UNIVERSITY OF EDUCATION, WINNEBA

STIGMATISATION AND DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY: A CASE STUDY OF THE WEIJA LEPROSARIUM

SAMPSON GYIMAH AMOAH

2016

UNIVERSITY OF EDUCATION, WINNEBA

STIGMATISATION AND DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY: A CASE STUDY OF THE WEIJA LEPROSARIUM

SAMPSON GYIMAH AMOAH

8140230010

A THESIS FOR THE DEPARTMENT OF SOCIAL STUDIES EDUCATION, FACULTY OF SOCIAL SCIENCE SUBMITTED TO THE SCHOOL OF RESEARCH AND GRADUATE STUDIES OF THE UNIVERSITY OF EDUCATION, WINNEBA, IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF MASTER OF PHILOSOPHY DEGREE IN HUMAN RIGHTS

OCTOBER, 2016

DECLARATION

Student's Declaration

I, Sampson Gyimah Amoah, do hereby declare that this thesis, with exception of quotations and references contained in published works which have all been identified and acknowledged, is entirely my own original work, and it has not been submitted, either in part or whole, for another degree elsewhere.

Signature : ……………………………………………

Date : ……………………………………………

Supervisor's Declaration

I, hereby declare that the preparation and presentation of this thesis was supervised in accordance with the guidelines on supervision laid down by the School of Research and Graduate Studies, University of Education, Winneba and recommend for acceptance.

Supervisor's Name : Dr George Hikah Benson

Signature : ……………………………………………

Date : ……………………………………………

ACKNOWLEDGEMENTS

I am so grateful to the Almighty God for taking me through another academic stage. First and foremost, a very special "thank you" goes to my Supervisor, Dr. George Hikah Benson, of the Department of Social Studies, University of Education, Winneba, for his guidance, suggestions and more importantly for his patience in reading through my scripts that have made this work a success. Again, I thank him for making his research knowledge available to me. God bless you sir. I appreciate the contributions of all the wonderful and hard-working lecturers of the Department of Social Studies, University of Education, Winneba, especially Dr. Ansah Koi, Dr. Harrison Golo, Mr. Alexander Kaakyire Frempong, Dr Lawrence Oduman and Dr Jim Weiler for making the Discipline of Human Rights important to social, economic, political and cultural development discourse in Ghana. I would like to thank all my colleagues for their support. I sincerely appreciate the moral support from Dr. Eric Ananga, National Centre for Research into Basic Education (NCRIBE), University of Education, Winneba and Madam Patience Appiah – Boateng, I. E. D. E, University of Education, Winneba. My profound gratitude goes to Lepers Aid Committee especially Rev. Fr. Andrew Campbell, Mrs Cynthia Oti- Acheampong and Martin for their assistance. I am so grateful to Mr. George Quansah, Miss Esther, Miss Victoria and all the inmates of the Weija Leprosarium, who willingly co-operated with me during my study and made this work a remarkable one. My warmest appreciation goes to my family and friends especially Mr. Turkson Kofi Gyimah and the late Madam Vida for their encouragement that kept me on through- out the study. Finally, my colleagues (course mates) contributed immensely to the success of this work. God bless you.

DEDICATION

I dedicate this work to my wife, Gifty Mensah Hayford, mother, Janet Appau , my son, Prince and my father, the late Samuel Gyimah, for their prayers, inspirations, sacrifice and support for my education.

TABLE OF CONTENTS

LIST OF TABLES

TABLE **PAGE**

LIST OF FIGURES

ACRONYMYS

PAL	Persons Affected by Leprosy
VDPA	Vienna Declaration and Programme of Action
CRPD	Convention on the Rights of Persons with Disability
UDHR	Universal Declaration on Human Rights
ICCPR	International Covenant on Civic and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
CRC	Convention on the Rights of the Child
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
WHO	World Health Organisation
MOH	Ministry of Health
LEP	Leprosy Elimination Programme
CDPA	Copenhagen Declaration and Programme of Action
BDPA	Beijing Declaration and Platform for Action
QOF	Quality of life
AHC	Ad Hoc Committee
TSLHR	Third Symposium on Leprosy and Human Rights
GA	General Assembly

ABSTRACT

The rights of persons affected by leprosy (PALs) have been violated over the years and it appears policies and measures put in place to protect them have not been working. The specific objective of this study is to determine the extent of stigmatisation and discrimination against PALs. This thesis seeks to find out the factors and effects of stigma and discrimination and how public institutions are accessible to PALs. It further seeks to determine the relationship that exists between administrators, nurses, family members and persons affected by leprosy. A qualitative approach and a case study design were adopted for the study. Sixteen (16) respondents were selected; which included PALs, administrator, nurses and family members of PALs. The analysis of the qualitative data from respondents and other related materials reveal that curse, deformity, body odour, perception about the disease, derogatory names and fear of contracting the disease were identified as major factors of stigma and discrimination against persons affected by leprosy. The study also found out that the rights to education, health and employment of PALs are denied. Apart from these, right to marriage, family, social security and standard of living of PALs have been negatively affected. The relationship between PALs and their family members is poor while the relationship between nurses, administrator and PALs is cordial. It is recommended that; counseling services should be freely provided to all PALs and their family members, special schools for the PALs have to be established by the state, independent institution for example the ‘Ghana Disability Authority’ for Persons with Disability has to be established to promote and protect the interest of members including persons affected by leprosy.

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Every human being is born with inherent rights which are to be promoted, protected and respected by all no matter his or her status. However, there are instances where deformity and other issues have led to people being stigmatised and discriminated against. Historically, people affected with leprosy have been stigmatised and discriminated against which is a violation of their rights. Many international, regional and national human rights laws frown on this and this is the focus of the current work. The United Nations (UN) has adopted several international covenants, conventions, protocols and treaties to promote and protect the rights of special groups of people which the (bill of rights) Universal Declaration of Human Rights (UDHR, 1948), International Covenant on Civic and Political Rights (ICCPR, 1966) and International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966) did not make clear provisions for them because of their unique interest. For instance, Convention on the Rights of the Child (CRC, 1990), Convention on the Elimination of all forms of Discrimination Against Women (CEDAW, 1979) and Convention on the Rights of Persons with Disability (CRPD, 2007) have been promulgated by the United Nations to promote and protect the rights of children, women and persons with disability respectively .In 2007, the United Nations (UN) adopted and ratified the Convention on the Rights of Persons with Disabilities (CRPD) and entered into force in 2008, following the requisite number of signatories by member states including Ghana. The CRPD represents a universal framework of promoting and protecting the rights of Persons with Disability (PWD). The CRPD focuses on inclusivity, non discrimination, equality, accessibility and participation of PWDs, including those affected with leprosy. The Convention on the Rights of Persons with Disability has obliged all members of the UN to put up internal mechanisms to recognise, respect and fulfill the provisions in the Convention. The 1992 Constitution of Ghana has guaranteed the rights of persons with disability (Article 29). Some of the provisions in the constitution include; right to live with their families and to participate in social and recreational activities, protection against differential treatment, provision of good environment and living conditions, protection against all exploitation, judicial provisions and access to public facilities. Ghana has enacted the Disability Act (Act 715, 2006) to ensure its commitment to respect, promote and protect the rights of Person's With Disability (PWDs), including those affected by leprosy. The Act has made special provisions to ensure that public institutions such as Education and Health facilities have to be available, accessible, acceptable and adaptable for Persons with Disability (PWDs). However, persons affected by leprosy (PALs) are not enjoying the provisions in the international and national human rights laws due to stigmatisation and discrimination.

On the 18th of June 2008, the United Nations Human Rights Council unanimously adopted a resolution (A/HRC/8/L.18) on 'The elimination of discrimination against persons affected by leprosy and their family members'. This historic resolution made specific reference to key earlier human rights documents, namely the Universal Declaration of Human Rights (1948) and the International Covenant on Economic, Social and Cultural Rights (1966). The Council called upon Government to take effective measures to eliminate any type of discrimination and stigmatisation against persons affected with leprosy and their family members. It also requested the Office of the High Commissioner for Human Rights to collect information on the measures that Government have taken to eliminate discrimination and stigmatisation against persons affected with leprosy and their family members and to submit a report to the Council. People affected by leprosy should enjoy the same human rights as all other people especially provisions in the International Covenant on Economic, Social and Cultural Rights (1966). Almost all the articles of this Covenant can be seen to remain unfulfilled and not respected for people who have been affected by leprosy. These articles cover self- determination, economic and social and cultural rights, right to work and fair remuneration, protection of the family, adequate living standards, physical and mental health, education, participation in cultural life, and access to the benefits of scientific progress.

The WHO Global Strategy on Leprosy highlights the importance of social justice and equity and stresses that this must be integral to all leprosy work including approaches to preventing disability, stigma and discrimination. Specific practical strategies are therefore needed to ensure that States meet their obligations to respect, protect, fulfill and promote the rights enshrined in these various Conventions and Covenants including the latest UNHRC resolution to end leprosy-related issues regarding discrimination and stigmatisation (WHO, 2016). The 17th International Leprosy Congress in Hyderabad (2008) highlighted the need to attach the issue of leprosy to human rights to ensure the integration of people affected by leprosy in our society.

Leprosy, also known as Hansen’s disease, is a slowly progressive chronic disease caused by the intracellular parasite mycobacterium leprae. Mycobacterium Leprae mainly affects peripheral nerves and skin cells and is viable for up to 36 hours in an optimal environment. The time of incubation is usually between two and seven years (Guimarães, Barros, Bassoli, Salotti & Oda 2009). However, reports have been made of incubations of up to 20 years (Ofosu & Bonsu, 2010). The early signs of leprosy include spots on the skin that may have a different colour compared to the surrounding skin usually appearing on the arms, legs and back, nausea and feverishness. However, spots do not always appear and in some cases the only noticeable symptom is numbness in one or a few of the fingers and toes. If leprosy goes untreated small muscles become paralyzed and the entire hands become numb which causes the fingers to curl. When leprosy affects the legs, communication of sensation in the feet weaken hence the ability to feel pain is lost (numbness). Infections in the legs may also create wounds which if unattended to can cause tissue loss. The ability to blink is lost when the nerves in the face are affected which eventually leads to dryness, ulceration and blindness. Also, bacteria may enter the mucous lining of the nose which can lead to scarring and internal damage which in time causes the nose to collapse. Thus, if leprosy goes untreated it can lead to crippling, blindness and deformities (American Leprosy Mission, 2014).

Leprosy is one of the few chronic diseases that can be eliminated if the correct diagnosis is given and addressed at an early stage and there are opportunities to receive treatment with multi - drug therapy (Dogra, Narang & Kumar, 2012). A person who has suffered from leprosy can be medically treated and cured within a year and then return to a normal life, provided the disease has not come to the stage where it is disabling (Rafferty, 2005). Today there is realistic hope that leprosy may be non-existent at the end of this century (de Stigter, de Gaus & Heynders, 2000).

The 1992 Constitution of the Republic of Ghana prohibits discrimination particularly Article 17:1 which states that all persons shall be equal before the law. Article 17: 2 states that, a person shall not be discriminated against on grounds of gender, race, colour, ethnic origin, religion, creed or social or economic status. Article (2) of the

UN Convention on the Rights of People with Disabilities (CRPD) defines discrimination on the basis of disability as any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. The 1992 Constitution of the Republic Ghana defines discrimination in Article 17 (3) as giving different treatment to different persons attributable only or mainly to their respective descriptions by race, place of origin, political opinions, colour, gender, occupation, religion or creed, whereby persons of one description are subjected to disabilities or restrictions to which persons of another description which are not granted of persons of another description are not made subject or are granted privileges or advantages which are not granted to persons of another description. Discrimination is treatment or consideration of, or making a distinction in favour of or against, a person or thing based on the group, class, or category to which that person or thing belongs rather than on individual merit. To discriminate against someone is to exclude that person from the full enjoyment of his or her political, civic, economic, social or cultural rights and freedoms. Discrimination contradicts a basic principle of human rights; all people are equal in dignity and entitled to the same fundamental rights. The principle of non-discrimination is provided in several human rights conventions and treaties; UDHR (Article 2), CRC (Article 2), ICCPR (Article 2), CEDAW (Part IV), ACRWC (Article 2) and ACHPR (Article 2).

Stigmatisation is a Greek word which originally means a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people (Rebecca, 2003). These individuals were to be avoided, particularly in public places. The word was later applied to other personal attributes that are considered shameful or discrediting. Goffman (1963) defined stigma as an attribute that signifies that an individual is different from 'normal' people and, further, that the person is of a less desirable kind in the extreme, a person who is bad, or dangerous or weak. To increase the understanding of his definition, Goffman (1963) proposed three categories of attributes that are discrediting. They are abominations of the body or stigma of physical disfigurement; aberrations of individual character and personality such as mental disorder, imprisonment, unemployment, and tribal stigma such as of race, nation and religion. Jones et al (1984) have defined stigma as a mark or attribute that links a person to undesirable characteristics or stereotypes. This definition implies that one group sees the other as abnormal. It introduces the concept of 'them and us'. Stafford and Scott (1986) proposed that stigma is a characteristic of a person that is contrary to a norm of a social group or unit. Norm is defined as a shared belief that a person ought to behave in a certain way at a certain time (Stafford and Scott, 1986). Crocker et al (1998) argued that stigmatised individuals possess or are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context. Link and Phelan (2001) referred to stigma as a dynamic process that is linked to competition for power and tied into existing social mechanisms of exclusion and dominance.

Parker and Aggleton (2002) defined stigma as a social process that involves identifying and using differences between groups of people to create and legitimize social hierarchies and inequalities. Castro (2005) commented that stigma is a result of structural violence perpetrated by the larger social forces that are rooted in historical and economic processes.

Jacoby (2005) pointed out that stigma is a label associating a person to a set of unwanted characteristics that form a stereotype. Weiss and Ramakrishna (2006) defined stigma as a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem. It is interesting to note that, while Goffman's (1963) definition focuses on individual attributes, Link & Phelan (2001) expanded the nexus between an attribute and a stereotype. Although their definition of stigma did not include societal issues, Stafford and Scott elaborated that society could create negative stereotypes to preserve the social structure or to permit exploitation of a group or its resource (Stafford and Scot, 1986). They also pointed out that social inequality dramatically influences the process of stigmatisation of certain individuals or groups. Those who have control in a society have the power to impose their norms, values and beliefs, including cultural meaning of an attribute and the stigma attached to it, on people who are powerless. This argument supports the views of Link and Phelan, Parker, Angleton (2001) with regard to the role of social power the process of stigma and discrimination. The suggestions of Stanford and Scott (1986) are also supported by the studies of Waxler (1981), who reported that, because of racial prejudice and the perceived economic threat from the Chinese labourers among Hawaiians and others, the Chinese labourers employed in Hawaii were blamed for introducing leprosy into the country.

Stigmatisation is typically a social process, experienced, characterized by exclusion, rejection, blame or devaluation; those results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. Fear of stigma, and the resulting discrimination, discourages individuals and their families from seeking the help they need. Leprosy is associated with many problems like avoidance, negligence, separation, torture and less respect in society because of which affected people hide their disease and do not seek treatment. Hiding disease may relieve their anxiety initially but leads to unavoidable sufferings because treatable condition remains untreated, progresses and reaches a stage when it is no more treatable.

Stigmatisation can be categorised into felt, self, enacted and institutional. Felt stigma refers to the negative attitudes of the community towards those with a stigmatised condition. Internalised (self) stigma refers to the way sufferers feel, or perceive themselves to be at the receiving end of stigma. This usually leads to reduce self-esteem. Enacted stigma denotes actual occurrences of discrimination. Institutional stigma is whereby part of institutional arrangements or policies denies others access to the institution. This includes separate clinic arrangements for people affected by leprosy, insufficient arrangements for confidentiality, laws sanctioning divorce or social exclusion on the basis of the disease.

The call to end stigmatisation and discrimination against persons affected by leprosy has become a collaborative effort from the United Nations, African Union, NGOs, and civil societies to every individual to respect their dignity and rights. Mr. Yohei Sasakawa, Goodwill Ambassador for persons affected by leprosy (PALs), has initiated a campaign to end discrimination, stigma and other human rights violations faced by people affected by leprosy around the world (WHO 2008). The Prime Minister of Ethiopia, His Excellency, Mr Hailemariam Desalegn, has underscored the need to fight stigma and discrimination against people affected by leprosy and their families. He expressed concern that many people affected by leprosy fail to seek timely treatment due to fear of discrimination, resulting in low rate of diagnosis and missed opportunities. He emphasized the need for action to tackle stigma and discrimination against those affected by the disease (TSLHR, 2013). Dr Amankrah-Otabir has identified stigma as a major problem confronting persons affected by leprosy and advised the public not to use the phrase 'Cured Lepers' as nobody was born with leprosy (LEP –GHS,2014). Rev. Fr. Andrew Campbell has appealed to Ghanaians to stop the stigma and discrimination against persons affected by leprosy in other for them to participate actively in the society (Field Notes, Lepers- Aid Committee, Wed, 6th May, 2016). Sister Patricia, a Co-Director of the Ankaful Enyinda camp, said stigma and discrimination is a major problem for the cured patients who could not mix with society. Millions of men, women and children continue to suffer social, economic and legal discrimination, simply because they or a member of their family has leprosy (LEP- 2014).

There are about two to three million people in the world estimated to be permanently disabled because of leprosy (WHO, 1990). In 2000, the World Health Organization (WHO) listed 91 countries in which Hansen's disease is endemic. India, Myanmar and Nepal contained 70% of cases. India reports over 50% of the world's leprosy cases. The ten most affected countries in the world are India, Brazil, Indonesia, Nigeria, Ethiopia, Bangladesh, Congo, Democratic Republic of Congo, Nepal, Burma and Tanzania (United Nations, 2009)

In Africa, there are about one million people living with leprosy with an average detection of new cases of about 30,000 per year (WHO, 2010). The proportion of the severe form of the disease, called multi-bacillary, represents 66% of new cases in Africa. The proportion of children among new cases is 9% while the new case with grade 2 disability (that is patients with non-reversible physical damage) is 11% (WHO, 2010). Six countries are high leprosy burden countries with a risk of rapid expansion of the disease: the Democratic Republic of the Congo, Ethiopia, Madagascar, Mozambique, Nigeria and Tanzania. Six other countries are medium burden countries with low risk of expansion: Angola, Côte d'Ivoire, Ghana, Guinea, Malawi and Niger. Six countries need a close surveillance to early detect any increase in the trend of the disease: Burkina Faso, Cameroon, Chad, Liberia, Sierra Leone and Zambia (WHO, 2010).

It is estimated that about 10,000 people are living with leprosy in Ghana (Ghana Health Service,1990). Ghana was ranked twenty-second (22nd) among the most affected countries in the world with a percentage share of 3% (United Nations, 2009). Ghana has reached the elimination phase of leprosy with a prevalence ratio of 0.18:10,000 despite WHO target for elimination of 1:10,000 population or less (Ghana Leprosy Elimination Programme, 2014). There are six (6) leprosy camps in Ghana; Weija (Greater Accra) with twenty- nine (29) inmates, Ho (Volta Region) with one hundred and twenty (120) inmates, Nkanchina (Northern Region) with ninety five (95) inmates, Wa (Upper West Region) with four hundred and seven (407), Kokofu (Ashanti Region) with forty –nine (49) inmates and Ahotokrom (Central Region) with eighteen (18) inmates (Field Notes, Weija Leprosarium, Tuesday, 5th May,2016). Currently, the registered cases of leprosy in Ghana are 385 (GNA, 2016). These Leprosaria are managed by Lepers Aid Committee, Ghana; with the aim to support Ghanaians affected with leprosy, provide their basic needs such as food, housing, clothes and health, hence restoring their dignity as human beings.

1.2 Statement of the Problem

Ghana has signed and ratified many international covenants, conventions and treaties regarding promotion and protection of human rights of all persons including PALs. Prominent among the international human rights laws include UDHR (1948), ICCPR (1966), ICESCR (1966), CEDAW (1979), CRC (1989) and CRPD (2007), which frown on discrimination. The ratification of the Convention on the Rights of Persons with Disability (CRPD) and its protocol by Ghana indicates her commitment to make laws, establish institutions and formulate policies to promote and protect the rights of persons with disability. Ghana has given credence to CRPD by passing the Disability Act (Act 715) which has inspirations from the 1992 Constitution (Article 29).

Despite these international conventions and national laws, Persons affected by Leprosy seem to be stigmatised and discriminated against based on their physical deformity. Stigmatisation and discrimination against PALs have been considered as health related issue but not as human rights. This is the gap this work seeks to fill and that is to find out the extent of the stigmatisation and discrimination against PALs.

1.3 Purpose of the Study

The purpose of the study is to determine the extent /degree of stigmatisation and discrimination against persons affected by leprosy.

1.4 Objectives

- To determine the factors that account for stigmatisation and discrimination against persons affected by leprosy.
- To determine the effects of stigmatisation and discrimination on persons affected by leprosy.

- To examine the relationship between family members, nurses, administrators and Person's affected by leprosy
- To evaluate the accessibility of public institutions by persons affected by leprosy.

1.5 Research Questions

- What factors account for stigmatisation and discrimination of persons affected by leprosy?
- What are the effects of stigmatisation and discrimination on persons affected by leprosy?
- How has leprosy affected the relationship between family members, nurses, administrators and persons affected by leprosy?
- To what extent are public institutions accessible by persons affected by leprosy?

1.6 Justification of the Study

Stigmatisation and discrimination is a phenomenon that is associated with leprosy because of physical deformity the disease leaves on the affected persons. The PALs have been neglected and excluded in the society because of the disease. Most policies, measures and studies on leprosy related stigma and discrimination have considered the phenomenon as a health related issue but not as human rights. This is because leprosy is regarded as a special public health problem and it can cause permanent disability if intervention is delayed. Stigmatisation and discrimination against PALs should have inter- disciplinary approach for broader understanding and solutions. For instance, if the people in the society fail to recognise and respect the rights of PALs, then it will be difficult to promote and protect their rights. Hence, there is a need to study stigmatisation and discrimination against PALs in human rights. This will help to reveal human rights provisions for PALs and encourage people to recognise, respect, promote and protect them. This will help to reduce human rights violations against PALs.

