding was reports of a lack of parental involvement in the needs of a child with a mental health disability or disorder.

Many of the barriers identified exist due to the socio-economic situation of families, a lack of acceptance of mental health disorders by families, the community and service providers, and the lack of services available. In many areas service provision does not meet national or international standards. There is a need for greater resource provision and intervention in this area.

# APPENDIX A

# INFORMATION ABOUT NAMIBIA

Namibia, located in Southern Africa, borders Angola, Zambia, Botswana and South Africa (Figure A). According to the 2006 Namibia Inter-Census Demographic Survey, Namibia has a population of 1.95 million (National Planning Commission, 2010). Covering approximately 824 000 square kilometres, the population density is low, with just 2.1 people per square kilometre (National Planning Commission, 2001). Despite being classified as an upper-middle income economy (World Bank, 2010), Namibia has been cited by at least one source as having the highest level of inequality in the world (UNDP, 2009). The rate of unemployment under a "broad definition' is 51.2%, whilst a 'strict definition' puts unemployment at 37.6% (The 'strict definition' of unemployment includes all persons aged 15-65 years who are without jobs and available for work, and are actively seeking employment. The 'broad definition' of unemployment includes all such persons whether or nor they are actively seeking employment; Ministry of Labour and Social Welfare, 2009).

**Figure A: Map of Namibia**

## PREVALENCE OF MENTAL HEALTH DISORDERS BY REGION

Table A correlates the prevalence of mental health disorders with factors such as poverty, distance from services and population.

**Table A: Prevalence of mental health disorders, poverty, mental health facility and distance from hospital/clinic by region**

| Region* | Population (NPC, 2001)** | Percentage with a mental disability (NPC, 2001) | Poverty ranking (1 = poorest region) (NPC, 2008) | Mental health facility | Average distance from hospital/clinic km (poor/non-poor) (NPC, 2008) |
|---|---|---|---|---|---|
| Omusati | 228 842 | 14.8 | 5 | | 8.3/9.4 |
| Kavango | 202 694 | 14.4 | 1 | | 5.4/7.7 |
| Oshikoto | 161 007 | 11.8 | 3 | | 12.9/18.1 |
| Ohangwena | 228 384 | 11.3 | 2 | Oshakati Psychiatric Unit | 12.4/10.0 |
| Oshana | 161 916 | 8.6 | 11 | | 4.5/5.7 |
| Caprivi | 79 826 | 7.6 | 7 | | 5.1/7.7 |
| Khomas | 250 262 | 6.7 | 13 | Windhoek Central Hospital | 5.2/11.3 |
| Otjozondjupa | 135 384 | 6.6 | 8 | | 20.5/19.4 |
| Hardap | 68 249 | 5.4 | 4 | | 18.0/15.1 |
| Omaheke | 68 039 | 3.8 | 6 | | 34.2/30.2 |
| Erongo | 107 663 | 3.4 | 12 | | 4.3/8.4 |
| Kunene | 68 735 | 3.0 | 9 | | 32.6/21.4 |
| Karas | 69 329 | 2.6 | 10 | | 16.6/17.2 |
| **Total population** | **1 830 330** | **5.6** | | | **10.8/12.5** |

* Table organised in order of prevalence of mental health disorders

** National Planning Commission

# APPENDIX B:

## PROPOSED QUESTIONS FOR DISCUSSION AT THE FOCUS GROUP DISCUSSIONS

1. What do you understand to be the meaning of the terms “mental health” and “mental illness”?

2. What mental health services have you accessed for your child? What services were provided by the government? What services were provided through private healthcare? To what extent were the services provided in primary care? Has your child been admitted into hospital for treatment? Why was this?

3. Have you experienced problems regarding the service you have received for your child (based on the mental health needs only)? Can you describe positive aspects of the service provision that you have received?

4. Have you experienced any problems relating to stigma and/or discrimination? If so, from whom? (Community members? service providers?)

5. Have you experienced any barriers regarding access to services? What type of barriers did you experience?

6. Can you explain how a person may access help regarding the barriers you have experienced? Are there any places that you would not go for help? Why?

7. What services should be offered to children with mental health challenges? Who should offer these services? What other suggestions do you have that might solve the problems we have talked about today?

8. What five things do you think are most needed to improve services regarding mental health needs? Why are these services needed?

9. Are there any issues relating to mental health that we didn’t talk about today but you would like to discuss?

## APPENDIX C

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
*Tel: +27 21-959, Fax: 27 21-959*
E-mail:

## INFORMATION SHEET

**Project Title:** **Experiences of parents of children with mental disability regarding access to mental health care**

**What is this study about?**
This is a research project being conducted by Rachel Coomer at the University of the Western Cape.

We are inviting you to participate in this research project because you are a parent, caregiver, relative or family friend of a child [hereafter referred to as parent or caregiver] who has mental health challenges for whom access/attempted access to mental health services has been attempted.

The purpose of this research project is explore the experiences of caregivers of children with mental disability regarding access to mental healthcare.

**What will I be asked to do if I agree to participate?**
You will be asked to participate in a focus group discussion to explore the experiences of parents and caregivers of children with mental disability regarding access to mental healthcare.

The purpose of the discussion will be to describe the problems that parents or caregivers experience when accessing healthcare resources and compare how these challenges relate to positive aspects of care. The topics discussed will be the types of services accessed and the barriers and positive events experienced. The participants will be asked to help develop a list of recommendations for the improvement of mental health services.

The focus group discussions will be conducted in Windhoek and will last between two-three hours.

**Would my participation in this study be kept confidential?**
We will do our best to keep your personal information confidential. All participants will be warned that confidentiality by their fellow participants cannot be guaranteed and the participants will be encouraged only to discuss general issues. The names or identifying information about the participants will not be recorded in any reports related to the study. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

This research project involves digitally recording the focus group discussions. This is to help the researcher to record the discussion and ensure that all relevant comments are noted. Only the researcher will have access to these digital recordings. The recordings will be destroyed following the acceptance of this study.

___ I agree to be digitally recorded during my participation in this study.
___ I do not agree to be digitally recorded during my participation in this study.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others.

**What are the risks of this research?**

There may be some risks from participating in this research study. The information discussed at the focus group discussions may be challenging for the participants. The researcher will provide opportunities for individual discussions should participants wish to provide information they do not want to share with the group. If requested, the participants will be referred to an appropriate source of assistance. Debriefing and support after the focus group discussions will be made available to the participants. Contact will be made with the participants within one month of the focus group discussion to check whether they have experienced any emotional problems from having participating in the study. Should this be the case, the participants will be referred to an appropriate counseling source.

### What are the benefits of this research?

This research is not designed to help the participants personally, but the results may help the investigator learn more about the problems they experience and to make recommendations to stakeholders, including government, for the improvement of service provision. We hope that, in the future, other people might benefit from this study through improved understanding of the challenges children face when attempting to access mental health resources.

### Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

### Is any assistance available if I am negatively affected by participating in this study?

A contact point for referral will be identified and presented to the participants. Should a participant request assistance with a mental health issue or a referral to healthcare services, the participant will be referred to the appropriate contact point. Participants who wish to discuss their situations in depth will be referred to an experienced counselor.

### What if I have questions?

This research is being conducted by Rachel Coomer at the University of the Western Cape. If you have any questions about the research study itself, please contact Rachel Coomer by telephone +26481 3552862, email rachel.a.jones@talk21.com or at her workplace, the Legal Assistance Centre, 4 Körner Street, Windhoek.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:
Head of Department:
Dean of the Faculty of Community and Health Sciences:
University of the Western Cape
Private Bag X17
Bellville 7535
This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

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