Ajedirani, Sylvester and Fidelis (2013) conducted a study on the Health Related Quality of Life (HRQOL) among leprosy affected elderly people to determine their quality of health and the standard of living. The UNDP (2010), measured standard of living is by referring to long and healthy life, life expectancy at birth and education index. These human development index dimensions were missing out in assessing the quality of life of PALs. Therefore, it is relevant to address stigmatisation and discrimination against PALs from human rights perspective.

Bergman and Asabea (2014) conducted a study on nurse's experience of leprosy related stigma in the Central region of Ghana. They identified exclusion, lack of knowledge and social circumstances as significant factors of leprosy related stigma. They did not address education, exclusion and social circumstances as human rights violations. This indicates that, if people do not know their rights, it will be difficult to demand them.

1.7 Significance of the Study

The research will serve as an additional literature for the Social Welfare Department in addressing the challenges of persons affected by leprosy. Social protections are normally given to the needy and persons with disability by the Department of Social Welfare. The research will unveil the requisite needs of persons affected by leprosy and offer unique recommendations to their needs.

Ghana Health Service will also benefit immensely from the research. It will help the institution to identify the gaps between persons affected by leprosy and health personnel. The outcome of the study will help Ghana Health Service to revise the curriculum for training health workers to provide adequate health care delivery to persons affected by leprosy. It will also help the institution to develop a scheme to provide in- service training to build the capacity of health workers in providing health care to persons affected by leprosy.

Also, Non – Governmental Organisations (NGO's) such as Lepers Aid Committee will benefit from the research since it will help understand the extent of stigma and discrimination against persons affected with leprosy. It will help the NGO's to put up a strategy and educate the public on their perception on leprosy.

Additionally, it will help the Government to put up policies and programmes that will ensure the realization and promotion of economic, social, political and cultural and civic rights of persons affected by leprosy.

The general public will also benefit from the study because it will educate the people and remove all the prejudice about leprosy and persons affected. This can help to reduce the stigma and discrimination against persons affected with leprosy.

1.8 Delimitation

The study was limited to the cured lepers in Weija Leprosarium and other people that have direct relations with their daily activities even though other areas could have added more insight to the research. The problem of stigma and discrimination to PAL's could be testified by other people such as family members of the cured lepers, nurses and administrators of the leprosarium.

1.9 Organisation of the Study

The study comprises six chapters; Chapter One deals with the background to the study, the statement of the problem, purpose of study, objectives and research questions. Others are the justification and significance of the study, limitations and delimitations. Chapter Two focuses on the review of the related literature. Chapter three deals with the methodology of the study, the research approach and design, the population sample and sampling techniques, data collection instruments and data collection procedures and finally data analysis. Chapter Four focuses the presentation of findings of the study and Chapter Five discusses the findings as presented. Finally, the summary of findings, conclusions, recommendations and suggestions for future research form Chapter six of the study.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter focuses on relevant literature related to the topic. The literature is reviewed under the following; Theoretical Framework, history of leprosy, Historical Perspective of the Weija Leprosarium, Universal Declaration of Human Rights, evolution of Convention on the Rights of Persons with Disability, Convention on the Rights of Persons with Disability, Ghana's Disability Act (Act 715), Rights of the Disabled Person (Vienna Declaration of Action, 1993), the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, the Constitution of Ghana (1992) and Disability Rights, Stigma and Discrimination in Leprosy and other related literature.

2.1 Theoretical Framework (Intersectionality)

2.1.1 Intersectionality

Intersectionality (intersectional theory) is the study of overlapping or intersecting social identities and related systems of oppression, domination and discrimination. The theory suggests and seeks to examine how various biological, social and cultural categories; gender, race, class, ability, sexual orientation, religion, caste, age and other social identities interact on multiple and often simultaneous levels. The theory proposes that we should think of each element or trait of a person as inextricably linked with all of the other elements in order to fully understand one's identity (Hocks, 2014). This framework can be used to understand how systemic justice and social inequality occur on a multidimensional basis. Intersectionality is an important paradigm in academic scholarship and broader contexts such as social justice work or demography, but difficulties arise due to the many complexities involved in making multidimensional conceptualizations (Browne, Irene; Misra, Joya, 2003). It explains the way in which socially constructed categories of differentiation interact to create a social hierarchy. For example, intersectionality holds that there is no singular experience of an identity. The understanding of men's health solely through the lens of gender may not be complete because it is necessary to consider other social categories such as class, ability, nation or race, to have a fuller understanding of the range of men's health concerns.

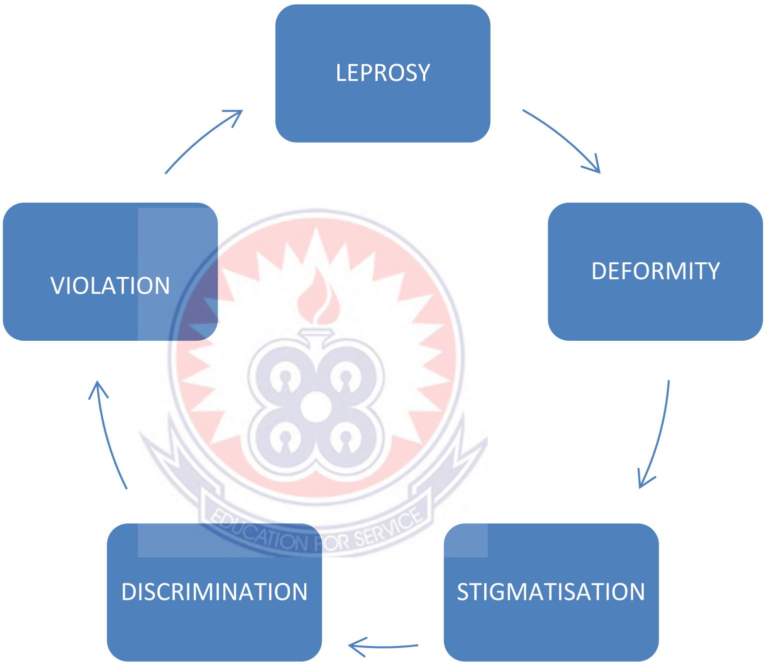
The theory of intersectionality also suggests that seemingly discrete forms and expressions of oppression are shaped by one another (Browne, Misra & Joya, 2003). While the theory began as an exploration of the oppression of women of colour within society, today the analysis is potentially applied to all categories including statuses usually seen as dominant when seen as separate statuses. The concept of intersectionality came to the forefront of sociological circles in the late 1960s and early 1970s in conjunction with the multi-racial feminist movement (Thompson & Becky, 2002). It came as part of a critique of radical feminism that had developed in the late 1960s known as the "revisionist feminist theory". This revisionist feminist theory challenged the notion that gender was the primary factor for determining a woman's fate (Hooks, 2014). This exploration sprang from a historical exclusion of black women from the feminist movement. Similarly, women of colour have long been excluded from the civil rights movement. In many ways, the introduction of intersectional theory supported claims made by women of colour that they belong in both of these political spheres.

Leslie McCall, a leading intersectionality theorist, argues that the introduction of the intersectionality theory was vital to sociology, claiming that before its development there was little research that specifically addressed the experiences of people who are subjected to multiple forms of subordination within society (McCall & Leslie, 2005).

The term intersectionality was introduced by Kimberlé Crenshaw (1991), a law scholar, to help illustrate the lack of objectivity in the United States judicial system. Intersectionality is based on the tenet that attributes cannot exist independently of each other, but rather are intertwined and mutually constructive. For example, how stigma affects African-American women. This pre- supposes that one cannot simply examine race and gender separately. Therefore the study of two attributes interacts and co-exists. This dynamic interaction creates a unique experience with stigma and stigma management for individuals. For instance, in other to fully explore African-American women's life experiences and to understand how they manage these multiple stigmas, it means you need to study and understand what it means to be African-American and what it means to be a woman.

In this situation, the researcher cannot explore leprosy and leave out stigmatisation and discrimination of the PALs. This means leprosy is closely associated with stigma and discrimination because of deformity of the body. Leprosy stigmatisation and discrimination are interlinked, interrelated, indivisible and interdependent. Leprosy will lead to deformity, deformity leads to stigma and stigma also leads to discrimination. According to the Vienna Declaration (1993), human rights are interrelated, interlinked, interdependent and indivisible because violation of one rights lead to the violations of other rights. Enjoyment of one right by individual will lead to enjoyment of several rights. For instance, when an individual enjoys rights to education, it will enable him or her to enjoy rights to health, economic, political, privacy, conscience, legal and environment. Leprosy is directly related to stigma and stigmatisation is also linked with discrimination; hence stigma and discrimination against PALs cannot be separated. This theory confirms paragraph (c) of the preamble of the CRPD, which states that: Reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination.

Figure 2.1: Cycle of Stigma and Discrimination in Relation with Leprosy



(Author's Construct)

The above diagram describes how persons affected by leprosy are perceived in a society. Leprosy is a disease that normally leads to deformity of the body such as the limbs, fingers, eyes, nose and the skin. The deformity of the body leads to stigmatisation where the society and even family members shun away from them. This then leads to discrimination against PALs from accessing various social amenities such as schools and hospitals. This therefore leads to the violation of the rights of PALs who are equally human beings and have rights just as any other person. For instance, Articles 1 and 2 of the UDHR reinforce this position.

2.1.2 History of Leprosy

Leprosy was well recognised in the oldest civilizations of China, Egypt, and India. The first known written reference to leprosy appeared in an Egyptian papyrus document written around 1550 BC. Throughout history, leprosy has been feared and misunderstood, and has resulted in significant stigma and isolation of those who are afflicted. It was thought to be a hereditary disease, a curse, or punishment from the gods. During the Middle Ages, those with leprosy were forced to wear special clothing and ring bells to warn others as they walked by. A cumulative total of the number of people who, over the millennia, have suffered its chronic course of incurable disfigurement, physical disabilities, or psychological trauma can never be estimated. There are many countries in Asia, Africa, and Latin America with a significant number of leprosy cases and 1 to 2 million people worldwide is visibly and irreversibly disabled due to past and present leprosy. In 1921, the U.S. Public Health Service established the nation’s first leprosarium, located in what is now known as Carville, Louisiana. The leprosarium served as an institution for people with leprosy and a hospital for experiments with treatments for leprosy as well as a laboratory to study the organism. The centre, which became known simply as “Carville,” became a refuge for leprosy patients and one of the premier centres of scientific research and testing in attempts to find a cure for the disease. In 1941, the discovery of Promin, a sulfone drug, was shown to successfully cure leprosy, but this treatment also involved painful injections. Promin became known as the Miracle of Carville. In the 1950s, dapsone pills, pioneered by Dr. R. G. Cochrane at Carville, became the treatment of choice for leprosy. Dapsone worked wonderfully at first, but Mycobacterium leprae bacteria eventually began developing dapsone resistance. In the 1970s, the first successful multidrug treatment (MDT) regimen for leprosy was developed through drug trials on the island of Malta. In 1981, The World Health Organization began recommending MDT, a combination of three drugs; dapsone, rifampicin, and clofazimine. The completion of MDT takes from 6 months to a year or even more, depending on clinical manifestations of the leprosy infection. In 1986, the Carville facility became known Gillis W. Long Hansen's Disease (Leprosy) Centre, named after the distinguished U.S. Congressman, close friend, and associate of the people working and living with leprosy. During its century of service, Carville was home to several hundreds of patients, some of whom met and married there and spent a majority of their lives on the picturesque campus. When the hospital at Carville closed in 1998, its few remaining patients were reluctant to leave. The buildings and grounds were transferred to the State of Louisiana in 1998, and the clinical centre relocated to Baton Rouge. A museum archiving the history of the Centre and a National Cemetery remain open to the public. Some elderly patients continue to live at the facility (Browne, 2003). .

2.2 A Historical Perspective of the Weija Leprosarium

The inmates of Weija Leprosarium first migrated from Jomo in La, a suburb of Accra, where the current La Poly Clinic is situated. Their migration was necessitated as a result of constant pressure from the Chiefs of the land. In 1946, Mr. Essumantey formed the society of Lepers named “friends of lepers” with the intention of soliciting for funds for the up keep of the lepers at Jomo. The leading members of the society were; Dr. Wilson (Medical Doctor), Mr. Gray (Teacher), Miss. Nash (Teacher) and Rev. Sister Barbara all from Achimota school. In 1947, Dr. McCarthy arrived in the Gold Coast with the mission of helping to cure leprosy. He heard the plight of the lepers at Jomo and decided to help. Dr. McCarthy was given a land at Cape Coast (Ankaful) to construct a clinic in order to start his mission. A year later, the pressure for the evacuation of the lepers from Jomo became so intense that Dr. McCarthy decided to convey all the lepers there to Ankaful. This plan was contradicted when Richard Kweku, the first leper at Jomo told Dr. McCarthy that, the customs of Ga's does not permit lepers to cross River Densu. This made Dr. McCarthy to acquire land in Weija (Accra) to accommodate the lepers. In 1949, Dr. McCarthy, Rev. Sister Barbara and Bishop Anglobin started the housing project at Weija. Sadly Sister Barbara and Bishop Anglobin left for the United States of America and did not see the dawn of the project. By the first quarter of the year 1950, the housing project was completed. On 14th August, 1950, eighty five (85) lepers moved in to Weija Leprosarium assisted by Mr. Koomson and Mr Tawiah, under the care of the Ministry of Health (MOH). After three months at Weija, Mr. Koomson left for Ankaful. Some officers who took turns for the up keep of the lepers at the Leprosarium were Mr. Yorke, Mr. Doddoo, Mr. Hodenyo, Mr. Quaye, Mr. Yemo, then Mr. Darku and currently Mr. George Quansah (Field Notes,Weija Lepprosarium, 3rd, May, 2016).

2.3 Universal Declaration of Human Rights

For the first time in history, the international community embraced a document considered to have universal value of a common standard of achievement for all peoples and all nations. Its Preamble acknowledges the importance of a human rights legal framework to maintaining international peace and security, stating that recognition of the inherent dignity and equal and inalienable rights of all individuals is the foundation of freedom, justice and peace in the world. Elaborating the United Nations Charter's declared purpose of promoting social progress and well-being in larger freedom, the Declaration gives equal importance to economic, social and cultural rights and to civil rights and political liberties, and affords them the same degree of protection. The Declaration has inspired more than 60 international human rights instruments, which together constitute a comprehensive system of legally binding treaties for the promotion and protection of human rights. The Universal Declaration covers the range of human rights in 30 clear and concise articles. The first two articles lay the universal foundation of human rights: human beings are equal because of their shared essence of human dignity; human rights are universal, not because of any State or international organization, but because they belong to all of humanity. The two articles assure that human rights are the birth right of everyone, not privileges of a select few, nor privileges to be granted or denied. Article 1 declares that "all human beings are born equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." Article 2 recognizes the universal dignity of a life free from discrimination. "Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. The first cluster of articles, 3 to 21, sets forth civil and political rights to which everyone is entitled.

The right to life, liberty and personal security, recognized in Article 3, sets the base for all following political rights and civil liberties, including freedom from slavery, torture and arbitrary arrest, as well as the rights to a fair trial, free speech and free movement and privacy. The second cluster of articles, 22 to 27, sets forth the economic, social and cultural rights to which all human beings are entitled. The cornerstone of these rights is Article 22, acknowledging that, as a member of society, everyone has the right to social security and is therefore entitled to the realization of the economic, social and cultural rights "indispensable" for his or her dignity and free and full personal development. Five articles elaborate the rights necessary for the enjoyment of the fundamental right to social security, including economic rights related to work, fair remuneration and leisure, social rights concerning an adequate standard of living for health, well-being and education, and the right to participate in the cultural life of the community.

The third and final cluster of articles, 28 to 30, provides a larger protective framework in which all human rights are to be universally enjoyed. Article 28 recognizes the right to a social and international order that enables the realization of human rights and fundamental freedoms. Article 29 acknowledges that, along with rights, human beings also have obligations to the community which also enable them to develop their individual potential freely and fully. Article 30, finally, protects the interpretation of the articles of the Declaration from any outside interference contrary to the purposes and principles of the United Nations. It explicitly states that no State, group or person can claim, on the basis of the Declaration, to have the right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth in the Universal Declaration.

Although countries have signed and ratified the UDHR but they do not in practice give equal weight to the different types of rights. Some Western cultures have often given priority to civil and political rights, sometimes at the expense of economic and social rights such as the right to work, to education, health and housing. Similarly the ex-Soviet bloc countries and Asian countries have tended to give priority to economic, social and cultural rights, but have often failed to provide civil and political rights. According to Judeo - Christians, many theories have been developed to explain the foundations of human rights. According to the legal (or positivist) view of human rights, all human rights stem from the law and nothing else. For example, the source of human rights would be found in the Universal Declaration of Human Rights (UDHR). Natural law theory (Natural Rights theory), in contrast, bases the foundations of human rights, and in particular human freedom and equality, on the understanding that they have a natural, universal and an eternal aspect. There is also the religious theory which places human rights within the context of a moral vision. The issue is an important one since many have asserted that these foundations of human rights especially UDHR are essentially western ideas, ideas that do not embrace or reflect principles of non-western cultures. This view is espoused in the context of the universality and cultural relativist debate. Muslim authors or organizations have recently published a number of Islamic declarations of human rights. Thus, in their own way, human rights reflect the culturalism inherent in essentialist "Western" interpretations because Islamic declarations, too, often claim an exclusive cultural and religious heritage of human rights. One of the earliest advocates of this new tendency is Mawdudi, an Islamist author from Pakistan, who vehemently attacks Western arrogance in the context of human rights. Alluding to the history of Western colonialism and imperialism, Mawdudi writes, "The people in the West have the habit of attributing every good thing to them and try to prove that it is because of them that the world got this blessing". Against human rights standard so the United Nations, which in Mawdudi's opinion were one-sidedly shaped by "Western" philosophy. Mawdudi Raftsa specifically "Islamic" conception of human rights based primarily on the Qur'an and the tradition (Sunna) of the prophet Muhammad (Heiner, 2000).

The UDHR lack the institutions that enforce its provisions. United Nations member states have ratified the UDHR but do not promote and protect the various rights intended to protect. The promulgation of International covenant on civil and political rights and International covenant on economic, social and cultural rights indicate the shortcomings of UDHR. Another criticism on the UDHR is that the number of countries that were signatory to the UDHR were about a quarter the current membership of the UN. For instance, Africans and the Asian countries were few in the UN. This has brought the development of regional protocols and instruments such as "The African Charter on the Welfare and the Rights of the People" to fill the gaps of the UDHR. The development of other two conventions, thus ICCPR and the ICESCR has placed much emphasis on civil and political rights than economic and social rights. Civil and political rights protect and promote individual rights than group rights. The basic needs of man are food, clothes and shelter. If an individual economic right is limited, his or her political and civic rights could be easily manipulated.

2.4 Evolution of Convention on the Rights of Persons with Disability

In the 1940s and 1950s, the United Nations focused on promoting the rights of persons with physical disabilities through a range of social welfare approaches. In the 1960s, initiatives within the disability community, coupled with the adoption of the International Covenant on Civil and Political Rights (UN, 1966) and the International Covenant on Economic, Social and Cultural Rights (UN, 1966). In the 1970s, the growing international concern with human rights for persons with disabilities was specifically addressed by the General Assembly in the Declaration on the Rights of Mentally Retarded Persons, (UN, 1971), the Declaration on the Rights of Disabled

Persons (UN, 1975) and by proclaiming 1981 as the International Year for Disabled Persons (UN, 1976).

The human rights of persons with disabilities became an important part of the international policy agenda in the 1980s. The World Programme of Action concerning Disabled Persons (UN, 1982). The World Programme of Action is a comprehensive global strategy that utilizes “equalization of opportunities” as its guiding principle for the achievement of full participation of persons with disabilities, on the basis of equality, in all aspects of social and economic life and development. The World Programme transformed the disability issue from a "social welfare" issue to that of integrating the human rights of persons with disabilities in all aspects of development processes. In the early 1980s, the Sub-commission on Prevention of Discrimination and Protection of Minorities (currently the Sub-commission on Prevention of Discrimination and Protection of Human Rights) appointed Mr. Leandro Despouy of Argentina as Special Rapporteur to study the connection between human rights, violations of fundamental human freedoms and disability which resulted in his final report, “Human Rights and Disabled Persons” (ECOSOC, 1992).

Mr. Despouy’s report, a benchmark in the field of human rights and disability, provided a comprehensive framework for the promotion of the human rights of persons with disabilities. The report recognized that in order for the human rights of persons with disabilities to be realised, there must be further development in jurisprudence within the human rights mechanisms and institutions at international and at domestic levels and an increased effort to adjudicate the rights of persons with disabilities at a national level. The available data suggests that many recommendations submitted by Mr. Despouy in his report remain to be substantiated by the international community. A number of initiatives have been taken to address the issue of elaborating a new disability-specific international instrument. The first initiative emerged in the Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-point of the United Nations Decade of Disabled Persons. The Government of Italy, in reference to the expert meetings held in Stockholm and Ljubljana, raised the issue of the possibility of an international convention in 1987 at the forty-second session of the General Assembly (UN, 1989). At the forty-fourth session of the Assembly, in 1989, the Government of Sweden proposed the elaboration of an international instrument on the rights of persons with disabilities (UN, 1989). However, a consensus was not reached on a legally binding instrument; many representatives expressed the view that existing human rights instruments would seem to guarantee persons with disabilities the same rights as persons without disabilities.

Agreement was ultimately reached on elaboration of a non-binding instrument on the rights of persons with disabilities. In May 1990, the Economic and Social Council authorized the Commission on Social Development to consider establishment of a working group, funded by voluntary contributions, to elaborate the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Following a series of technical meetings and consideration by the Commission for Social Development, the Standard Rules were unanimously adopted by the General Assembly at its forty-eighth session in 1993 (UN,1993). Mr. Bengt Lindqvist was appointed by the Secretary-General as Special Rapporteur on Disability of the Commission for Social Development initially from 1994-1997. In February 1997, the Special Rapporteur presented his report on the results of his first mandate to the thirty-fifth session of the

Commission for Social Development and outlined options to further implement the Standard Rules. The Standard Rules are an international instrument with a human rights perspective for disability-sensitive policy design and evaluation as well as for technical and economic cooperation on the developments concerning the broad human rights framework to promote the rights of persons with disabilities. The United Nations conducted a comprehensive comparative study of global disability policies and programmes in 1997, issued as a Report of the Secretary-General, "Review and appraisal of implementation of the World Programme of Action concerning Disabled Persons." (UN, 1995). This study indicated that a broad human rights framework must be further developed and established for disability policies and programmes to promote social, economic and cultural rights as well as the civil and political rights of persons with disabilities. Major international conferences and summits that were organized during the first half of the 1990s (VDPA, 1993, CDPA, 1995 and BDPA, 1995) on a range of development agendas adopted action plans and programmes in which participation, inclusion and improved well-being of persons with disabilities were accorded a special emphasis. The study further indicated that in order for the rights of persons with disabilities to be recognized, a broad human rights framework, drawing upon the considerable body of international norms and standards in the social, economic, civil, cultural and political fields is needed. This framework does not simply benefit persons with disabilities but also contributes to the advancement of the rights of all persons in society.

President of Mexico (Mr. Vincente Fox), during General Assembly debate of the Fifty – Sixth session of the General Assembly (2001), called on the international community to combat poverty and social exclusion. He stated that society should involve all citizens as stakeholders and that a just world must be inclusive of all groups. For that reason, Mexico had proposed establishment of Special Committee to study the elaboration of an international convention on promoting the rights of persons with disability. The General Assembly adopted resolution 56/168 which established an Ad Hoc Committee (AHC) to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development. It should be noted that the Commission on Human Rights no longer exists, and has instead been replaced by the Human Rights Council as part of initiatives to reform and improve the effectiveness of UN human rights bodies. The first such instrument was the Declaration on the Rights of Mentally Retarded Persons, adopted by the General Assembly in 1971. Later documents reflected the evolving understanding of disability, with the UN Standard Rules on the Equalization of Opportunities for Disabled Persons (adopted by General Assembly resolution 48/96 of 20 December 1993) arguably being the most progressive non-binding international standards-setting document to have been adopted prior to the CRPD. The Context section provides more information on the existing body of international disability “soft law”. The AHC met for a total of eight sessions at UN Headquarters in New York between July 2002 and December 2006, with each session lasting approximately two weeks.

In addition, a temporary sub-body of the AHC, known as the Working Group, met for two weeks in January 2004, for the purpose of drafting the “Working Group Text” that would form the basis for future negotiations. Subsequent AHC sessions conducted readings of the text, during which time delegations had the opportunity to propose amendments. Those amendments that garnered sufficient support were later synthesized in two further texts, the “Chair’s Text” (issued in October 2005) and the “Working Text” (issued in February 2006). In August 2006 the AHC finalized the substance of the Convention and forwarded the consensus text to a technical Drafting Committee: a temporary sub-body of the AHC mandated to format and proofread the text, ensures linguistic concordance between the six official UN languages, and ensures internal consistency in use of concepts and terms. The work of this Drafting Committee was accepted by consensus by the AHC at a brief “resume” meeting of its Eighth Session on December 5, 2006, and immediately transmitted to the General Assembly (GA). The GA unanimously adopted the CRPD on December 13, 2006, making it, as UN Secretary General Kofi Annan noted, the most rapidly negotiated treaty of its type in the history of international law. The Convention was opened for signature at the UN Headquarters in New York on March 30th, 2007, and entered into force on the 30th day as a human rights instrument for ratification.

2.5 Convention on the Rights of Persons with Disability (CRPD)

The Convention follows the civil law tradition, with a preamble, in which the principle that "all human rights are universal, indivisible, interdependent and interrelated" of Vienna Declaration and Programme of Action is cited, followed by 50 articles. Unlike many UN covenants and conventions, it is not formally divided into parts.

Article 1 defines the purpose of the Convention: to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Articles 2 and 3 provide definitions and general principles including communication, reasonable accommodation and universal design.

Articles 4–32 define the rights of persons with disabilities and the obligations of states parties towards them. Many of these mirror rights affirmed in other UN conventions such as the International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights or the Convention Against Torture, but with specific obligations ensuring that they can be fully realised by persons with disabilities. Rights specific to this convention include the rights to accessibility including the information technology, the rights to live independently and be included in the community (Article 19), to personal mobility (article 20), habitation and rehabilitation (Article 26), and to participation in political and public life, and cultural life, recreation and sport (Articles 29 and 30). In addition, parties to the Convention must raise awareness of the human rights of persons with disabilities (Article 8), and ensure access to roads, buildings, and information (Article 9). Articles 33–39 govern reporting and monitoring of the convention by national human rights institutions (Article 33) and Committee on the Rights of Persons with Disabilities (Article 34). Articles 40–50 govern ratification, entry into force, and amendment of the Convention. Article 49 also requires that the Convention be available in accessible formats.

The CRPD is the first ever universally accepted document in the world that protects and promotes the rights of persons with disability. The obligation placed on states by UN to enact laws and establish human rights institutions to protect and promote the rights of persons with disability in their respective countries. The establishment of special committee to receive report from countries and monitor the recognition of the

CRPD serves as means of fulfilling, promoting, recognising and respecting the rights of persons with disability. However, the optional protocol to the CRPD is a setback. This is because the optional protocol indicates gaps in the original convention. Also, the Committee on the Rights of Persons with Disability lacks the authority to impose sanctions on any country that fail to comply the convention after signatory and ratification.

2.5.1 Review of the Convention on the Rights of Person with Disability

Article 1 of the CRPD states that the Convention's main purpose is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promote respect for their inherent dignity" The Convention provides a broad compendium of existing human rights recognized by the UN, though elaborated upon within the context of disability issues. It reiterates such basic rights as the freedom of expression and opinion (Article 21), freedom from torture (Article 15) and the rights to life, liberty and security of the person (Articles 10 and 14). It provides direction to states parties on steps they must take to ensure that people with disabilities share the same rights as others. It clarifies the type of actions that state parties should take to promote and protect the rights of persons with disabilities in such areas as freedom of expression and opinion, respect for home and the family, health, employment and access to services.

By ratifying the Convention, a country accepts its obligations under the treaty and must ensure that its domestic laws fully implement them (Barnett, 2012). The obligations range from general to specific. The general obligations require states parties to take whatever appropriate measures are required to ensure that the rights contained in the Convention are properly protected and promoted. Other general obligations include taking such steps as adopting legislation to abolish discrimination (Article 4), encouraging research and development in accessible goods, services and technology for persons with disability, promoting international corporations among states parties, international and regional organisations and society (Article 32). The specific obligations in the Convention indicate what actions should be taken to promote its main principles. For instance, Article (8) of the Convention begins with a general obligation for state parties to raise awareness about persons with disabilities generally, to promote their capabilities and contributions, to foster respect for their rights, and to combat stereotypes and harmful practices. It then specifies that such measures may include running public education campaigns.

2.5.2 Definitions of Disability

The 1975 UN Declaration on the Rights of Disabled Persons defined a " disabled person" as anyone unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and or social life, as a result of deficiency either congenial or not, in his or her physical or mental capabilities. This definition stresses the inabilities of persons with disabilities and their dependence on assistance. Since this was written, attitudes towards disability have shifted. For instance, the term "disabled" has been largely replaced in common use by "persons with disabilities," since the latter places emphasis on the person and not his or her disability. Though the Convention uses the term "persons with disabilities," it is not included in the definitions section. The absence of a formal definition permits people to define their own in relationship with disability. It recognizes, as noted in the preamble, that "disability" is an "evolving concept." To provide some guidance, however, the Convention states in its "Purpose" section that the term "persons with disabilities" includes, but is not limited to, " those who have long – term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in the society on an equal basis with others"(Article 1). This wording recognizes the diverse types of disabilities, which a person may have. Perhaps most importantly, it emphasizes that a person with a disability is only limited in their ability to participate in a society as a results of their interaction with the barriers that any society permits to exist, which may be physical obstacles, policies, legislation, discrimination behavior and prejudicial attitudes (CRPD, 2007). The Convention requires States Parties to identify and eliminate these obstacles and barriers.

This considered use of language is also reflective of the rights – based approach and the shift as noted by the UN's Secretariat for the Convention on the Rights of Persons with Disabilities on its Enable website, from viewing persons with disabilities as 'object' of charity, medical treatment and social protection toward viewing persons with disability as subjects with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (CRPD, 2007).

2.5.3 Key Principles of CRPD

i) Equality and Non-Discrimination

The Convention is intended to ensure that persons with disability enjoy access to human rights just like everyone else and free from discrimination, the importance of equality is stressed throughout. The general principles that are to guide the interpretation of the Convention, as enumerated in article 3, which include full and effective participation and inclusion in the society, equality of opportunities and equality between men and women. The Convention addresses many areas where persons with disabilities have traditionally been discriminated against, including access to justice, participation in political, cultural and public life, education and employment. Legal equality is fundamental right that ensures individuals are empowered to access justice and challenges the violation of any of their rights. The Convention states that "all persons are equal before and under the law and entitled without any discrimination to the equal protection and equal benefit of the law" (Article 5). States parties must also ensure that persons with disability have access to justice on an equal basis with others (article 13), including ensuring that appropriate accommodations are made to facilitate their participation in all legal proceedings (including as a trial witness, complainant or defendant).

Article 12 uses some similar language to article 5, but adds that persons with disability are entitled to equal recognition before the law. This provision also includes an important development not seen in the previous UN instruments. It focuses on ensuring that persons with disability are able to exercise their own legal capacity and that the state provides support as necessary to allow them to do so. The intention here is that persons with disabilities are to be supported in making their own decisions concerning their personal, financial or legal affairs and their best interest are always considered by those assisting them. The Convention focuses not on whether a person has capacity to make decision, but upon how that person can be assisted so that he or she is able to make decisions affecting their life (Montigny, 2009). Article 12 of the Convention also add that persons with disability should have equal opportunity to own and possess property , control their own financial affairs and participate in all decisions affecting them. It also requires that State Parties have sufficient legal safeguards to protect this equal legal capacity from being abused, such as through the review of important legal decisions by an impartial authority or judicial body. There is a reservation to article 12 in order to permit it to continue to use substitute decision – making arrangements; " in appropriate circumstances and subjects to appropriate and effective safeguard" (UN, 2014). This refers to such cases where a person is deemed to not have the mental capacity to make decisions on their own and therefore supportive decision making may be appropriate (Bach & Kerzner, 2010). Article 2 of the Convention covers another aspect of ensuring substantive equality for persons with disability by requiring that States Parties promote the principle of reasonable accommodation of persons with disabilities. In brief, this is a duty imposed on public and private employers, service providers and landlords to ensure that their policies, programmes, infrastructure or operations do not have discriminatory effect and prevents persons with disabilities from fully enjoying and exercising their rights (Bammett, Nicol & Walker, 2012). If they do, then the duty holder will have to undertake any reasonable modification or adjustments that do not impose an undue burden or hardship in order to provide accommodation to the person seeking it. Examples might include ensuring that a workplace is accessible to any employees with mobility impairments or providing large print menus to restaurant patrons with visual impairments or providing sign language interpretation to audience members with hearing impairments. The Convention seeks to address the complexity of the inequalities individuals face in society by noting in the preamble that many persons with disabilities face "multiple or aggravated forms of discrimination" on the basis of sex, age, ethnicity, religion, religion and other grounds. Two articles place special emphasis on the need for States Parties to recognize the rights of women and children with disabilities and for States Parties to take the necessary or appropriate measures to ensure they enjoy all human rights and fundamental freedoms (Articles 6 & 7) (51).

(ii) Accessibility

The importance of accessibility is emphasis throughout the convention. It is included as one of the eight general principles set out in article (3). It is underscored in numerous articles and requires state parties to ensure access in such areas as justice (article 14), education (article 24), health (25), and work and employment (article 27). Article 9 articulates the key areas where accessibility is to be promoted, and barriers and obstacles eliminated, including transportation, information and communications, and other facilities and services open or provided to the public, whether operated by the public or private sector. It also requires that State Parties do not provide only access but also develop minimum standards for the accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost. Article 28 is an important guarantee for persons with disabilities to an adequate standard of living and social protection, including through access to such necessities as clean water, affordable services and supports for disability – related needs, housing, poverty reduction and social protection programmes, and assistance to families for disabilities – related expenses.

(iii) Participation and Inclusion

Removing the barriers that impede persons with disabilities means more than simply making places and services accessible, It also means making sure that persons with disabilities are not impeded from full and effective participation and inclusion in society (article 3). To promote inclusion, State Parties must consult and actively involve persons with disabilities in the development and implementation of legislation and policies to implement the present Convention, and in other decision- making process concerning issues relating to persons with disabilities (article 4, 3). To guarantee this active participation, article 29 focuses on political and public life, including protecting the right to vote and to participate in the conduct of public affairs (including organisations representing persons with disabilities). Article 30 of the Convention affirms that persons with disabilities have the same rights as others to participate in and enjoy sports, the arts and other cultural activities. On one level, it is intended to ensure that such sites such as theatres, museum, libraries, sport venue and children's playgrounds, as well as such materials as books, films and recordings are accessible to everyone. It goes further and requires that State Parties take active steps to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit , but also for the enrichment of society as well as to participate in disability – specific sporting and recreational activities (article 30/5) (52).

2.9 Stigma and Discrimination in Leprosy

Stigma and its consequences have a negative effect on individuals, families and leprosy Control Programmes. Some patients diagnosed with leprosy may conceal their illness out of fear of rejection and exclusion from society. Others may stop their treatment prematurely out of fear for stigmatisation because they experience drastic appearance changes due to side effects of treatment e.g. uneven darkening of skin due to clofazimine and facial swelling and weight gain because of prednisone (Bainson et al 1998; White, 2007). There are times when people report late due to stigma and because of that the opportunity for the transmission of the disease increases. This has consequences for control efforts and not only that it will have financial consequences as well because the condition of the person affected may worsen and therefore people will need prolonged treatment and special care. Late reporting can have adverse consequences for the patients as they may suffer physical impairments and disabilities, which could have been prevented if they had come earlier (Bainson et al, 1998). Physical impairments cause difficulties for a leprosy affected person in carrying out activities he could do well before. If these impairments have become permanent the person may experience greater disadvantages for example losing his/her job, not able to work well and because of that unable to earn enough for a living, denied to go to school, loss of social status. Through participation restriction the person affected will become more and more isolated and excluded from society as s/he cannot fulfill the role which was expected of him or her (Kaur & van Brakel 2002). Psychological changes occur in the patient due to impairments and disabilities that are perceived as negative by the patient resulting in negative expectations of him with respect to life. A variety of emotions like fear, grief, confusion and anxiety may develop and could lead to depression, loss of self-esteem, withdrawal and mental problems (Tsutsumi et al, 2004). As a result of the disabilities, people affected by leprosy are more prone to be stigmatized. Visibility of wounds and ulcers can aggravate the fear of contagion (Jopling, 1991; Seddon et al, 2006). People affected by leprosy have experienced isolation and discrimination as they were rejected by their families and pressurised by community members to leave their villages (Shieh et al, 2006). Stigma is not only associated with fear of catching the disease or a result of a person's strong feelings of dislike towards disabilities. Some traditional and religious beliefs also play a major role. For example, in many Hindu societies, persons affected by leprosy are blamed for their condition, which is thought to be a punishment for something they have done wrong in a previous life. In this case, stigma involves a moral judgement (Seddon et al, 2006). As much as disabilities can be a determinant of stigma, this is not always the case as it is not only the person suffering from leprosy who is affected by stigma, but people associated with the patient as well. These people do not have any signs of leprosy but are still stigmatised and the impact weighs heavily on their lives. The prospect of getting a job or getting married can be at stake (Seddon et al, 2006). Leprosy is still a stigmatised disease despite the fact that it is curable and that MDT is available. Strong beliefs and fear still persists. It is those beliefs, attitudes and behaviour that need to be taken into account in order to address the struggle against stigma in leprosy (Seddon et al, 2006).

2.9.1 Types of Stigma

i. Felt stigma

Felt stigma refers to the imagined or real fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease, or association with a particular group (Jacoby, 1994). For instance, women may delay seeking treatment if they suspect they have leprosy out of fear of being abandoned, anticipating less chances of getting married or that it may affect their role in the household. In the case of HIV, an individual may not disclose HIV-positive status for fear of being rejected by family and friends or out of fear of losing a job. Jacoby (1994) cited Scambler and Hopkin in saying that felt stigma was more prevalent than enacted stigma. She continued discussing about people with epilepsy that “they did not experience discrimination but felt stigma as a product of stigma coaching by key individuals such as parents”. Most likely the response of the parents with care and protection to deviance is high and stigmatizing and harmful effects of responding are often unintended (Dijker and Koomen, 2006). Acceptance of the disease leprosy or the HIV status by family and friends is important for the person affected. Acceptance will help the person affected to accept his or her condition and continue to live a positive life (Siyam’kele, 2003).

ii. Enacted Stigma

Enact stigma is the real experience of discrimination that means unjust and unfair actions in a society towards people affected by a certain condition or associated with a particular group (Jacoby, 1994). Examples include rejection by the family/community, restrictions in participation in religious activities and loss of a job because of leprosy.

iii. Public Stigma

Public stigma refers to the attitudes of the community concerning a certain illness or condition such as leprosy, HIV/AIDS and mental illness. It encompasses three parts, stereotypes, prejudice and discrimination. Social psychologists view “stereotypes as knowledge structures that are learned by most members of social group” (Corrigan & Kleinlein, 2002). Stereotypes give information about social groups, which are categorized and agreed upon by society. They give quick impressions and expectations of individuals belonging to the stereotyped group. People become prejudiced if they endorse a negative stereotype (“That’s right; people with mental illness are violent!”) and it may lead to negative emotional reaction as a result (“They scare me!”). Prejudice is a cognitive and is an effective response, whereas discrimination is the behavioural response. Anger may lead to withholding help, whereas fear may lead to avoidance (Corrigan & Kleinlein, 2002 p.17). The impact of public stigma affects many people; not only the person with the condition, but also family, friends and even care givers.

iv. Self - Stigma

Self – Stigma results from internalisation of negative stereotypes and agreement with these. Self-prejudice can lead to emotional reactions resulting in low self-esteem and low self -efficacy. In addition to that, self-prejudice may lead to behavioural responses. Low self-esteem and demoralization may stop a person from pursuing work or going to school. Self-stereotyping, self-prejudice and self-discrimination will have an impact on a person's purpose in life and on the quality of life. Self-stigma has often been presented as an automatic result of being a member of a stigmatised group. However, not everyone loses self-esteem, as studies have revealed. There are different ways to respond to stigma. In part, this depends on the person's level of identification with the stigmatized group. A person can comply with the perceived threat of stigma and view oneself poorly, or s/he can oppose the negative evaluation, which may result in a positive self-perception (Corrigan & Kleinlein, 2002).

2.9.2 Determinants of Stigma and Discrimination

i. Socio - Cultural

In order to understand more of the social and cultural aspects related to leprosy we need to look at the concepts of disease, illness and sickness. The disease of leprosy is the biomedical perception. The illness of leprosy is self- perception. The sickness of leprosy is the social perception. The health professional will perceive the disease by its physical symptoms. Illness is experienced by the patient and shaped by the social cultural influences. Sickness is perceived by society and may be expressed as social stigma (Stigter et al, 2000). Jopling (1991) stated it nicely: "The problem with leprosy is not what the disease is, but what the people believe it to be". The stigma against leprosy is partly due to traditional beliefs and misconceptions about the causes and transmissions of leprosy. A common belief is that leprosy is hereditary. Other beliefs and theories among various cultures are bad blood; bad spirits/curses, curse of God, supernatural causes; touch, sweat; water, air, defecation; food/breaking of food taboos; sex with prostitutes and therefore a punishment for moral lapse; sexual contact in the open air, sex with a woman during her monthly period; a spell/witchcraft/evil magic; disturbing the djinn (ghosts); direct punishment by God for one's sins or evil character; getting the disease as a consequence for one's own irresponsible actions. (Reddy et al, 1985; Jopling, 1991; Rao et al, 1996; Bekri et al, 1998; Scott, 2000; Stigter et al, 2000; Idawani, undated p.52; Kaur et al, 2002; Nicholls et al, 2003; Wong, 2004; Barkataki et al, 2006; Try, 2006) Other misconceptions and beliefs are that leprosy is highly contagious, incurable and disabling (Rao et al, 1996; Stigter et al, 2000; Kaur et al, 2002; Wong, 2004; White, 2007). Because of these beliefs, some members of the community feel justified discriminating people affected by leprosy and, as a result, the latter may delay Determinants, Consequences seeking help. Negative attitudes may also affect adherence to treatment. These attitudes have an effect on the psychological wellbeing of the leprosy-affected person. Sometimes the translation of the word leprosy in a local language can have a totally different meaning. The meaning of the word for leprosy in Amharic is 'to cut' or 'mutilate'. So the Amharic word has a negative connotation in relation to the early signs of leprosy. People think that deformities are the first signs for leprosy (Bekri et al, 1998). In Nepal, the word 'khori' is used for a leprosy-affected person, which means 'curse'. This implies that it is not only through a curse that the disease is brought on a person, but the person affected by leprosy him or herself is the curse. Due to the supernatural connotation of curses, people in the community try to avoid contact with people who are believed to be a curse. The community feels it is justified to exclude those affected by leprosy (Cross, 2006). The way people view their illness and healing process needs to be seen and understood in the context of that culture (Opala & Boillot, 1996).

In many cultures the people will go to the traditional healers before going to a medical doctor, often because they believe witchcraft or other supernatural causes are involved

(Opala & Boillot, 1996; Scott, 2000, Idawani et al, undated). Biblical references regarding leprosy are always taken from the Old Testament, which in some passages refers to leprosy as a punishment for sins (Jopling, 1991, Awofeso, 2005). In Brazil, some of the Catholic churches still preach that Hansen's disease (leprosy) is a shameful and spiritually polluted condition. Evangelicals in Brazil suggest that complicated diseases may be the result of demon possession and can only be cured through prayer. "These forms of societal stigma may affect treatment-seeking behaviour, adherence and overall patient experience" (White, 2007). Leprosy is not mentioned in the Qu'ran. To Muslims, all events including diseases are caused by the will of God. But diseases should not be seen as a punishment by God for sins. Most beliefs, practices and attitudes in Islamic countries originate from indigenous tradition (Haidar, 1984). Hindus often view deformity as divine punishment for sin in a previous life. Parents examine the families of a prospective bride or groom for their children for the presence of conditions like leprosy or mental illness, which makes it very difficult for a person affected by leprosy to get married.

ii. Socio-economic factors

Socio-economic status is recognized as a major determinant of exposure to disease risk (Le Grand, 1997). Some other conditions associated with that are poor housing, lack of clean water and lack of sanitation. Also associated is lack of nutrition, which undermines the immune system and cause people to be more vulnerable to get sick. Leprosy is seen as a disease of the poor. Many leprosy-affected people have no formal or limited education and that limits them in their choice of jobs (Withington et al, 2003). Kaur and van Brakel (2002) described the way leprosy-affected people ended up in beggary. Leprosy and the social stigma attached to the disease had changed their lives completely. They had a job before, lost it because they got leprosy and were discriminated by the community. Verbal abuse and being forbidden to use common places in the community made life unbearable, causing them to leave their villages. Sometimes a person left home by him/herself in order not to be in the way so his/her siblings had a chance to get married. This kind of situation gave a lot of emotional stress and anxiety. Others were rejected by their families. Their physical impairments had often worsened, which restricted them in earning a living. Some beggars live in slum areas. Many of their children do not go to school, but get involved in beggary (Barrett, 2005). The effects of poverty can be more severe on women. The stigma of leprosy is often compounded by gender inequalities and lack of protection. Women may experience physical and sexual abuse and at times they are forced into prostitution (Barrett, 2005). Employers may dismiss an employee affected by leprosy out of fear of getting the disease and of losing customers in their businesses. Another reason for dismissing is that people with impairments due to leprosy may not be able to perform well on the job (Calcraft, 2006, Scott, 2000). However, there have been occasions where the employers could be persuaded to let the leprosy-affected persons continue to work despite their impairments. However, their income was reduced (Reddy et al, 1985). For a leprosy-affected person not being able to work will mean to become more dependent on the family and if resources are scarce this will give a lot of tension. The feeling of uselessness because of not being able to contribute to the income of the family will lead to loss of identity and self-worth.

iii. Health Services

Under the health services we will have a look at the accessibility of services, delivery of services by health professionals and the attitude of health professionals towards people affected by leprosy. Reports reveal different situations in which the people affected by leprosy are stigmatised and discriminated by the health care system. In

Guyana, a study was conducted in two hospitals with the aim to assess attitude, knowledge and ideas of the disease amongst health care workers. A self-completing questionnaire was distributed and 185 questionnaires returned. It was found that half of the health care workers did not know leprosy is curable and many still thought it could be transmitted through touch (Briden and Maguire, 2003). A study amongst nursing students in Nigeria revealed that they thought leprosy is a highly contagious disease and that deformities are inevitable in leprosy (Awofeso, 1992). Scott (2000) documented that fear of leprosy still exists among many health workers in general hospitals in South Africa. These misconceptions often lead to negative attitudes towards people affected by leprosy. The organization of the health services will affect the accessibility and the utilisation of the services. In eastern Nepal a qualitative study was conducted to explore the quality of services. Heijnder (2004) argues that privacy during examination was a problem especially for the women. Distribution of medication could only happen on a certain day before a certain time. Sometimes people were blamed for not being motivated to take their treatment. If leprosy affected people would come late, the health worker would refuse to give the medication. The attitude of the health worker was very different to a rich leprosy-affected person than to a poor person. Some people continued their medication despite the negative treatment they received, while others defaulted (Heijnders, 2004).

iv. Gender

Gender inequalities in health have a significant impact on women’s health (le Grand, 1997; Shieh et al, 2006). Gender is not only related to sex but encompasses the social, cultural and economic aspects designated to men and women by social structures (le Grand, 1997). In many developing countries the women bear the responsibilities for the family. Women are often already disadvantaged because of illiteracy, less education and no power to make decisions. It is the husband or the mother in law (India), who make the decisions. Their actual situation is characterised by dependency and often discrimination. In India, in most situations both men and women are negatively affected by leprosy in the area of cooking, eating together, touching others, sleeping together in one room, using common articles, mixing with other members (Rao et al, 1996, Zodpey et al, 2000).

It is especially hard on the women not being allowed to touch their children or to be touched by them. They feel rejected. Another matter, which is strongly felt by women, is the fact that they are often not allowed to participate in domestic work. That makes them feel useless. The social impact on women is worse than for men. Women are more isolated (Rao et al, 1996; Zodpey et al, 2000). These restrictions result in greater morbidity, depression and anxiety and affect their treatment. Women may delay seeking treatment if they suspect they have leprosy out of fear of being abandoned, anticipating less chances of getting married or that it may affect their role in the household. Other factors like lack of money, time, mobility and traditional customs are contributing to the delay in health seeking and adherence to treatment. In many communities the women already have a low status and they will be treated differently by the members in the family and the wider society. Several investigators reported that women were insulted by family members. Men received more support of their spouses and family than women (Rao et al, 1996; Le Grand, 1997; Zodpey et al, 2000). In Eastern Nepal, a similar difference in social status was expected between men and women; however this was not the case. Attitudes and behaviour towards people affected by leprosy was associated with the visibility of the disease only and not with gender. The place women had in society was not affected (Stigter et al, 2000). In Aceh, Western Indonesia, men and women affected by leprosy are treated equally. Men have the same problems as women in getting married (Idawani et al, n.d.). In South East Nepal, men also have problems with getting married. A man was abandoned by his wife because she and even his family put so much pressure on her to divorce him. Some women experienced the same; the influence from others was so strong that their husbands left them because they were pressured to do so (Try, 2006).

v. Legislation and Human Rights

There are still laws in India that are stigmatising and discriminating to leprosy affected people. The Hindu Marriage Act of 1955 allows separation and divorce on grounds of a spouse suffering from leprosy. Similar provision can be found in the Muslim Marriage Act 1939, the Christian Marriage Act and the Special Marriage Act 1954 (Jopling, 1991; Kaur et al, 1994). In December 2005, people affected by leprosy presented the Delhi Declaration during the National Conference on "Integration & Empowerment of Persons Affected by Leprosy". As participants, they stated their dignity and their right to be involved in making decisions related to their daily lives and future. Through these recommendations they wanted to counter the effects of stigma and discrimination they and their families had experienced, in order to promote quality of life. One of the recommendations was that "all discriminatory laws, including the law that facilitates divorce due to leprosy should be repealed". This refers to the above mentioned laws (Leprosy-affected people, 2005). The conference was good for all the people affected by leprosy to realize they are not alone and that together they can demand respect and claim equal treatment which is a right for everyone.

In August 2005, the United Nations Sub-Commission on Promotion and Protection of Human Rights passed a resolution titled "Discrimination against leprosy victims and their families". Some of the aspects of the resolution are as follows: the request that the Governments forbid discrimination of any type against people affected by leprosy and their families and that the Governments provide appropriate remedies to people affected by leprosy who had been forced to live in colonies or leprosaria in the past. In the beginning of this year, the residents of Lo Sheng, a former leprosarium in Taiwan, were told by the government to move out by April as the land belonging to Lo Sheng was going to be used for a station. One of the residents spoke up about the unreasonableness of this decision. The people had been segregated for public health reasons and now again they had to move because of a public construction. Sympathisers in Taiwan were demonstrating against the government ruling, and in the USA, people affected by leprosy marched the streets of New York in support of the people affected by leprosy in Taiwan. Many leprosy-affected people have become members of IDEA. IDEA stands for 'International Association for Integration, Dignity and Economic Advancement' and represents the interests of persons affected by leprosy around the world (ILEP, 2007). The people of Lo Sheng made their voices heard with the support of the members of IDEA, as well as the members of society in Taiwan in presenting their case.

vi. Media

Over the past 30 years, it has been demonstrated through research that the mass media are of great influence on belief systems. People seem to form their attitudes on what they see through news reports, television programmes and films (WHO, 2004). Linguistic terms describe not only the disease but a deeper meaning attached by socio-cultural perceptions. For example, "Tai Ge", which is the Taiwanese term for leprosy, describes the open and ulcerative wounds as unclean, filthy, and foul. The person affected by the disease is stereotyped as lowly, untouchable, unwelcome, unclean and contagious (Shieh et al, 2006) In India derogatory words like leper, maharogi and kori are still used which is inappropriate and stigmatising (Nippon foundation, 2006). In Brazil, the use of “lepra” which means dog mange is discouraged by law (Wong, 2004). For decades the words leprosy, leper and leprous have been used by writers, journalists and even politicians to imply something evil, degrading or immoral (Jopling, 1991; Frist, 2000; Awofeso, 2005; Sasakawa, 2006). In the past leprosy was often depicted in a negative way through pictures of people with severe deformities. This is changing and different countries have been using mass media to change the image of leprosy by showing pictures of leprosy patients without visible impairments and by doing this stressing the result of early detection and treatment (Wong, 2004; van Brakel & Gopal, 1999).

2.10 Other Related Literature

i. Bipin Adhikari , Nils Kaehler, Robert, S. Chapman, Shristi Raut, Paul Roche, (June , 2014) studied the factors affecting perceived Stigma in Leprosy Affected Persons in Western Nepal . It came out that ,the factors associated with higher stigma were illiteracy, perceived economical inadequacy, change of occupation due to leprosy, lack of knowledge about leprosy, perception of leprosy as a severe disease and difficult to treat. Similarly, visible deformities and ulcers were associated with higher stigma. There is an urgent need of stigma reduction strategies focused on health education and health awareness programs in addition to the necessary rehabilitation support. The factors identified by the researchers in Western Nepal were true but they failed to realise that all those factors were human rights violations against persons affected with leprosy.

ii. Stigter, de Geus & Heynders (2000), did a study on how community behaves towards persons affected by leprosy in the eastern Terai districts of Nepal. The results show that 95% of the persons affected by leprosy recognised by the community have visible signs such as wounds, swellings and deformed feet or hands. Motives for negative community behaviour are mostly found in the fact that people fear infection by germs, but fear of a curse from God is also mentioned. Leprosy control programmes should focus on prevention of impairments and disabilities, because it seems that a visible sign is an important trigger for negative community behaviour. The recommendations of the researchers were good but human rights education on the rights of PALs should have been added so that the community could learn the rights of disadvantaged people like PALs so that their rights could be recognised and respected.

iii. Tsutsumi, Izutsu, Akul Islam Ahmed, Nakahara, Takagi and Wakai (2004) did a study on the quality of life (QOL) and general mental health of leprosy patients compared with the general population, and evaluates contributing factors such as socio-economic characteristics and perceived stigma. A total of 189 patients (160 outpatients, 29 inpatients) and 200 controls without leprosy or other chronic diseases were selected from Dhaka district, Bangladesh, using stratified random sampling. A Bangladeshi version of a structured questionnaire including socio-demographic characteristics-the Bangla version of the World Health Organization Quality of Life Assessment BREF (WHOQOL-BREF)-was used to assess QOL; a Self-Reporting Questionnaire

(SRQ) was used to evaluate general mental health; the Barthel Index to control activities of daily living (ADL); and the authors' Perceived Stigma Questionnaire was used to assess perceived stigma of patients with leprosy. Medical records were examined to evaluate disability grades and impairment. QOL and general mental health scores of leprosy patients were worse than those of the general population. Multiple regression analysis revealed that factors potentially contributing to the deteriorated QOL of leprosy patients were the presence of perceived stigma, fewer years of education, the presence of deformities, and a lower annual income. Perceived stigma showed the greatest association with adverse QOL. We conclude that there is an urgent need for interventions sensitive to the effects of perceived stigma, gender, and medical conditions to improve the QOL and mental health of Bangladeshi leprosy patients.

The researchers did not recognise the human rights of leprosy patients under any international, regional and national human rights conventions, treaties and laws. The conclusion made by the researcher indicated that the researchers evaluated the QOL of PALs on medical conditions and not on the fundamental rights everyone has to enjoy. They should have advocated for human rights laws to be enacted in the country to protect and promote the rights persons affected with leprosy.

iv. According to Hagens (2007), there are similar determinants of stigma and discrimination against persons affected with HIV/ AIDS and Leprosy in Ghana. Socio- cultural, economic, health, media and the laws of various countries discriminate against individuals affected by HIV/ AIDS and Leprosy. Recommendations made were on sensitizing the individuals, communities, workers and traditional leaders from their act of stigma and discriminating against such individuals. However, the researcher failed to identify the rights and violations of the rights of Persons affected with HIV/AIDS and Leprosy. She did not take into account that persons affected with HIV/ AIDS and Leprosy have been provided and protected by international, regional and national human rights laws and institutions. Educating the citizens on human rights of every individual irrespective of your status could have been another suggestion.

v. According to Ajedirani, Sylvester, Fidelis (2013), the Health Related Quality of Life (HRQOL) among leprosy-affected elderly people at three leprosoria located in South Ghana is low. Quality of Life among the sampled elderly people affected by leprosy at the selected leprosoria is poor. They recommended the need to put up measures that could improve their health and socio-economic status within the settlements. Despite their significant realization and recommendation about their study, the low quality of life among persons affected by leprosy was not related to any human rights instruments and laws. It is also a violation of the rights of PALs. This is because, persons affected by leprosy should enjoy equal rights as other people that are provided by all international human rights laws especially UDHR. Low quality of life among persons affected by leprosy indicates violations of their social, economic, cultural, civic and political rights.

IV. According to Bergman and Asabea (2014), Leprosy has long been associated with stigma and the disease causes a lot of suffering to those affected, not only physically but also emotionally and psychologically due to the effects of stigma. The study aimed to describe nurse’s experiences of

> leprosy related stigma in the Central Region of Ghana. A qualitative study with semi-structured interviews was used as an instrument to collect data. Seven individual interviews were conducted with four nurses working at a hospital, specializing in leprosy care, at in the Central Region of Ghana. The data was analyzed using a content analysis based on Graneheim and Lundmans concept. The nurses described an exclusion affecting leprosy patients because of their disease. Significant factors, such as lack of knowledge and social circumstances, could be linked to leprosy related stigma. The result was discussed using Watson's theory of human, referring to eight of her ten curative factors. Three main subjects were identified and discussed related to the result. These were educational factors, social factors and stigmatization.

The factors identified as leprosy related stigma were discussed as social and healthcare problems. However, exclusion and other human rights related issues were not considered. Human rights instruments that protect and promote the rights of persons affected with leprosy were not considered. For instance, one of the key principles of CRPD is promotion of inclusion among persons with disability. Exclusion was not identified as a violation of the rights of persons affected by leprosy; hence it would be difficult for the researcher to realize that neglect and rejection of PALs as leprosy related stigma. Again, the researcher did not consider human rights laws as a means of promoting and protected PALs.

Conclusion

This chapter has identified several international, regional and national human rights laws that seek to promote and protects the rights of persons affected by leprosy. The review points out that some studies have been conducted on stigmatisation and discrimination against persons affected by leprosy in Ghana but they are all related to health and compare it associated stigma with other diseases such as HIV/AIDS. Little is known about leprosy related stigma and discrimination as a human rights issue in Ghana.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

The focus of this work is to determine the extent of stigmatisation and discrimination against PALs and how this could be minimised in our society. This chapter therefore deals with the general methodology used for the research. The chapter discusses the research approach and design, the population and the sample size of the study. It would also discuss the sample and sampling procedure, selection of the interview methods and the interview schedule. Ethical issues were explained and how the challenges were surmounted. Finally, how the transcription was done and the data analysis will be discussed.

Research Design.

According to Durkheim (2000), research design is a strategic framework that serves as a bridge between questions, the execution and implementation of a research. It is also an arrangement of conditions for collecting and analysing data which will be relevant to the researcher in the most economical manner (Amoani, 2005). Qualitative approach and case study design were adopted by the researcher to reveal the extent of stigmatisation and discrimination against PALs. Qualitative research approach is a method of inquiry which involves an in-depth understanding of human behaviour, the reasons that govern such behaviour and also enables the participant to say what matters to them and why (Cresswell, 2008). Qualitative research is a naturalistic inquiry, the use of non-interfering data collection strategies to discover the natural flow of events and processes and how participants interpret them. Qualitative research is suitable for this study because it can be used to describe and analyse people, individuals and collective thoughts, beliefs, perceptions and actions. Persons Affected by Leprosy (PALs) are unique individuals and their thoughts, beliefs and challenges has to be identified through qualitative research approach. The approach enables the researcher to gather data by interacting with the selected persons in their settings to obtain relevant documents on topics under study (McMillan & Schumacher, 1997).

Qualitative research takes place in the socio-cultural context of participants of a study and it involves an interaction between the researcher and the researched. PAL live in isolated areas (Leprosarium) due to stigma and discrimination and the researcher has to build a friendly relationship with them in order to understand their social conditions. It is designed to enable researchers understand people and the socio-cultural context within which they live. In a qualitative study, data are collected in the form of 'words' rather than 'numbers' and reflect the experiences, feelings, or judgments of individuals taking part in an investigation of the problem (Verma & Mallick, 1999). In qualitative research, research questions are not framed by testing hypothesis but most often they come from real world observation and dilemmas. Depth and details are revealed through direct quotations and careful descriptions of behaviour. According to Holloway (1997), qualitative research are often more concerned about uncovering knowledge about the circumstances in which they find themselves than they are in making judgments about whether those thoughts and feelings are valid, it is exploratory in nature but cannot be represented in mathematical terms. Qualitative approach will help the researcher to unveil the stigma and discrimination associated with leprosy. Qualitative research mostly derives their data base from interview transcript from open- ended, focused but exploratory interviews. Other sources that constitute a qualitative data base are recorded observation (both video and participatory), focus groups, texts and documents, policy manuals, photographs, lay autobiographical accounts and others.

In qualitative research method, the data collection consists of using forms with general emerging questions to permit the participants to generate responses and to gather words or image data (Creswell 2005). It is a site of multiple methodologies and research practices which encompass enormous variety that result in understanding and clarity.

3.1.1 Case Study

The case study design was used for the study. The case study was used because it is an empirical enquiry design that allows the researcher to investigate and understand the dynamics of the phenomenon being studied. It also focuses on contemporary issues such as human rights violations which relate to stigmatisation and discrimination. It again probes deeply and therefore gives proper meaning to what is being investigated (Amedahe, 2002). The case study aims to understand the case in-depth, and in its natural setting, recognizing its complexity and context. Yin (1984, cited in Merriam, 1988) argues that case study is a design particularly suited to situations where it is impossible to separate the phenomenon's variables from their context. This is a clear situation where the state, communities and families are not recognizing the rights of persons affected with leprosy. A case study, according to Robson (2003), is a strategy for doing research which involves an empirical investigation of a particular compulsory phenomenon within its real life context using multiple source of evidence. Typically, case study researchers neither aim at discovering generalised truth, nor look for cause –effect relations quantitative researchers do (Cohen, Manion & Morrison, 2000). Instead they focus on describing, explaining and evaluating a phenomenon. To achieve these aims requires the researchers to spend adequate time in the context of the study to collect extensive data using multiple instruments to develop in-depth understanding of the phenomenon under study. Multi – dimensional focus of the study requires much time to understand the situation of the PAL. According to McMillan and Schumacher (1997), a case study helps the researcher to understand a phenomenon in-depth. Case study explores an instance or few instances of a phenomenon by interacting with the participants in their socio-cultural background. It gives the researcher a deeper understanding of what he or she is researching into. The researcher adopted case study for this study because of its flexibility and adoptability to processes, people and context. A case study will help the researcher to finding the extent of stigma and discrimination against persons affected with leprosy especially how their rights are been recognized, respected and promoted. Again, a case study design was adopted to carry out the research because the phenomenon under investigation is a real life contemporary developmental issue and needs a combination of methods to investigate. In addition, the case study brings the investigator to a direct contact with the problem in the field. This leads to a better conversance with the circumstances of a case and helps to assess the reactions of group to questions and issues raised in the cause of the investigation (Kumekpor, 2002).

3.2 The Population of the Study

Population is the number of people, objects or events having common observable characteristics in which the researcher is interested (Agyedu et al., 1999). The population for the study included the Administrator, Nurses, Family members of PAL and all the Persons Affected with Leprosy in Weija Leprosarium.

3.3 The Sample Size

Sixteen (16) respondents were chosen for the study; 10 PALs, 1 Administrator, 2 Nurses and 3 Family members.

3.4 The Sampling Technique

3.4.1 Purposive Sampling

Purposive sampling was used as a tool for selecting the population and area of study. Purposive sampling allows the researcher to select individuals and sites to learn or understand the central phenomenon (Creswell 2008). Weija Leprosarium is among the few camps for PAL's in the country which is the main focus of the study.

3.4.2 Homogeneous Sampling Strategy

Homogeneous sampling strategy was used as an instrument by the researcher to select the sample size of the PALs. According to Creswell (2008), homogeneous sampling strategy allows the researcher to select people of common characteristics or phenomenon in a study. The PALs in the Weija Leprosarium were selected because they have similar phenomenon and the focus of the study. The PALs have developed categories of deformity due to leprosy and they are the main population under this study because of their common feature.

3.4.3 Convenience Sampling

Convenience Sampling was used by the researcher to contact respondents who do not stay at the leprosarium. Family members of PALs really stay in the leprosarium and this sampling technique was used to select family members and arrange the time convenient for them to be interviewed. This technique merely sampled those who were readily accessible with a minimum effort (Peterson, 2000). Convenience sampling was used because people family members of PALs have no sampling frame and they were difficult to be located.

3.5 Instruments for Data Collection

3.5.1 Semi - Structured Interview

The researcher adopted semi – structured interview as a tool to seek information from the respondents. This is because it makes the interviews neither fully fixed nor fully free. Semi- structured interview generally starts with some defined questioning plan, but pursue a more conversational style of interview that may see questions answered in an order natural to the flow of the conversation. In other words, semi- structured interview may start with a few defined questions but be ready to pursue any interesting tangent that may develop (O' Leary 2005). The open-ended questions were used in order for the researcher to be able to probe further, based on the responses of the interviewees and the questions were confined to the issues relating to my research objectives. Probes are either pre- stated or posed in the course of the interview, making the interview process flexible (Wragg, 2002). The instrument permitted the researcher the opportunity to seek classification through probing and expansion of the responses of respondents to ascertain their feelings and experiences.

Semi- Structure interview is crucial to a study of this nature because it leads to in-depth discussions with participants and sought data from different point of views. It must be pointed out that the quality and usefulness of the information given by the respondent is dependent on the quality of the various questions asked by the interviewer. This style of interviewing was used in gathering information from the PALs, nurses, family members and administrator in Weija Leprosarium. All respondents accepted to be tape recorded during the interview. The interviewer ensured smooth conduct of interview without disruption. Again, it helped the researcher to acquire the needed information from the respondents without omission or losing their content. The questions which were originally in English had to be translated by me into our local dialect " Akan" for the PALs and their family members while nurses and the Administrator gave their responses in English. Translation of the questions gave better understanding to the respondents and allowed them to speak freely about stigmatisation and discrimination in their own words. This made it possible for the researcher to collect a detailed perspective on the issue from the respondents. All the cured Lepers were asked the same questions; similar questions were answered by the Administrator, Nurses and Family members respectively. This provided uniform information which helped the researcher to compare responses of each group of respondents at the end of the interview. Semi structured interview was chosen as an instrument for data collection of the study because of leprosy related deformity which has made some of the PAL's lost their fingers and it would be difficult for them to answer questionnaire by writing. Moreover, the level of education of most the PALs is low which would make reading, writing and understanding the questionnaire difficult.

3.6 The Sampling Procedure

The phenomenon of stigmatisation and discrimination against Persons affected by Leprosy is very significant in promoting and protecting the rights of PALs especially their dignity. It could have been better to consider all PALs in Ghana for the study but it was impossible to involve all PALs and their family members, nurses and administrators in this study because of time and financial constraints. Therefore it was considered suitable to conduct a 'bite- size' research covering PALs, nurses, family members of PALs and administrators in one particular location rather than an 'elephant-size' study covering the whole country. Weija Leprosarium was 'handpicked' (O'Leary, 2005) as the case of the study.

The sample population was 16 and it was drawn from four zones in the Weija Leprosarium, family members of the PALs, administrator and nurses in the leprosarium. The Leprosarium is divided into four zones; blocks A, B, C and D. Each of the blocks in the Leprosarium was considered as a zone for the study. Names of the housemates in each of the blocks were written on sheets of paper and folded into a container; shook and three of them were randomly picked. This strategy was adopted because all PALs have similar characteristics and each inmate was a potential respondent. However, there were only two household in the fourth block (BLOCK D) and one was not in good condition to be considered as a respondent, the other person in the block D was automatically selected.

The selection of the administrator and nurses were done purposively. According to Neuman (2000), purposive sampling is used when one selects respondents with a specific purpose in mind. This was found the most appropriate because they were the only people who could provide the information needed. This was done to enquire how PALs are stigmatised and discriminated.

Family members who were conveniently selected were potential respondents. The researcher wrote three (3) 'YES' and the rest were 'NO' on the pieces of paper and folded them. They were put in a container and shook; each family member was asked to pick randomly and those who picked 'YES' were selected as respondents for the study. This process was done to arrive at the (3) three respondents representing the family members of the PALs.

3.5.2 Interview Guide

Regarding the semi structured interview, interview guide was prepared to control the conduct of the interview. The interview guide was discussed with respondents for them to have fair idea and key items were explained. During the interview sessions, a tape recorder was used to record all the voices of the interviewees and interviewers for transcription. In order to ensure that the tape would be correctly recorded, reliability was ensured by pilot testing the interview schedule.

3.5.3 Observation

The researcher adopted the participant observation techniques. In order to have first-hand information about the lives of the respondents, they were also observed on some occasions. Observation can be done through directly participating (participant observation) or merely observing others (non – participant observation) their acts or their environment. For additional information, the researcher adopted the direct observation. In the process, the identity of the researcher and the purpose of the research were disclosed to the respondents. The interviewer observed facial expression, body language and demeanour, relationship between administrators and persons affected by leprosy, relationship between persons affected leprosy and nurses and their relationship with their families, physical appearance, environment and their residence of the respondents for additional data for the study.

3.6 Sources of Data collection

The main sources of data collection for the study were primary and secondary data. The primary data were taken from Persons Affected by Leprosy, Family members of the affected persons, nurses, administrator and documentary source. Secondary data made up of documents of various kinds such as International Human Rights Laws, Constitution of Ghana, newsletters, brochure, newspapers, journals and internet (search engines) on leprosy were all used to gather data for this project.

3.7 Validity

According to Creswell (2007), the goal of a good research is to have measures that are reliable and valid. Validity means the extent to which an instrument measures what it is claimed to measure. This means that the question of validity only applies to the conclusion or inference we make from what we observe. According to Anastasia (1988) as quoted in Onivehu and Amoah (2002) validity is the degree to which a test or an instrument measures what it purposes to measure. In other words validity is the extent to which an instrument measures what it is supposed to measure. It also means that the question of validity only applies to the conclusion or inference we make from what we observe. This is sometimes called face validity. The validity of the interview guide was ensured through analysis by an expert (supervisor) before being applied. This was done purposively to enable the researcher come out with necessary corrections before the final interview was conducted. The modified interview guides that were later conducted indicated similar results from the pilot-test. The instruments were then refined on the basis of issues raised and noted during the exercise.

3.8 Reliability

Reliability, according to Cohen and Morrison (2003), implies that scores from an instrument are stable and consistent, and that they nearly remain the same when researchers administer the instruments multiple times at different times. Punch (2005) defines reliability of a measure as how much error variance is in the scores. Even though all reliability of measure must produce exactly or almost the same measure of the same object at different times. Thus he explains further that reliability enables us to estimate error and since reliability and error are related reciprocally, the larger the reliability, the smaller the error and conversely the smaller the reliability the larger the error. The researcher measured the reliability of the interview guide by using the test-retest reliability. According to Krysik and Finn (2007), test-retest reliability provides information on how consistent a measure is when it is administered twice in a relatively short time frame. Reliability for the instruments was certain by pilot testing the interview guide. Regarding the semi- structured interview guide, permission was sought from the respondents concerning their willingness to participate in the interview. The nature of the interview guide was explained to them. During the interview session a tape recorder was used to record all that ensued in order to ensure that the tapes would be correctly transcribed. Reliability was ensured in this research by pilot testing the interview schedule.

3.9 Data Analysis

Thematic Data Analysis will be used to analyse the data. Thematic Data Analysis will enable the researcher to organize or prepare a data, transcribe the data and generate themes and codes for the data. Common themes and codes generated will be descriptively analysed. Researchers have adopted different methods of analysing qualitative data. Walliman (2005) argued that the analytical frame chosen for a study depends on the theoretical and philosophical perspectives which inform it, the goal of the study, the questions addressed and the methodology used. This study was informed by the ontological assumption that knowledge was acquired, subjective in nature and the results of human cognition (Cohen et al, 2000; Sikes, 2004). This was further informed by the interpretive paradigm which argued that knowledge is created through the interaction between the researcher and the researched. The instruments used in the data collection produced mainly qualitative data. This data was analysed thematically (Creswell, 2005; Grbich, 2007). The findings of the interview schedules and observations made were presented. The data presentation and analysis were done manually. This strategy was chosen because the volume of data collected was manageable, making it less difficult to identify relevant text passages and my desire was to interact and have a hands-on feel for the data (Creswell, 2005). The problem associated with analysing data manually is that it is laborious (Creswell, 2005; Marshall and Rossman, 2006). Since the instruments used generated mainly qualitative data, the presentation went through the same stages. The first stage was a preparatory where the interview data for presentation began with the organisation and transcription of the audio-tape recordings. The transcription involved listening to each tape repeatedly to familiarize myself with the conversations and carefully writing them down in the words of each interviewee. The interview data was then categorised into four types of respondents for effective management and comparisons. The next stage involved intensive and repeated reading of the data with the aim of submerging myself in it. The aim of this activity was to determine analytical categories or themes (Schmidt, 2004; Creswell, 2005) using my professional judgment (Denscombe, 2003). The development of the themes was guided by the research questions and the literature review. The coding process began after identifying the themes. Contributions, responses and comments made by PALs and family members were attached to names and years but they were pseudonyms. However, the capacities of the nurses and administrator were attached to their responses. Brief quotations from the data were used to add realism (Creswell, 2005) to the description. Since the data was collected from different categories of respondents, it was analysed from their perspectives in order to build some kind of complexity into the study (Creswell, 2005). In the data analysis and discussion stage, which was contained in a separate chapter, the findings of the interviews and the observations were put together and analysed. In the discussion, references were made to the interview and observation findings for detailed explanation and validation. Also, I compared and contrasted issues and ideas with the existing body of knowledge.

3.10 Ethical Considerations

An introductory letter from the Department of Social Studies (U.E.W) was sent to the Weija Leprosarium and Ga South Social Welfare to seek permission and collect information from the persons affected by leprosy in the camp. This was done in order to get respondents' consent for their maximum participation in the research. In addition, I discussed the benefits of the findings with the respondents. Before the interview, I assured them of the confidentiality of their identity. I collected names of inmates, nurses and administrators to be sampled. An arrangement was made with the respondents on convenient time and dates for the interview. I used both participatory, non –participation and observation to prevent the respondents from pretending. All the observations and interviews were done by the researcher.

3.11 Conclusion

In this chapter, I have explained the research process, choice of methods, instruments used for the collection of data and the direction. I have also discussed my approaches to data analysis. Educational research studies must be rigorous and present results that are acceptable to other educators and researchers and to accomplish this task, the concept of validity and reliability of the data collected in the research design were comprehensively discussed. The next chapter is presentation of the responses of the participants and the literature reviewed.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.0 Introduction

The study applied qualitative approach and a case study design to explore the research questions raised in chapter one. This Chapter presents the findings from the respondents of the study; Persons Affected by Leprosy, Nurses, Administrator of the leprosarium and family relations of Persons Affected by Leprosy. The interview guide used for the data collection was divided into four sections in respect to the categories of respondents for the study. The data collected through observation and documentary evidence were considered and linked to the research questions. The data collected from the respondents was used to ascertain stigmatisation and discrimination against PALs. The respondents for the study were sixteen (16); ten (10) PALs, three (3) family members, two (2) nurses and one (1) administrator. The interview data was organized into five sections. The first section reveals demographic characteristics of the respondents. The rest of the four sections cover the themes and findings on the research questions of the study. The research questions were;

a) What factors account for stigmatisation and discrimination of persons affected by leprosy?

b) What are the effects of stigmatisation and discrimination on persons affected by leprosy?

c) How has leprosy affected the relationship between family members, nurses, administrators and persons affected by leprosy?

d) To what extent are public institutions accessible to persons affected by leprosy?

The structure of the presentation of the findings under the various sections is to show clarity and easy reference.

4.1 Demographic Characteristics of the Respondents

Table 4.1 Persons Affected by Leprosy

Category	Frequency	Percentage (%)
Male	7	70
Female	3	30
Total	10	100

The total number of respondents selected from persons affected by leprosy was 10. The male formed the majority of the respondents, representing 70% of total respondents. The female on the other hand formed 30% of the total respondents of persons affected by leprosy. The table indicates that the male respondents were more than the female.

Table 4.2 Marital Status

Category	Frequency	Percentage (%)
Separated	1	10
Divorced	2	20
Married	2	20
Single	5	50
Total	10	100

From the table, it indicates that the majority of the respondents in the leprosarium are single (50%). They expressed their willingness to have a life partners (marriage) but most of the partners they meet, accepted their proposals on the grounds of material benefits and not for marriage. According to the men, they belief the women do not want to marry them because of the disease. Three men in this category have children with different women but none admitted for marriage after conceiving for them. One female is single because the husband has passed on. The other women are also not married because their husbands deserted them and the children upon realizing that they have been affected by leprosy. From the table above, 20% of the respondents are married. They are all male respondents. One of them was fortunate to find his wife in the leprosarium, who is also a PAL. The other man is still maintaining his wife after been affected by leprosy. The divorced population is 20% of the total respondents. They were all males. According to one of them, his wife divorced him because of the disease. The other man indicated that, his wife decided to go against the traditional practices by getting involved in adultery. According to him, adultery is a taboo in their custom and anyone testified by such an offence may cause for a divorce. He beliefs the ex-wife deliberately engaged the man so that she can run away because of the leprosy. One person among the respondents is separated which represent 10% of the sample size. According to her, the husband is married to three women and the man has not visited her since she came to the leprosarium.

Table 4.3 Occupational Status

Category	**Frequency**	**Percentage (%)**
Employed	1	10
Unemployed	9	90
Total	10	100

The table indicates that 10% of the Persons Affected by Leprosy is employed. He is self-employed as an artist. He is into picture and portrait making. He works in the leprosarium and occasionally organizes fairs to display his handy works. The majority of the respondents in this category are unemployed. The unemployment is due to disabilities and other related diseases such as diabetes associated with leprosy. However, some of the respondents wish to gain employment by applying for casual works but they are refused due their status as PALs. Their main source of their livelihood is based on philanthropic support from the general public.

Table 4.4 Educational Status

Category	**Frequency**	**Percentage(%)**
Literate	2	20
Illiterate	8	80
Total	**10**	**100**

The table above indicates that only 20% of the respondents in this category are literates. The literate respondents are all males with tertiary and middle school qualifications. This indicates that despite their disability, few of the respondents in this category have the academic qualification that can earn them job. However, they have not gained employment after they were affected by leprosy. Majority respondents are illiterates; representing 80%. They have never attended school in their live.

Table 4.5 Deformity (Body Part Affected)

Category	Frequency	Percentage (%)
Finger	6	35
Limb	7	41
Eye	3	18
Mouth/ Nose	0	O
None of the above	1	6
Total	**17**	**100**

The table indicates that leprosy deformity affects several parts of the body. Some respondents are having more than one deformity. Others are having one deformity. It was identified that, leprosy deformity affects the fingers, limbs, eyes and the skin of the idividual. From the Table, 6 persons have disability with their fingers (35%), 7 respondents are affected with their limbs (41%), the eyes of 3 respondents are affected (18%) and no deformity to the mouth and the nose. However, one (1) person does not have deformity with neither of the categories but he had severe skin burns (scalds) due to the disease.

Table 4.6 Other Respondents

Category	Frequency	Percentage (%)
Nurse	2	100
Administrator	1	100
Family Member	3	100

These categories of respondents have several responsibilities to perform in the Weija Leprosarium and have close relationship with the PALs. The Nurses have been working at the Leprosarium for thirteen (13) and four (4) years respectively. They are responsible to provide health care to the cured lepers and two nurses were selected for the study. The Administrator has been in office for seven (7) years. He is responsible to manage the Leprosarium and one administrator was selected for the study. Each of the inmates in the leprosarium has both nuclear and extended family members and three of them were selected for the study.

The total number of respondents for the study was sixteen (16); ten (10) were Persons Affected by Leprosy, two (2) Nurses, one (1) Administrator and three (3) Family Members. The names and ages used in the presentation and discussion of the findings are pseudonyms.

4.2 What factors account for Stigmatisation and Discrimination of Persons Affected by Leprosy

Six themes emerged out of the first research questions based on the data collected. These were cultural, perception, physical deformity, body odour, derogatory names and fear formed the themes of the first research question.

All the respondents revealed that culture is a contributory factor to stigma and discrimination against PALs. Responding family member emphasised that leprosy is a disease of curse from the gods. The PALs added that the people see them as unclean to perform any traditional activities in the communities. Again, the PALs believe leprosy is a spiritual disease which can be given to you by witches and wizards. All the PALs with the exception of one indicated that, their partners have left them due to the disease. All the responding family members indicated that people do not want to marry from our family because of our relations with PALs.

> Adam, a 40 year old man in the Leprosarium said he was not born with leprosy but he believes he did something against the gods of the land for his infection of the disease. He was an able bodied man and normally come to Ahafo- Kanyaase to work in a small scale mining (galamsey). He strongly believes that if not what he did against the gods, he would not have been affected by Leprosy.
>
> Adwoa, a 57yr old woman said, her rival in a marriage spiritually gave the disease to her. She said, we are three women married to a man and my husband was very closed to me than the others. Her rivals decided to separate them by spiritually given her leprosy. Truly, my husband has never visited me since she came to the leprosarium.
>
> (Fynn) An 87yr old man also said his Ante, who was a witch gave the disease to him to destroy his future fortune. I was staying with my ante at my tender age and to be honest, I was the best among the children in the house. I had a cut on my ankle and my Ante decided a special herb to heal the wound. The herb she used has nothing to deal with healing of wounds and carried for years and later diagnose with the disease. She bewitched me with this disease to spoil my future.

However, the Nurses and Administrator agreed to the view that cultural practices are source of stigma and discrimination but they did not accept that leprosy is a spiritual disease.

According to the administrator, one of the inmates was asked to live in a forest because he had contracted leprosy. This is because, the tradition in the town does not allow PALs to stay with the native. Even when she was brought here, she always gets nightmare about big snakes and wild animals in the forest.

The perception of the people in the society about leprosy is a contributing factor to stigma and discrimination against PALs. All the respondents gave a similar view that people in the society have some pre – conceived idea about leprosy. A responding family member and the PALs emphasised that, people do not want to come closer to them when they realise that they are affected by leprosy. The nurses especially emphasised that leprosy is not a communicable disease so people should change their thought about the PALs.

> Adwoa, 65year old cured leper said, people sometimes do not sit closer to me in a public transport due the deformity. People think they will contract the disease when they get contact with me. I sometimes feel bad and do not understand why people do that because whatever has happened to me we are all human beings.

Physical deformity is another cause of stigma and discrimination against Persons Affected by Leprosy. Responding PALs indicated that when people see the deformity on our bodies then their attitude toward us change drastically. A family member indicated that, someone failed to sell to my mother when she saw that she has no fingers.

> Ayitey, 53year old man narrated; I developed an unusual spots on my skin. I thought I was a normal rushes but it spreads over my body. The spots became bigger and more on my skin which made friends and customers stop coming to me and my shop to buy respectively. Sometimes, people see me and run from me because of the disease. He added, people distant themselves when I go to hospital. The administrator and nurses narrated that people do not get close to the PALs when we go to hospital especially those that the disease has affected their eyes and nose.

Responding Family Members, Nurses and Administrator gave a similar view that body odour is a source of stigma and discrimination against PALs. They emphasised that most PALs do not have fingers to hold sponge, soap and towel well when bathing. They normally wash down only with water. Again, PALs easily develop wounds because of the disease. Most of the PALs indicated that regular washing down can spoil the dressing of their wounds, so we take our bath intermittently. Improper taking of ones' bath can cause body odour.

> Ali, a 62year old cured leper narrated his ordeals when taking his bath. You can see I don't have fingers because of leprosy. I cannot take soap and sponge simultaneously to bath. I try my best to scratch the sponge with soap and rub the body as possible but I cannot do it proper as someone with proper fingers.
>
> Adwoa, a 70 year old cured leper narrated her view of not regularly taken her bath. A Nurse of my daughters' age got on my nerves because I have wet my bandage. In order to avoid such future embarrassment, I take my bath intermittently to avoid wetting the bandage.

On the use of derogatory names, the PALs and family members emphasised that the society use the name of the disease (leprosy) to call us and our entire family. Again, the disease is used for insulting others in the community.

> (Ama, 45 year old family member) I was directing someone to my house in my community and surprisingly the best way for him to locate the house was 'lepers house'. This is because my Anti is affected with leprosy. I remember I had a quarrel with a neighbour and all her insults raised on me were leprosy related insults.

Responding nurses and administrator on the other hand had never got such experience from the society as workers in the leprosarium.

All the respondents shared a common view of fear in the people about the disease as a contributing factor of stigma and discrimination. A responding PALs and family members emphasised that some people in the community are scared to get closer to the PALs. The nurses and administrator indicated that some people are afraid to get closer to the PALs especially when we take them to hospital.

> Aba (85 year old woman) of the leprosarium narrated their painful eviction from Jomo – La in 1950 to their present residence. We are staying here because of the effort of Dr. McCarthy who acquired this place for us. She said, the Chiefs and the people of La evicted us because they were afraid that they would be infected with leprosy.
>
> Adam, a 50 year old man said, i was left to sleep in an open place for a period of time before an NGO provided a shelter for me. Anytime i want to travel, I have to hire the car to and fro of my destination because passengers consistently refuse to sit in the same car with him. The fear in the people on the disease prevented other drivers and passengers from providing such service and sit in the same car with me.

4.3 What are the effects of Stigma and Discrimination on PALs

This part of the chapter presents the findings relating to the effectss of Stigma and discrimination against Person Affected by Leprosy. Stigmatisation and discrimination against PALs have several effects on the family members, society and healthcare providers. Five themes were generated for the effects of stigma and discrimination on PALs according to the data. These were effects on the rights to education, rights to health, economic rights, social life and psychological effects.

It came out from all the categories of respondents that the rights to education of the PALs are greatly affected due to stigmatisation and discrimination. They indicated that almost all the PALs are illiterate. Few literate among the PALs were able to attend school before they were affected by the disease.

> I was asked to stop schooling by my parents because they did not want anyone to realise that I have been affected with leprosy (Johnson, A 70 year old man).
>
> I am fortunate to be educated before getting this disease because I don’t think I could have gone to school with the disease. Education has helped me to express myself everywhere I go and mostly my colleagues envy me because I am the only person among them that can read and write well in English. If any philanthropist comes around especially the foreigners to donate, i normally speak on behave them. The problem here is that, they sometimes think I do tell donors only my problems and they may be send some support

> to me alone. However, there are procedures for sending and receiving donations in the Leprosarium (David, 57 year old man).

Stigmatisation and discrimination has effects on the rights to health of the PALs. Responding PALs and family members indicated that, it could have been better for medical officers to attend to us here when we are sick. The treatment given to us by some medical officers and attitude of patients towards us in public hospitals are not good.

Nurses and the administrator emphasised that the PALs do not want to attend public hospitals because some medical officers and patients look down on them and do not treat them as human beings.

> Ibrahim, 87year old cured leper narrated; a doctor refused to attend to me at the hospital because of the disease. The Doctor was new at Akawe Hospital, i was in a critical condition at the ward and the nurse called him to duty but when he came, he pretended something is missing and rushed back to his office and never returns to attend to me. I was fortunate to have another medical officer around to safe my situation.

The social life of the PALs is greatly affected by stigma and discrimination. Three (3) categories of the respondents (PALs, Nurses and Administrator) indicated that family members and the society have neglected PALs due to the disease. Most of the inmates are in the leprosarium because of neglect by the family and society. According to the administrator, the leprosarium was created to bring back life and happiness in the PALs. Responding family members emphasised that it is the wish of the family not to neglect PALs but the means to accommodate them has always been the problem.

> Isaac, a 62 year old man narrated his story on the treatment given him by family members when he was affected by leprosy. I was staying with my Ante when I diagnosed with the disease (leprosy). They took me to Ankaful for treatment and never came for me again. I came to Wieja leprosarium when I was cured. I heard the passing of my parents but I could attend because of my condition now

> David, a 55 year old man said, I was sleeping in an open place for several months without shelter after been diagnose with the disease. My family was afraid of getting the disease and the some members in the community run away when they see me. It was a terrible moment in my life.

Stigmatisation and discrimination has effect on the economic rights of the PALs. All the 4 categories of the respondents indicated that none of the PALs is employed. The livelihood of the PALs in the leprosarium mainly depends on donor support. The PALs indicated that they cannot buy what they want and own any property.

> (Abiba, 58 year old woman).You can see I have no fingers, if anybody is willing to employ me, how will I do the work? If I go out to search for job and the employers realise I do not have fingers, they will laugh at me. Through the help of Rev. Fr. Campbell, we will eat and sleep free. God bless him.

Stigmatisation and discrimination has psychological effect on the PALs. Responding PALs indicated that they sometimes feel that they are not human beings because of the way some people treat us. They also emphasised that there are several diseases that are more dangerous than leprosy but they are accepted as normal by the people in the society. Leprosy is also a disease so why are we treated as an outcast. I do not often go out because of odd attitude towards us. Again, the PALs revealed that they sometimes feel they do not exist because how they are treated by the society. The PALs were full of praises to Rev. Father Campbell for making life better for them. A responding family member indicated that, PALs are often quite and sometimes do not want others to see that s/he is affected by Leprosy.

4.4 How has leprosy affected the relationship between Nurses, Administrators, Family Members and Persons Affected by Leprosy

Three themes came out to answer the above research question. The themes were the knowledge about leprosy, why the PALs are living in the leprosarium and how the PALs are living in the leprosarium.

It came out from the three categories of the respondents that they did not know anything about leprosy. Family members do not have any idea about the causes of leprosy and it seems strange to them when their relatives were affected by disease. PALs have little knowledge about the disease. Most of them know that they have a medication for leprosy and it is free. The Administrator admitted that he had no knowledge about leprosy before taken his new job but he had learnt a lot about leprosy as an administrator of Weija Leprosarium. The Nurses on the other hand have studied about the disease in school but did not have practical experience with the affected persons. They emphasised that working at the leprosarium has made them better professionals as healthcare providers.

The question of why PALs are living in the leprosarium; all the respondents shared a common view that PALs are neglected and rejected by their families and the society. The Leprosarium is the new home and PALs have formed new family with themselves.

> Mensah, a 55year old man said, I was asked to sleep in an open place and had no option because of the disease. Instead of my family to look for money and take care of me, they were thinking of raising money to buy coffin for my burial. I had swollen body so they thought I will die. No family member has visited me since I came here. A family member told me to commit suicide because the disease is a disgrace to the family.

AS to how the PALs live in the Leprosarium; all the respondents indicated that their lives have been sustained by the philanthropic support from the civil society groups, NGOs and individuals. Lepers Aid Committee has been good to us by providing us with food, water and place to sleep without a charge. The Administrator indicated that he has to take records of the PALs, ensure that the facilities available are functioning, keep records of donations, prepare report of the leprosarium to Lepers Aid Committee and resolve differences among PALs in the leprosarium. Again, I collaborate with the nurses to ensure the welfare of the cured lepers. He pointed out that some PAL's defy the rules in the Leprosarium to beg on the street. The nurses emphasised that we consider the PALs as our own family members but we ensure that they take their medication and prepare them for medical review as scheduled. We organise programmes to educate them on how to protect and prevent themselves from getting other disease. We also encourage them to be happy in life because if their families do not care about them, we care. The Nurses were not happy about certain attitude of PALs. PALs do not inform us when they are sick unless we notice it during our daily routine check on them. Responses from the PAL's indicated that the condition in the Leprosarium is favourable for them. The Nurses have been there for us when we are sick. The Administrator is a father to all and we recommend him for having listening ears for our concern.

> Fusana, 58year old woman; life in the leprosarium is good (koraa) than life back in my hometown. Through the help of Fr. Campbell and Ghanaians, we have what to eat, sleep, wear, go to hospital free and take stipends from the State. I would have been dead by now if still lives in my hometown

4.5 To what extend are public institutions accessible by Persons affected by Leprosy

This part of the chapter presents interview findings relating how public institutions are accessible to persons affected by leprosy. Two themes emerged from the data to address the above research question. The themes were; availability of public institutions to PALs and acceptability of public institutions to PALs.

All the four categories of respondents came out that, public institutions are available to persons affected by leprosy. Public institutions such as hospitals, schools and banks are opened to everyone including individuals affected by leprosy. The responding nurses indicated that, we have a clinic here, we take care of minor cases such as malaria and fever. PALs are taken to public hospitals to access healthcare but the attitude of healthcare providers and patients towards PALs are not encouraging. The Administrator emphasised that schools in Ghana do have facilities to teach PALs even if they want to go to school. He said, am not surprise PALs are not educated.

Jeffery, 45 year old man narrated, I go to church and market every time to worship God and buy foodstuffs respectively.

> Afua, 42year old family member, my mother had the opportunity to live here through the help of our church. The Elders of our church realized the difficulty she was going through in the house and arranged for her stay here.

On the aspect of accessing public institutions, it emerged out of the data that public institutions are not acceptable to PALs. All the respondents considered the need to accept PALs in public institutions without difficulties. The Administrator and Nurses indicated that not all public institutions open their door for them in times of need. Some health care providers do not understand why PALs have to attend public hospitals rather they always direct them to Ankaful hospital despite their professional training. Sometimes it becomes very disturbing that they refuse to go to public hospital despite been sick. Again, when you take PALs to hospital, we will wait for a long time before they would be attended to. A responding PAL indicated that, I cannot write with my hand and school is not part of my life.

> Millicent, 60year of cured leper was of the view that, we should have special medical officer to attend to us when we go hospital. The attitude of some health care providers towards us is horrible in the hospital. I sometimes regret to be in the hospital when I meet such nurses and doctors.

Responses from the PALs indicated that school is a last option they wish to consider because of deformity to the body especially the fingers. This will not permit PALs without fingers to write. They belief that people will laugh at them when they realised we have leprosy. As PALs, we get wounds and takes time to heal. We will not be comfortable going to school every day in bandage. Even when we are admitted in schools, the teachers will not be comfortable with us in the class. Also, our family members will not allow us to go to school because students will use the name of the disease to insult me and my family.

> Odoom, 54year old cured leper narrated that, he will do everything possible to support my children to school no matter the situation because I did not have the opportunity to attend to school due to the disease.

Family Members indicated PALs must be allowed in all public institutions but not school. They emphasised that PALs have no business with education because of deformity. However, they recommended that given them training on trade and skills development will help to make the PALs economically prudent.

4.6 Conclusion

This chapter presented the findings of the respondents in the study. Their responses covered four main areas. The first area examined the factors that account for stigmatisation and discrimination against PALs. From the data, cultural practices, perception, physical deformity, body odour, the use of derogatory names and fears came out as the factors that account for stigma and discrimination. The second area considered the effects of stigma and discrimination on PALs. It was realised that stigmatisation and discrimination have impact on rights to education, rights to health, economic rights, social life and psychology of the PALs. The third area examined the relationship between family members, nurses, administrator and persons affected by leprosy. It came out that family members and PALs have little knowledge about the disease whereas nurses and administrator have adequate knowledge on leprosy. This has affected the relationship of PALs with others. Cordial relationship is established between nurses, administrator and PALs while poor relationship exists between PALs and family members. Finally, it was shown that public institutions are available but they are not acceptable to the PALs due to discrediting attitude towards PALs by medical officers (healthcare providers) and patients. The next chapter will focus on discussions of the data presented in this chapter.

CHAPTER FIVE

DATA ANALYSIS AND DISCUSSION

5.0 Introduction

This chapter focuses on the discussion of the data gathered with reference to relevant literature to explain the meanings of the responses and understand the phenomenon of stigmatisation and discrimination against persons affected by leprosy. This chapter is divided into four sections. The first part discusses the factors that account for stigmatisation and discrimination against PALs and the second part focuses on the effects of stigma and discrimination on PALs. The third and the final parts cover the relationship between Nurses, Administrators, Family Members and PALs and accessibility of public institutions by PALs respectively.

5.1 What factors account for Stigmatisation and Discrimination against PALs

The findings of the study indicated that there are several factors that contribute to stigmatisation and discrimination against PALs. In other to discuss the research question above, six themes emerged from the data and they are discussed below. They are cultural, perception, physical deformity, body odour, the use derogatory names and fear contribute to stigmatisation and discrimination against PALs. The research findings revealed that, culturally the norms, customs, beliefs and practices of the people contribute to the stigma and discrimination against PALs. Traditionally, people believe leprosy is a disease of curse from the gods. They are of the belief that, if you do anything bad against the gods of your land, you will be affected by the disease as a form of punishment from them. This means, anytime an individual is affected with leprosy in the community, the person is considered to being punished by the gods for his or her bad deeds. The family of the affected person has to perform certain rituals to pacify the gods of the land. If such ritual is not performed then there is the possibility of the spread of the disease in the family. Again, people believe that leprosy is a spiritual disease. If someone does not want you to progress in life, s/he can bewitch you with the disease so that it will bring disgrace to you and the family. Persons affected with leprosy are not allowed to take traditional leadership in the society. This is because; the affected persons are unclean to perform rituals to please the gods. Even if a traditional leader is affected by leprosy, s/he will be asked to step down. These cultural believe and practices should be abolished to ensure respect and recognition of the cultural rights of persons affected with leprosy. Article 26 (1 &2) of the 1992 Constitution of the Republic of Ghana, recognises cultural rights and frown on cultural practices that dehumanise citizens of Ghana. Also, international human rights laws such as UDHR (Article 27) and ICESCR (Article 15) have made provisions for all persons to enjoy cultural rights without discrimination. The data also revealed that most PALs and family members do not know that leprosy is caused by bacteria called mycobacterium leprae.

Perception of people about the disease is another contributing factor of stigma and discrimination against Person Affected by Leprosy. There is a perception that when you get closer to a person affected by leprosy, you will also be infected. This perception is in the minds of healthcare providers, people in the society and family members of the affected persons.

The data revealed that, some of the people that donate items to the PALs wear gloves during presentation and remove them when leaving the leprosarium. These people have the intention to show love and care to the PALs but some of their actions contribute to discrediting attitudes towards persons affected by leprosy. At times, donors do not want to get closer to the PALs and not even thinking of taking pictures with them. The perception sometimes extends to the nurses and administrator at the leprosarium. Some donors do not want to shake hands with them and others immediately apply sanitizers after hands shaking. Perception creates Stereotype on PALs and leads to discrimination. Stereotype creates quick impressions and expectations of individuals belonging to the stereotyped group. People become prejudiced if they endorse a negative stereotype and it may lead to negative emotional reaction. Perception is cognitive and gives effective response, whereas discrimination is the behavioural response. This indicates that perception on PALs leads to discrimination against them. Human rights instruments such as UDHR (Article 2), CRC (Article 2), ICCPR (Article 26), CEDAW (Part V) and ACHPR (Article 2) have made provisions for all persons to enjoy rights equally without discrimination.

The aftermath of the disease causes physical deformity to the body. The data revealed that the disease normally darkens the skin, deforms the fingers and limbs; deforms the eye, mouth and the nose. The physical deformity to the body changes the entire physical structure of the PALs. The new body conditions of the PALs do not allow them to associate well with others. The people in the society see them as different group of people. Family members and the society disassociate and neglect them due to the deformity. The general public discredit against the PALs and it has affected their active participation in our communities. The dignity of PALs is not respected due to physical deformity. The deformity does not allow the PALs to participate and associate well in the society. Participation, association, assembly, respect for dignity and integrity are human rights provisions that every individual has to enjoy. UDHR (Articles 20&21), ACHPR (Articles 10, 11&13) and the 1992 Constitution of the Republic of Ghana (Article 21/3) have made provisions for the rights to participation, association and assembly. Rights to dignity have been provided in the UDHR (1), ACHPR (4) and the 1992 Constitution of the Republic of Ghana (Article 15/3).

The data of the study indicated that body odour is another cause of stigma and discrimination. Leprosy causes deformity to the body especially the fingers. Deformity to the fingers does not enable affected persons to take their bath regularly and properly. It is not their will not to take bath regularly and properly but they find it difficult to handle the sponge, soap and towel. When the body is not properly washed continuously, it will cause body odour. Also, the disease comes with wounds to the body and such wounds take some time before they are healed. Sometimes, they avoid bathing to prevent the wounds and the dressing of the wounds from getting wet. The body will smell when proper and regular bathing is not taken. The data revealed that the PALs sometimes smell bad and do not want to go public to prevent shun. The PALs have identified this and they do not feel comfortable to be in the public and socialise. The people in the society do not want to get closer to them because of the unusual smell of the PALs. This attitude to the PALs does not respect their dignity and integrity. The following human rights laws have granted respect for dignity and integrity of all individuals: UDHR (1), ACHPR (4) and the 1992 Constitution of Ghana (Article 15/3).

The findings of the study suggested the use of derogatory names for PALs contributes to stigma and discrimination against persons affected by leprosy. Traditional names given to the disease are used to ridicule people in the community. " Kwata", is the name given by the Akans for leprosy. " Kwata" is used by the Akan's to insult lazy people in the society; 'kwadwofo) ad3n wonsa atwitwa anaa woye kwata'. Kpiti is a local name for persons affected by leprosy in Ga. Ga's also use kpiti to insult. "Kw3 ewoabii kpitibii ooole33 kpitiyel)". The name of the affected persons is changed to the name of the disease. For instance, in Akan and Ewe the affected persons are referred to as ' kwatani' and 'kpotor' instead of the person's real name. The use of derogatory names disregards the dignity and integrity of the PALs. The rights to participation, association and assembly are denied because of public stigma. The respect for dignity of man is enshrined in the UDHR (1), ACHPR (4) and the 1992 Constitution of Ghana (Article 15/3). UDHR (Articles 20&21), ACHPR (Articles 10, 11&13) and the 1992 Constitution of the Republic of Ghana (Article 21/3) are human rights laws that ensure fundamental freedoms of participation, association and assembly to everyone.

It emerged from the data that the fear of leprosy in the people contribute to stigma and discrimination against PALs. There are some of the people in the society which do not have pre- conceived idea about leprosy but when they come in contact with affected person with deformity, they become afraid to get closer to them. It also came out that the mere mentioning and hearing of leprosy scare some people. The fear society has developed about the disease has made it possible for the lepers to be treated as an outcast. Prejudice may lead to withholding help, whereas fear may lead to avoidance (Corrigan & Kleinlein, 2002). The fear about the disease causes public, self and enacted stigma which may lead to discrimination. Human rights instruments such as UDHR (Article 2), CRC (Article 2), ICCPR (Article 26), CEDAW (Part V) and ACHPR (Article 2) have made provisions for all persons to enjoy their rights without discrimination. However, the disease does not spread through normal contact. Therefore people do not have to be afraid of getting contact with PALs.

5.2 What are the effects of Stigmatisation and Discrimination on PALs

In answering the research above, five themes emerged; these are effects on rights to education, rights to health, social life, economic rights and psychology of the PALs. The data is discouraging in terms of enjoying human rights especially rights to education. The rights to education have an influence on other rights such as economic and health. Stigmatisation and discrimination prevent PALs from enjoying their educational rights. Most of the PALs are illiterates (Table 4.4).

They do not enjoy educational rights because the educational system in Ghana does not have facilities that will make access to education adaptable and acceptable to PALs especially those without fingers. There are special schools for other persons with disability in Ghana such as school for the blind and deaf. However, none of such schools have been established for persons affected by leprosy. When the right to education is denied, other rights such as rights to health, political, economic and environment would be violated. This is because human rights are interrelated, interlinked and interdependent. Therefore, violation of one right leads to the violations of other rights. The label attached to leprosy is crucial and influences the way we think about them and how PALs respond to social environment. The special tag on leprosy makes it difficult for the affected persons to access education. Right to education has been universally provided in the following human rights instruments; the 1992 Constitution of the Republic of Ghana (Article 25), Article 26 (UDHR, 1948), Article 13 (ICESCR, 1966), Article 28 (CRC, 1989), Article 17 (ACHPR, 1989), Article 10 (CEDAW, 1979) and Article 24 (CRPD, 2007). The above human rights laws have made provisions for persons with disability to enjoy educational rights without limitations. Despite these human rights laws, PALs rights to education are violated because countries such as Ghana have failed to enforce and implement the provisions in the laws.

From the data of the study, it became obvious that stigmatisation and discrimination has compromised the health rights of the PALs. Persons Affected by Leprosy are marginalized in accessing healthcare in Ghana. Some healthcare providers assume that PALs should attend special hospitals for leprosy patients especially Ankaful. It must be noted that persons affected by leprosy can also be attacked by other diseases such as malaria and deserve prompt attention before it gets out of hand. Mycobacterium leprae that causes leprosy can destroy the immune system of the affected person and if any sicknesses are not attended to quickly, it can cause the life of the PALs.

Moreover, leprosy infection comes with other diseases such as diabetes and ulcer and if regular medical care is not provided, their conditions will get out of control. PALs have the right to access healthcare at any point in time without discrimination and limitation in the following human rights laws; CRPD (Article 25), UDHR (Article 25), CEDAW (12), CRC (24), ICESCR (Article 12), ACHPR (Article 16) and the 1992 Constitution of the Republic of Ghana (Article 30). Some patients do not want to share seat with PALs at the hospital. Some prefer standing or distinct themselves from them on the seat whiles waiting to see a medical officer. Responding Administrator and nurse indicated that, PALs prefer to get instant medical attention immediately they get to public hospital for treatment. PALs were not disclosing their sickness to us due long to queues and discrediting treatment from patients at the hospital. They sometimes decline to go to the public hospitals for medical attention. This attitude from PALs became a difficult task to handle. We made this known to the general public through Nana Aba Anamoa (Journalist), Barclays Bank came to our aid and built Stanley Owusu's Clinic for us. The attitude of PALs has changed entirely since the construction of the clinic. Medical Officers from the District Hospital come to the clinic to provide healthcare to the PALs. Anytime there is emergency case, we call on a specific Doctor (Dr. Omari, Ga South Municipal Hospital) to assist us. PALs should not suffer in any form in accessing health care because rights to health have been provided in the international, regional and national laws. . PALs have the right to access healthcare at any point in time without discrimination in the following human rights laws; CRPD (Article 25), UDHR (Article 25), CEDAW (12), CRC (24), ICESCR (Article 12), ACHPR (Article 16) and the 1992 Constitution of Ghana (Article 30).

According to the findings, stigmatisation and discrimination has affected the economic rights of PALs. Persons Affected by Leprosy are mostly unemployed (Table 4.3). From the table, the affected person with job (self- employed), acquired the skill of art work (painting) before he was affected with the disease. This indicates that majority of the PALs do not learn any trade or craftsmanship to be employed in either formal or informal sector. Also, without educational qualification, it would be difficult for persons affected by leprosy to be gainfully employed. Even when they apply for manual jobs such as security, they are refused based on leprosy. When economic rights of an individual are denied, it will affect political, health and educational rights since human rights are interdependent. It will be difficult for PALs to own property because they are unemployed. Ghanaians have granted economic rights in Article 24 of the 1992 Constitution of the Republic of Ghana. Economic rights is provided to all persons including PALs in the following human rights instruments; UDHR (26), ICESCR (Article 6), CEDAW (Article 11) and ACHPR (Articles 14 &15).

The findings of the study revealed that social life of PALs is affected due to stigmatisation and discrimination. PALs do not enjoy the union of fundamental unit of family as they have adopted the leprosarium as their home. Some of the PALs have lost touch entirely with their families while others have intermittent visit from family members. PALs have lost their marriages due to leprosy. Partners of PALs have left them due the fear and perception that they might get infected. The standard of living of PALs is low because they are unemployed. The PALs cannot buy what they want and eat their preference because their choices are determined by donors. Social security of PALs is not adequately provided for by the state. The accommodation, water, food and some medical bills are provided by Lepers Aid Committee. Family neglect, breaking homes, poor standard of living due to leprosy and inadequate social security to PALs by the state violates their rights. Rights to family and marriage are provided in the following human rights laws; UDHR (Article 16), ICCPR (23), ICESCR (10), CEDAW (16), ACHPR (18) and CRPD (23). Adequate standard of living is a universal rights for everyone and it has been granted in CRPD (Article 28) and ICESCR (Article 11). The state (Ghana) has been mandated to provide social security to all citizens especially persons affected with leprosy. UDHR (22), ICESCR (9), CRC (26) and CRPD (14) are human rights instruments that have granted social security to all persons including PALs.

The findings of the study indicated that stigmatisation and discrimination have psychological effect on PALs. Stigmatised and discriminated persons respond to reactions of others in a variety of ways. They are often not sure about the attitudes of others towards them and therefore may feel to make a good impression. The PALs have recognised societal attitude and views about them and have accepted and rejected some discrediting viewpoints. Psychologically, the PALs have adopted several ways to overcome societal discrediting views about them and pretending as if all is well. The following strategies have been adopted by PALs towards societal attitude.

i. Coping

Culture may limit the coping choices that are available, particularly disclosing your health problems to others. In a study of West Indian women coping with depression, Schreiber, Stern and Wilson (2000) found that "being strong" was the culturally sanctioned behaviour for depression rather than disclosure. The PALs have decided to be strong by accepting their current state of life.

ii. Passing

Passing is pretending to be normal. It is one of the strategies used by individuals living with stigmatising condition. Pretending to have no disability or a less stigmatic identity (Dudley, 1983; Goffman, 1963; Joachim & Acorn, 2000) may be an option if the stigmatising attribute is not readily visible. Passing is a viable option for those with felt stigma associated with conditions such as PALs without visible deformity. The process of passing may include the concealment of any signs of the stigma. Some individuals refuse to use adaptive devices such as hearing aids because others may identify their disability. Another example is an abused client who provides reasonable explanations for bruises, swelling and injuries. The practice of passing may significantly impair the health – seeking behaviour of the abused individual, particularly where socio- cultural barriers to disclosure exist (Bauer, Rodriguez, Quiroga & Flores- Ortiz, 2000). Some of the PALs with deformity to the hands, always put their hands in the pocket because they do not want other people to see that my fingers are deformed.

iii. Covering

The potential threat and anxiety of deformity provoke natural disclosure of stigmatisation. This responses called covering is an attempt to make the difference seem smaller or less significant than it really is (Goffman, 1963). Covering involves understanding the difference between visibility and obtrusiveness. This means a condition is openly acknowledged but its consequences are minimized. The goal is to divert the attention from the defect, create a more comfortable situation for all and minimize the risk of experiencing enacted stigma. It is a humour used in a skilful manner by the stigmatised individual to decrease the anxiety and avoid an awkward encounter.

iv. Disregard

A person's first response to enacted stigma may be disregard. In other words, they may choose not to reflect on or discuss the painful incidents. Well-adjusted individual who are not comfortable with their identity, have dealt with stigma for a long time and choose not to respond to the reaction of others, may disregard it (Dudley, 1983). Going public with a serious medical diagnosis is another example of disregarding by acting in the face of negative consequences. One positive aspect of going public is the potential assertive political action and social change. Celebrities such as the late Mohammed Ali and Earving (Magic) Johnson have captured public attention and acted positively struggles with a variety of conditions. The PALs respond quite well to donors and outsiders but in the reality, they may wish otherwise.

v. Isolation

Human beings have a proclivity for separating themselves into small sub-groups because staying with one's own group makes it easier, requires less effort and for some individuals, it is congenial. However, this separation into groups tends to emphasis differences rather than similarities (Link et al., 1989). Closed interaction from within may enhance one's feeling of normality because the individual is surrounded by other who are similar (Camp et al., 2002). The process of isolation can occur any time outsiders are seen threatening or are reminders that the world is different from the in-group. Living in an identified group may be a source of support. The PALs admitted that living in the leprosarium is better than living in the house.

vi. Devaluing

People may believe that the person with the stigma is less valuable, less human or less desired. PALs are considered as less human or less privilege because of the deformity. Unfortunately, many of us practice more than one kind of discrimination and by so doing, effectively reduces the life chances of stigmatized individual (Goffman, 1963). Devaluing results in enacted stigmas demonstrated by those who categorize individuals as inferior or even dangerous. The use of derogatory names such as 'kwata' to PALs devalues their dignity as human beings.

5.3 How has Leprosy affected the relationship between Nurses, Administrators, Family Members and PALs

Under this research question, three themes emerged. They are knowledge about leprosy, why the PALs are living in the leprosarium and how the PALs are living in the leprosarium. The findings of the study indicated that the relationship between PALs and the Administrator is cordial. The PALs recommended the administrator for his dynamic ways of solving problems in the camp. The Administrator admitted that, he is confronted with difficulties that could destroy their relationship but he has adopted an open discussion on issues with them normally after morning devotion. His social life has not been affected by working in the leprosarium. However, some of his family members protected against accepting the job in the leprosarium because of the fear of getting the disease.

The relationship between nurses and the cured lepers is also cordial. Nurses in the leprosarium do understand the emotional and psychological features of affected persons and manage them well for peaceful co- existence. Socially, it was difficult at the initial stages to co-exist with persons affected by leprosy but the relation with them has improved. A nurse said, the PALs sometimes fail to report sickness to them at the clinic rather they expect them to recognize and attend to them in their rooms during routine check-up. Also, a person affected by leprosy request for drugs without knowing what actually is causing the sickness. Self-medication can also cause another sickness. Sometimes they feel reluctant to go public hospitals when we have cases beyond our control. The findings revealed that, the relationship between PALs and their family members is not good. Some PALs have been in the leprosarium for years without a visit from any family member. Others could not recount the last time they visited their families and home towns. Mostly, children and grandchildren of the affected persons do visit them. They have accepted and are content with their nuclear families and disregarded the extended families because they have rejected them because of their new condition. The leprosarium has become their home town and the inmates have formed a new family.

It emerged from the data that, PALs are living in the leprosarium because of rejection and neglect by the society. If they have been treated well in their various homes, the leprosarium would be a temporal place for those who have been diagnosed with leprosy seeking to be cured and return to their families when they are cured. The PAL's in the Leprosarium are now residence in the leprosarium.

5.4 To what extent Public Institutions are accessible by PALs

Two themes emerged out of the above research question. They are availability and acceptability of public institutions. According to the findings, public institutions are available to be accessed by PALs. However, PALs do not adequately access healthcare from public hospitals because they are not acceptable to the PALs due to unfair treatment given to them by healthcare providers. Some healthcare providers avoid attending to persons with affected with leprosy. Others turn them away from the hospital and few that will attend to them do that out of fear and on critical conditions. These treatment meted to persons affected by leprosy by some healthcare providers has created enacted stigma for cured lepers. Enacted stigma is the real experience of discrimination that means unjust and unfair actions in a society towards people affected by a certain condition or associated with a particular group (Jacoby, 1994). According to the data of the study, 80% of the PALs are illiterate. This indicates that educational institutions in Ghana do not have facilities to train PALs in schools. PALs have accepted their new conditions and in other to avoid public ridicule, they have decided not to seek for the opportunities to be trained in schools. However, they visit places such as markets, church, mosque and bank without difficulties.

Conclusion

In this chapter, the findings obtained in chapter four have been discussed in relation to the literature, especially those reviewed in chapter two. Firstly, the chapter discussed the research findings on the factors that account for stigmatisation and discrimination against PALs. Cultural practices and norms, perception, physical deformity, body odour, derogatory names and fear came out as the main factors. On the effects of stigmatisation and discrimination on PALs, it was realised that educational, health and economic rights of PALs were negatively affected. Also, stigma and discrimination affected the psychological and social life of PALs. On the relationship between family members, nurses, administrator and PALs, good and cordial relationship was established for PALs, nurses and administrator. However, the relationship between PALs and family members is not good. On the accessibility of public institution, it was realised that public institutions are available but they are not acceptable for PALs. The next and last chapter will present the summary of findings of the study. The summary of the findings will indicate how the key research questions set out in chapter one have been addressed. Conclusion and recommendation will be followed by suggestion for further studies.

CHAPTER SIX

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATION

6.0 Introduction

The UDHR is universally accepted for the promotion and protection of human rights. This document has motivated many countries such as Ghana to enshrine human rights provisions in their Constitutions. Ghana in addition has shown its commitment to international conventions and treaties by ratifying the Convention on the rights of Persons with Disability (CRPD, 2007). In this work, I have examined the extent of stigmatisation and discrimination against Persons affected by Leprosy in the Weija Leprosarium. This chapter gives an overview of the findings of the research questions, draw conclusions, makes recommendations and suggestions for further research. The study considered semi- structured interview and other data collection methods such as observation for obtaining the requisite primary data. Library and internet research were also done to obtain secondary information. In all ten (10) PALs, two (2) nurses, two (2) family members of PALs and one (1) administrator were involved in the study.

6.1 Summary of Main Findings

The main finding drawn from the study is that Persons affected by Leprosy in the Weija Leprosarium are stigmatised and discriminated against. The specific findings are summarised below in respect to the research questions.

6.1.1 What factors account for stigmatisation and discrimination against persons affected by leprosy?

The research findings indicated the following:

i. Cultural practices and beliefs indicated that leprosy is curse from the gods. Lepers are considered as offenders of the gods and they have to perform certain rituals to pacify them. Lepers are ungodly, recalcitrant and a disgrace to the society. PALs are not expected to hold any leadership role in the society. Also, leprosy is seen as spiritual and hereditary disease which cannot be treated medically. These cultural beliefs violate cultural rights and rights to dignity and integrity of PALs.

ii. People perceive leprosy as a contagious disease and they turn to shun the affected persons. The negative attitude towards PALs by the people creates rejection and exclusion in the society. Perception on PALs violates their rights of non – discrimination.

iii. The aftermath of leprosy is deformity. The Mycobacterium Leprae may cause deformity to the nose, eyes, fingers and limbs. Physical deformities make the affected persons look odd hence stigma and discrimination. However, not all the affected persons have obvious physical deformity rather the skin of others is scarily of burns.

iv. Physical deformity to the body especially fingers does not permit cured lepers to take their bath regularly and properly. This normally brings body odour and this does not make the PALs comfortable in public.

v. The PALs are mostly referred to by the name of the disease; ‘ Kwatani’ or ‘ kpiti yelo’ or ‘kpotor‘ are names given to PALs in Akan, Ga and Ewe respectively, instead of calling them by their real names.

vi. Physical deformity also creates fear and panic in people. The public avoid PALs because the scare of deformities by the Mycobacterium Leprae.

6.1.2 What are the effects of Stigmatisation and Discrimination on Persons Affected by Leprosy

The second research question was to find out the impact of stigmatisation and discrimination on persons affected by leprosy. The findings are as follows:

i. Educational rights of the PALs are denied because Ghana does not have schools that can educate them especially those without fingers. The PALs do not want to go to school because of the stigma with leprosy hence they are discriminated against on their rights to education. This has made the PALs uneducated (illiterates).

ii. PALs do not have full access to hospitals in Ghana despite their availability. The attitude of healthcare providers and patients towards PALs in the hospitals are discriminatory and stigmatising. This violates their rights to health.

iii. The PALs are economically challenged because they are unemployed. They do not have academic certificate or skills to guarantee them job. Even when they apply for manual jobs, PALs are denied because of their predicament. The PALs need financial support to cater for their nuclear families and personal needs but they depend on stipends and donors before such demands are satisfied. This has pushed some of the PALs on the streets to begging for arms, which is a violation of the rules in the leprosarium. They do not own properties because they are unemployed.

iv. Social life of PALs has been greatly affected because families, friends and the society have neglected them. They do not normally visit home, friends and social gatherings but sometimes go to church and mosque. The life of the PALs has been narrowed only to the people and activities in the leprosarium.

v. Stigmatisation and discrimination have severe psychological impact on the PALs. The neglect, rejection and differential treatment towards PALs have made them develop self, enact and public stigma. Psychologically, PALs have developed attitudes such as coping, covering and isolation to pretend that they are comfortable with their conditions.

6.1.3 How has leprosy affected the relationship between family members, nurses, administrators and persons affected by leprosy

The third research question was to examine the relationship between family members, nurses and persons affected by leprosy. The following findings were revealed:

i. The family members have little knowledge about leprosy and it has affected their relationship with the PALs. They did not know anything about the disease when their family member became affected. PALs were not treated well by family members because they thought, the PALs or the family has been cursed by somebody. However, the relationship between PALs, nurses and administrator is cordial because their level of knowledge on leprosy is high.

ii. PALs are living in the leprosarium because of rejection and neglect by family members and the society. The respect for their dignity as human beings is highly respected in the leprosarium than living in the community. The Weija Leprosarium has brought back life into the PALs because they access to social amenities without difficulties. The PALs have accepted the Leprosarium as their homes, build a new life and considered themselves as one family.

iii. The livelihood of the PALs is mainly sustained by donor support from NGOs, Civil Society Groups and Philanthropists. Stipends are given to PALs from livelihood empowerment against poverty (LEAP) every fourth night to cater for their personal needs. There are rules and regulations in the leprosarium to ensure discipline among the PALs. They have their leaders (prefects) who are regularly consulted by the Administrator in decisions taken at the Leprosarium.

6.1.4 To what extent are public Institutions Accessible by Persons Affected by Leprosy

The final research question was to find out how public institutions are accessible to Persons affected by leprosy. The findings are as follows:

i. Public institutions are available to be accessed by all people without limitation. Some of these institutions are not acceptable to PALs due to infrastructure and attitude of personnel. Schools in Ghana do not have educational facilities that will be used to train persons affected by leprosy.

ii. On the other hand, hospitals in Ghana have facilities that can provide health care to PALs but some health care providers deny them access to the facilities because of their conditions. Patients who are going to access healthcare do not want to share hospital facilities with the PALs. Educational facilities in Ghana are not acceptable to PALs especially those without fingers. However, PALs do not have any difficulty in accessing other public institutions such as electoral commission and banks.

6.2 Conclusion

Ghana has shown her commitment to promote and protect the rights of persons with disability by ratifying CRPD. The country is therefore obliged to comply with the provisions of the CRPD. The state has the responsibility to recognise, respect, promote, protect and fulfil the human rights of persons with disability. The state is obliged to put up mechanisms that will promote recognition and observance of disability rights. Ghana has made legislations, policies, programmes and measures in promoting and protecting disability rights.

However, these measures have failed to stop stigmatisation and discrimination against persons affected by leprosy. For instance, it is a decade now that Ghana's Disability Act (Act 715) was enacted; the state has failed to implement the major provisions in the act. PALs are being stigmatised and discriminated against by their families, institutions and society because the state has failed to put up action oriented policy to implement the CRPD to conform to our system of disability care.

It vividly came out of the study that, PALs are stigmatised and discriminated against; hence violation of their rights. The following conclusions came out of the study. Firstly, factors identified as determinants of stigmatisation and discrimination against PALs indicated clear violations of their human rights. The rights to dignity, culture, non- discrimination, equality and participation of PALs are violated.

Secondly, stigmatisation and discrimination have negative effects on PALs. PALs do not enjoy educational, health and economic rights because of stigma and discrimination. PALs are uneducated, unemployed and they are not properly accepted in public hospital. Again, PALs do not enjoy rights to marriage and family protection, rights to social security and good standard of living. Psychologically, PALs have developed certain strategies to contain the stigma and discrimination against them in the society. Passing, covering, devaluing and isolation have been adapted by PALs to surmount psychological difficulties. This has affected the mainstreaming of PALs to develop their potentials in the society.

Thirdly, the relationship between PALs and their families is poor due to low level of knowledge about leprosy. Neglect and exclusion of PALs by society and family members motivated the establishment of the Weija leprosarium. Donors support are the main financial and material support for the up- keep of the leprosarium.

Public institutions are available but the PALs are not ready to use them because such institutions are not friendly. Paramount among such institutions are schools and hospitals.

Educating the public on the causes and available preventive mechanism for leprosy will reduce stigma and discrimination against persons affected by leprosy. Human rights education must be inculcated in our educational curriculum at all levels for people to realize the need to respect and promote human dignity without discrimination. The country must establish schools such as vocational and technical institutions to train persons affected by leprosy to be gainfully employed so that they will not be a liability to their families and the society.

6.3 Recommendations

Based on the conclusion of the study, the following recommendations are proposed to reduce the extent of stigmatisation and discrimination against persons affected by leprosy in the Weija Leprosarium.

6.3.1 Counselling

Individual and group counselling should be organized for persons affected by leprosy at the Leprosarium by infectious disease specialist and psychologist. This will help to identify their challenges as individuals and group in other to find possible solutions to them. Counselling will encourage PALs to accept changes on the body and their new stage in life. Self-encouragement and confidence will take away self- stigma in the affected persons through counseling. Counseling can motivate persons affected by leprosy to cope with the disease and build self- esteem to overcome discrimination.

6.3.2 Establishment of Training Institutions Centres

Technical and Vocational institutions should be established by the state to equip persons affected by leprosy with knowledge and skills. The acquisition of skills can create employment for PALs in both formal and informal sectors. If affected persons are gainfully employed, their standard of living will improve and they may live a normal life as other individuals. All the PALs in the Weija leprosarium are not gainfully employed and they live by voluntary donors support from the public through Lepers Aid Committee.

6.3.3 Special School's for Persons Affected by Leprosy.

Again the state should establish a special school for persons affected by leprosy especially those with deformities. For instance, a person without fingers will find it difficult to be enrolled in the mainstream educational system. Persons affected by leprosy must be considered as one of the special groups under Special Education in the academic structure. Therefore, they need a replica of schools for the blind and the deaf in the country for them to enjoy educational rights. The state has to sponsor personnel to be trained as teachers for the school.

6.3.4 Empowerment of NGOs (LEPERS AID COMMITTEE)

The plight and dignity of persons affected by leprosy in Weija Leprosarium depends on Lepers Aid Committee (NGO). The various activities of Lepers Aid Committee are geared towards the development and betterment of persons affected by leprosy. Most of the leprosarium in Ghana is managed by Lepers Aid Committee and the workers are on voluntary contracts. The state should assist the NGO by giving in – service training to the staff, providing national platforms to the NGOs for advocacy and providing stipends to their staff and the inmates for their upkeep. The NGOs do campaign against stigma and discrimination in the communities through advocacy.

6.3.5 Abolish bad Traditional Customs and practices

Traditional leaders should try as much as possible to reform all customs, usages and practices that encourage stigma and discrimination against PALs in the society. For instance, banishment and pacification of gods by persons affected by leprosy must be stopped. Moreover, traditional practices must conform to modern medical practices to avoid victimization and violations of the rights of persons affected by leprosy. Traditional leaders can also lead a campaign against stigma and discrimination.

6.3.6 Awareness Creation

Sensitization on leprosy in the country will reduce the tag on the disease. Ghana Health Service must improve its campaign on Leprosy. Creation of awareness on leprosy in the social media, hospitals, schools, markets and banks may change the perception of people on persons affected by leprosy. Awareness creation may encourage people to go for voluntary testing and newly diagnose persons will be bold to seek medical care and prevent deformity. For example, sensitization on tuberculosis has helped to reduce the spread, stigma and discrimination on the affected persons.

6.3.7 Sponsorship from Corporate Institutions

Corporate Bodies in the country should sponsor NGO's like Lepers Aid Committee to offer free testing in our communities as part of their social responsibilities. The three northern regions has the highest number of new cases (Lepers Aid Committee, 2014) and if the disease is diagnosed early, affected persons can be encouraged to take medication and treatment and avoid the spread of leprosy. For instance, Ghana National Petroleum Corporation (GNPC) is sponsoring Ghana Sickle Cell Association to provide adequate healthcare for its members.

6.3.8 Education

State institutions such as Ghana Health Service and Ghana Education Service should include causes and treatment of leprosy in the curriculum at all levels to improve the perceptions of citizens on leprosy in the country. Leaflets, pamphlets and magazines should be printed and given out freely to pupils, students and the public to read and understand about leprosy. Community Health Nurses may be encouraged to embark on community base education to erase perceptions of people about leprosy. Persons affected by leprosy and their family members are to be educated about leprosy, their rights and available social security in the country. Education to the PALs will reduce self and enacted stigma in them while educating their family members will prevent exclusion and rejection by the family.

6.3.9 Better use of Media and Language

The media in all forms can promote and reinforce positive attitudes. Sometimes, it can be found guilty of perpetuating negative and disempowering attitudes. Vigilance and persistence are required to promote more inclusive terminology and appropriate language for leprosy. For instance, much has been achieved by the media in the case of HIV/AIDS, so why not in leprosy? Media should use their platform to challenge the prejudice, stereotype and labelling against persons affected by leprosy.

6.3.10 Legislative Reform

Attitudinal change may come out of availability and enforcement of existing laws in respect to fundamental human rights. Therefore, disability laws in the country should be amended to conform to international and regional human rights standards. The law enforcement agencies must also be empowered to ensure full realization of the laws. The state should enact a new act "Leprosy Health Act" to promote, protect, respect, recognize and fulfill the rights of persons affected by leprosy in Ghana. The legislation should make provision against stigmatization and discrimination.

6.3.11 Rights- Based Approach

There should be an integrated approach to the fight against stigma and discrimination. Persons affected by leprosy, family members of the affected person, communities, healthcare providers, NGO's, and the Government should consider various views from the stakeholders and possible human rights instruments and come out with a comprehensive guidelines to fight stigma and discrimination. The guided instrument must be acceptable, accessible, adaptable and available to persons affected by leprosy.

6.3.12 Human Rights Education

The state should make human rights education an integral part of the educational curriculum. Human rights education at all levels of the Educational System in Ghana will help the citizens to recognise, respect, promote and protect the human rights of all persons in Ghana. Again, human rights education will help to reduce human rights violations in Ghana.

6.3.13 Creation of an independent institution for persons with disability

Ghana should create a legally mandated independent institution ‘Ghana Disability Authority’ to cater for categories of issues related to disability in Ghana. As a national institution, the office shall receive financial support from the national budget to ensure effective operation of the institution. Annual report on the state of disability in Ghana would be presented to Parliament for deliberation and recommendation to improve the standard of living of persons with disability. Although, the current disability act of Ghana (Act 715) has created National Council on Person with Disability which operates under the Ministry of Employment but the capacity of the Council cannot handle the issues of disability in Ghana. The creation of Ghana Disability Authority will help to generate a national data on persons with disability, design and implement policies to resolve disability related problems.

6.4 Limitations

It took several weeks for the Administration of Weija Leprosarium to approve my interview guide used to collate the data for the study. Also, the respondents were not always ready for the interview because of illness and other activities in the Leprosarium. These caused a delay for the researcher to collate the data for the study on time.

6.5 Suggestion for Further Studies

It is suggested that further studies will be done on the inclusiveness of persons affected by leprosy in the communities. Also, further studies can be done in other leprosaria in Ghana as this study only focused on Weija Leprosarium.

REFERENCES

Agyedu, G. O., Donkor, F. & Obeng, S. (1999). *Teach Yourself Research Methods.* Accra: Adwinsa Publications.

Ahiadeke, C. (2008). *Research Methodology: Theory and Practice in the Social Sciences*. Accra: Sundel Services.

Ajediran, I. B., Sylvester, A. D., & Fidelis, T. I. (2013): Health related quality of life amongst people affected by leprosy in Southern Ghana: A needs assessment. Thesis in the University of Ghana.

Amadehe, F. K. (2002). *Fundamentals of Educational Research Methods, Mimeograph*. Cape Coast: University of Cape Coast.

Amoah, S. A., & Onivehu ,A. E. (2002). *Essentials in assessment,* Accra; R & B Publishers.

Amoani, F. K. (2005). *Introduction to Research Methodology*. Winneba: University of Education, Ghana.

American Leprosy Mission (2014). *Leprosy Frequently Asked Questions.* Retrieved from http://www.leprosy.org/leprosy-faqs/

Arminio, J. L., & Hultgren, F. H. (2002). *Breaking Out Of The Shadow: The question of criteria in qualitative research*. London: Routledge.

Awofeso, N. (1992). Appraisal of the knowledge and attitude of Nigerian nurses toward leprosy, *Leprosy Review* 63,169-172.

Awofeso, N. (2005). Concept and impact of stigma on discrimination against leprosy sufferers – minimizing the harm, *Leprosy Review* 76, 101-102.

Bach, M., & Kerzner, L. (2010). *Recognition of Sports and Accommodation in the United Nations Convention on the Rights of Persons with Disabilities*, *Part I, Section II ,* A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, Law Commission of Ontario, October 2010.

Barnett, L. (2012). *Canada's Approach to the Treaty – Making Process,* Publication no. 2008-45-E, Parliamentary Information and Research Service, Library of Parliament ,Ottawa, 6 November 2012.

Bainson , K. & Van den Borne, B. (1998). Dimensions and process of stigmatization in leprosy', *Leprosy Review* 69, 341-350.

Bamett, L., Nicol, J. & Walker, P. L. (2012). *An Examination of the Duty to Accommodation in the Canadian Human Rights Context*, Publication no. 2012- 01- E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, Canada.

Bauer, H., Rodriguez, M., Quiriga, S., & Flores- Ortiz, Y. (2000). Barriers to health care for abused Latina and Asian immigrant women. *Journal of Health Care for the Poor and Underserved,* 11(1), 33-44.

Barkataki, P., Kumar, S., & Rao, P. S. S. (2006). Knowledge of and attitudes to leprosy among patients and community members: a comparative study in Uttar Pradesh, India, *Leprosy Review* 77, 62-68

Barret, R. (2005). Self-mortification and the stigma of leprosy in northern India, *Medical Anthropology Quarterly*19, 216-230.

Bergman, L. & Asabea, B. (2014). *Nurse's experiences of leprosy related stigma in Ghana.* A thesis submitted to Esta Skondal Hogskola, Sweden.

Bekri, W., Gebre, S., Mengiste, A., Saunderson, P .R., & Zewge, S. (1998). *Delay in presentation and start of treatment in leprosy patients*: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia, *International Journal of Leprosy,* 66, 1

Briden, A., & Maguire, E. (2003*). An assessment of knowledge and attitudes towards leprosy/ Hansen's disease amongst healthcare workers in Guyana*, *Leprosy Review* 74, 154-162.

Browne, M., Irene, B., & Joya, M. (2003). *The Intersection of Gender and Race in the Labor Market, Annual Review of Sociology*, 29 (1), 487-513.

Browne, S. (2003). *The History of leprosy, in Hastings*, Leprosy. Edinburgh: Churchill Livingstone.

Calcraft, J. H. (2006). *The effects of the stigma of leprosy on the income generation of leprosy Affected people in the Terrai area of South East Nepal*, Asia Pacific *Disability Rehabilitation Journal*, 17.

Camp, D. L., Finlay, W. M. L., & Lyons, E. (2002). *Is Low Self-Esteem an Inevitable Consequence of Stigma?* An example from women with chronic mental health problems. *Social Science and Medicine*, 55 (5),823-835.

Castro, A., & Farmer, P. (2005). *Understanding and Addressing AIDS-Related Stigma*: From Anthropological Theory to Clinical Practice in Haiti, *American Journal of Public Health*, 1.

Cohen, L., & Manion, L. (1994). *Research Methods in Education* (4th ed.). London: Routledge.

Cohen, L., Manion, L., & Morrison, K. (2000). *Research Methods in Education* (5th ed.). London: Routledge Falmer.

Cohen, L., Manion, L., & Morrison, K. (2007). *Research Methods in Education* (6th ed.). London: Routledge Falmer.

Corrigan, P. W. (2005). *On the Stigma of Mental Illness, Practical Strategies for Research and Social Change,* Ch 1 The impact of mental illness stigma by Corrigan, P.W. and Kleinlein, P. Published by American Psychological Association, Washington, DC.

Centre for Policy Alternative. (2005). *A Profile of the Stigma and Discrimination faced by People living with HIV/AIDS*, study conducted by The Centre for Policy Alternatives (CPA) for The Asia Pacific Leadership Forum (APLF)

Creswell, J. W. (1998). *Qualitative Inquiry and Research Design: choosing among five traditions*, London: Sage Publications.

Creswell, J. W. (2003). *Research Design: qualitative, quantitative, and mixed methods approaches* (2nd ed.), London: Sage Publications.

Creswell, J. W. (2005). *Educational Research: planning, conducting and evaluating quantitative and qualitative Research*, New Jersey: Pearson Education.

Creswell, J. W. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (3rd ed.). London: Sage Publications.

Crocker, J., Major, B. & Steele, C. (1998). *Social stigma*. In: Gilbert DT, Fiske ST (eds). *The handbook of social psycology.(*2nd ed.). McGraw-Hill, Boston, 1998, 504–553.

Cross H., & Choudhary, R. (2006). *STEP: an intervention to address the issue of stigma related to leprosy in Southern Nepal. Leprosy Review*, 2005; 76, 316–324.

Cross, H. (2006). *Interventions to address the stigma associated with leprosy:* A perspective on the issues, *Psychology, Health & Medicine*, 11 (3), 367-373

Denscombe, M. (2003). *A Good Research Guide for Small Scale Social Research Projects.* Buckingham: Open University Press.

deStigter, D., de Geus, L. & Heynders, M. (2000). *Leprosy: between acceptance and segregation.* Community behaviour towards persons affected by leprosy in eastern Nepal, *Leprosy Review*, 71, 492-498.

Dijker, J. M., & Koomen, W. (2006). *A psychological model of social control and stigmatization:* Evolutionary background and practical implication. *Psychology Health Med,* 11, 296–306.

Dogra, S., Narang, T., & Kumar, B. (2012). *Leprosy - evolution of the path to eradication. Indian Journal of Medical Research,* 137, 5-35.

Dudley, J. (1983). *Living with Stigma:* The plight of the people who we label mentally retarded. Springfeild, IL: Charles C. Thomas.

Durkheim, E., & Representations. (2000). *Meaning and representation in the Social Science in W.S. F. Pickering (Ed.),*139- 56.

Montigny, E. (2009). *Roundtable on the United Nations Convention on the Rights of Persons with Disabilities,* ARCH Alert, ARCH Disability Law Centre, Ottawa.

Frist, T. F. (2000). *Stigma and Societal Response to Leprosy:* Experience of the Last Half Century, *Indian Journal Leprosy,*72 (1), 3-5.

Ghana Health Service. (2014). Ghana Leprosy Elimination programme.

Ghana News Agency. (2016). Ghana reaches Eradication Stage in fight Against leprosy.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Prentice-Hall, Englewood Cliffs (NJ), 1963.

Guimarães, H., Barros, A., Bassoli, S., Salotti, S., & Oda, R. (2009). *Helping a man with leprosy:* A Case Study. *International Journal of Nursing Terminologies and Classifications,* 20 (3), 141-144.

Grbich, C. (2007). *Qualitative Data Analysis:* An introduction. London: Sage Publications Limited.

Hagens, T. (2007). *A comparative study of stigma and discrimination related to Leprosy and HIV/AIDS.* A thesis submitted to the KIT (Royal Tropical Institute)/ Vrije Universteit Amsterdam, the Netherlands.

Haidar, A. A. M. (1985). *Leprosy – the Moslem attitude, Leprosy Review* 56, 17-21.

Heijnders, M. L. (2004). *The dynamics of stigma in leprosy*, *International Journal of Leprosy and Other Mycobacterial Diseases,* 72, 437-447.

Heijnders, M., van Der Meij, S. (2006). *The fight against stigma:* an overview of the stigma reduction strategies and interventions, *Psychology, Health and Medicine,* 11, 353-363.

Heijnders, M. L. (2004). *An exploration of the views of people with leprosy in Nepal;* concerning the quality of leprosy services and their impact on adherence behaviour, *Leprosy Review* 75, 338-347.

Hooks, B. (2014*). Feminist Theory:* From Margin to Centre. *3rd Edition*. New York: Routledge.

Holloway, R. (2001). *Towards Financial Self-Reliance. A Handbook of Approach to Resource Mobilization.* London: Earthscan.

Idawani, C., Yulizar, M., Lever, P., & Varkevisser, C. (2002). *Gender, leprosy and leprosy control:* A case study in Aceh, Indonesia. KIT, Amsterdam, 2002.

ILEP, (2007). Leprosy patients' case for referral to UN Human Rights Commission, International Federation of Anti-Leprosy Associations (ILEP).

Jacoby, A., Snape, D., & Baker, G. A. (2005). *Epilepsy and social identity*: the stigma of a chronic neurological disorder.

Jacoby, A. (1994). *Felt Versus Enacted Stigma:* A Concept Revisited, Evidence from a study of people with epilepsy in remission, *Soc. Sci. Med*. 38, 269-274.

Joachim, G., & Acorm, S. (2000). *Stigma of visible and invisible chronic conditions. Journal of Advanced Nursing*, 32 (1), 243-248.

Jones, E., Farina, A., Hastorf, A. et al. (1984). *Social stigma: The psychology of marked relationships* ,Freeman: New York.

Jopling, C. (1991). *Leprosy stigma*, *Leprosy Review* 62, 1-12.

Kaur, H., & Ramesh, V. (1994). *Social problems of women leprosy patients* – a study conducted at 2 urban leprosy centres in Delhi, *Leprosy Review* 65,361-375.

Kaur, H., & van Brakel, W. (2002). *Dehabilitation of leprosy-affected people* – a study on leprosy-affected beggars, *Leprosy Review* 73, 346-355.

Krysik, J. L. & Finn, J. (2007). *Research for Effective Social Work Practice*. New York: McGraw-Hill Companies, Inc.

Kumekpor, T. K. B. (2002). *Research Methods and Techniques of Social Research.* Accra: Son Life Press and Services.

Kimberle, C. (1989). *Demarginalizing the Intersection of Race and Sex:* A Black Feminist Critique of Antidiscrimination Doctrine. *The University of Chicago Legal Forum* 140: pp 139- 167.

Lepers Aid Committee. (2015). The celebration of the 70th Birthday Anniversary of Rev. Fr. Andrew Campbell.

Le Grand, A. (1997). *Women and leprosy:* a review *Leprosy Review* 68, 203-211.

Link, B. & Phelan, J. (2001). *Conceptualizing stigma*, Annual Review of Sociology, 2001; 27: 363-385. *Qual Life Res,* 13, 1633–1642.

Link, B., Bruce, G., Francis, T., Cullen, E. S., Patrick, E. S., & Bruce P. D. (1989). *A Modified Labeling Theory Approach to Mental Disorders:* An Empirical Assessment, *American Sociological Review*, 54 (3), 400-23.

Marshall, C., & Rossman, G. B. (2006). *Designing Qualitative Research (4th ed.).* London: Sage Publications.

Merriam, S. B. (1988). *Case study research in education: A qualitative approach.* San Francisco: Jossey-Bass.

McCall, L. (2005). *The Complexity of Intersectionality. Journal of Women in Culture*, 30 (3),1771 – 18100.

Monico, S. M., Tanga, E. O., Nuwagaba, A., Aggleton, P., & Tyrer, P. (2001). *Uganda: HIV and AIDS-related Discrimination, Stigmatization, and Denial*, UNAIDS, Geneva.

Morrison, K. (2006). *Breaking the Cycle: Stigma, Discrimination, Internal Stigma, and HIV*, USAID, Jan NAPWA, 2002 Submission to the review of the 4th National HIV/AIDS strategy, National Association of people living with HIV/AIDS, Australia.

Neuman, W. L. (2000). *Social Research Methods: Qualitative and Quantitative Approaches.* London: Sage Publications.

Ofosu, A. & Bonsu, G. (2010). *Case control study to determine the factors associated with leprosy* in the Sene District, Brong Ahafo Region of Ghana. *Ghana Medical Journal,* 44 (3), 93-97.

OHCHR. (2005). U.N. Human Rights Sub-Commission Passes Leprosy Resolution 11-8, The Nippon Foundation *http://www.nippon-foundation.or.jp/eng/leprosy/2005721/20057211.html accessed1-8-2007*

O'Leary, Z. (2005). *Researching Real-world Problems:* a guide to methods of Inquiry. London: Sage Publications.

O'Neil, C., & Samiel, S. (2004). *A Health Promotion Approach to Reducing Stigma and Discrimination:* A Framework for Action, Caribbean Epidemiology Centre (CAREC) PAHO/WHO.

Opala, J., & Boillot, F. (1996). *Leprosy among the Limba:* Illness and Healing in the context of World View, *Soc. Sci. Med.* 42, 1, 3-19.

Parker, R., & Aggleton, P. (2002). *HIV/AIDS-related stigma and discrimination:* A conceptual framework and an agenda for action. Retrieved from http://pdf.usaid.gov/pdf_docs/Pnacq832.pdf

Parliament of the Republic of Ghana. (2006). The Disability Act of Ghana (Act 715).

Parliament of the Republic of Ghana. (1993).The 1992 Constitutions of the Republic of Ghana.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action, *Social Science & Medicine*, 57, 13-24.

The Nippon Foundation. (2005). The Delhi Declaration, Persons affected by leprosy December 19, Retrieved from http://www.nippon foundation.or.jp/eng/leprosy/2006737/20067372.html

Punch, K. (2005). *Introduction to Social Research: quantitative and qualitative approaches* (2nd ed.). London: Sage Publications.

Rafferty, J. (2005). *Curing the stigma of leprosy*. *Leprosy review Journal*, 76, 119–126. SCB Befolkningsstatistik (2013). Viewed 2014-03-27, from http://www.scb.se/statistik/_publikationer/OV0904_2013A01_BR_05_A01BR 1301.pf.

Rao, S., Garole, V., Walawalkar, S., Khot, S., & Karandikar, N. (1996). *Gender differentials in the social impact of leprosy*, *Leprosy Review* 67, 190-199.

Rebecca, J. F. (2003). *Stigma health article:* Definition. Retrieved from :http://www.healthline.com/galecontent/stigma?utm_term¼stigmaandutm_medium¼mwandutm_campaign¼article.

Reddy, N. B. B., Satpathy, S. K., Krishnan, S. A. R., Srinivasan, T. (1985). *Social aspects of leprosy:* A case study in Zaria, Northern Nigeria, *Leprosy Review*, 56, 23-25.

Robertson, C. E. (2003). *McCance and Widdowson's the composition of foods – sixth edition*. Department of Epidomiology & Public Health, Imperial College, Faculty of Medicine , Norkfolk Place, LONDON W2 IPG.

Sasakawa, Y. (2006). *Media perception of leprosy*, *Leprosy Review* ,77, 1.

Schmidt, C. (2004). *The Analysis of Semi-structured Interviews.* In Flick, U., Kardorff, E. V. and Steinke, I. (Eds.). *A Companion to Qualitative Research*. London: Sage Publications.

Scott, J. (2000). The psychological needs of leprosy patients, *Leprosy Review* 71, 486-491.

Seddon, D., & Seeley, J. (2006). *Leprosy and stigma, Asia Pacific Disability Rehabilitation Journal*, 17,2.

Shieh, C., Wang, H. H., & Lin, C. F. (2006). *From contagious to chronic:* a life course experience with leprosy in Taiwanese women, *Leprosy Review* 77, 99-113.

Sikes, P. (2004). *Methodology, Procedures and Ethical Concerns, in Opie, C. (ed.), Doing Educational Research*: a guide to first time researchers. London: Sage Publications.

Simons, T. L., & Peterson, R. S. (2000). *Task conflict and relationship conflict in top managenement team;* the pivotal role of intra group trust. *Journal of applied psychology,* 102 – 111.

Siyam, K. (2003). *Tackling HIV/AIDS stigma:* Guidelines for people living with HIV/AIDS who interact with the media, Policy Project, South Africa; The Centre for the Study of AIDS, University of Pretoria, Pretoria.

Siyam, K. (2003). *HIV/AIDS stigma indicators, A tool for measuring the progress of HIV/AIDS stigma mitigation, Cape Town:* Policy Project, South Africa.

Stafford, M. C., & Scott, R. R. (1986). *Stigma deviance and social control:* some conceptual issues. In: Ainlay SC, Becker LM, Coleman LM (eds). *The Dilemma of Difference.* Plenum, New York.

Stigter de, D. H., Geus de, L., & Heijnders, M. L. (2000). *Leprosy: between acceptance and segregation.* Community behaviour towards persons affected by leprosy in eastern Nepal, *Leprosy Review* 71, 492-498.

The Nippon Foundation (2013). *Third International Symposium on Leprosy and Human Rights*. Addis Ababa, Ethiopia.

Try, L. (2006). Gendered experiences: Marriage and the stigma of leprosy. *Asia Pacific Disability Rehabilitation Journal* 17, 55–72.

Thompson, B. (2002). *Multiracial Feminism:* Recasting the Chronology of Second Wave Feminism. *Feminist Studies* Inc. 28 (2), 337.

Tsutsumi, A., Izutsu, T., Akul Islam, M. D., Amed, J. U., Nakahara, S., Takagi, F., & Wakai, S. (2004). *Depressive status of leprosy patients in Bangladesh:* association with self-perception of stigma .*Leprosy Review* 75, 57-66.

Tsutsumi, A., Izutsu, T., Islam, M. D .A., Maksuda, A. N., Kato, H. & Wakai, S. (2007). *The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh, Social Science and Medicine* 64, 2443-2453.

United Nations Human Rights Council (2008). *Elimination of discrimination against persons affected by leprosy and their family members.* Resolution A/HRC/8/L.18, http://www.ilep.org.uk/fileadmin/uploads/Documents/News_documents/HRC818discrimlepaffd.pdf.

United Nations. (1948). United Nations Universal Declaration of Human Rights Retrieved on March 14, 2012. www.un.org/en/documents/udhr/.

United Nations. (2007). Convention on the Rights of Persons with Disabilities, UN Dept. of Economic and Social Affairs, 2007; http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

United Nations. (2011). *Status of Treaties* – Convention on the Rights of Persons with Disabilities, Treaty Series, United Nations treaties Collection, 2515.

United Nations. (1995). *The Copenhagen Declaration and Programme of Action:* World Summit for Social Development, New York, United Nations Department of Publications.

United Nations. (1966). International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), 1966; Retrieved from http://www.unhchr.ch/html/menu3/b/a_cescr.htm

United Nations. (1966). International Covenant on Civic and Political Rights, G.A. res. 2200A (XXI), 1966; http://www.unhchr.ch/html/menu3/b/a_cescr.htm

Unites Nation Development Programme. (2010). Human Development Index Report. http: www. hdr.undo.org> content> human- develop…

United Nation Economic and Social Council. (1992). *General Comment Number 3:* The nature of states parties obligations (art 2, para 1, of the covanent). E/1991/23; 14/12/1990; New York.

United Nations. (2007). *Convention on the Rights of Persons with Disabilities*, UN Dept. of Economic and Social Affairs, 2007; http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

United Nations Human Rights Council. (2008). Stigma in leprosy 47th UN & Elimination of Discrimination Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members - extracted from UN General Assembly, 5TH Session 2-6 August, A/HRC/15/30 . 3-7.

United Nation Human Rights Council. (2008). The Elimination of discrimination against persons affected by leprosy and their family members. Resolution (A/HRC/8/L.18), Hyderabad, India.

United Nations. (1995). *Review* and appraisal of implementation of the World Programme of Action concerning Disable Persons.

United Nations. (1987). A Decade of Disable Persons.

United Nations. (1982). The World programme of Action concerning Disabled Persons.

United Nations. (1976). Declaration on the Rights of Disabled Persons.

United Nations. (1971). Declaration on the Rights of Mentally Retarded Persons.

Van Brakel, W. H. (2006). *Measuring health-related stigma* – a literature review *Psychology, Health & Medicine*, 11, 3, 307-334.

Van Brakel, W. H., & Gopal, P. K. (1999). *Portraying a positive image of persons (previously) affected by leprosy, International Journal of Leprosy* 67 , 4 ,477-479.

Van Brakel, W. (2006). *Measuring health related stigma, Psychology, Health and Medicine* 11, 307-334.

Van Brakel, W. (2003). *Measuring leprosy stigma* – a preliminary review of the leprosy literature, *International Journal of Leprosy and Other Mycobacterial Diseases* 71, 190-197.

Verma, G. K., & Mallick, K. (1999). *Researching Education: perspectives and techniques*. London: Falmer Press.

Vienna Declaration and Programme and Action. (1993). *The World Conference on Human Rights.* Vienna, Austria.

Wakai, S. (2004). *Depressive status of leprosy patients in Bangladesh:* association with self-perception of stigma .*Leprosy Review* 75, 57-66.

Walliman, N. (2005). *Your Research Project (2nd ed.).* London: Sage Publications

Waxler, N. E. (2008). *Learning to be a leper:* A case study in the social construction of illness. In: Mishler White C. Iatrogenic stigma in outpatient treatment for Hansen's disease (leprosy) in Brazil. *Health Educ Res* 23, 25–39.EG (ed.).

Weijer, C., Emanuel, E. J., Wendler, D., and Grady, C. (1999). Protecting communities in research: Current guidelines and limits of extrapolation. *Nature Genetics* 23 (3), 275-80.

Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). *Health-related stigma:* rethinking concepts and interventions. *Psychol Health Med* 11, 277–287.

Weiss, M. G., & Ramakrishna, J. (2004). *Health-Related Stigma:* Rethinking Concepts and Interventions, Research Workshop on Health-Related Stigma and Discrimination.

White, C. (2007). *Iatrogenic stigma in outpatient treatment for Hansen's disease (leprosy) in Brazil,* Health Education Research, Theory & Practice Health Education Research Advance.

Wilson, M. A. (2000). *Towards a model terrorist behaviour in hostage* – taking incidence. *Journal of conflict resolution,* 403 – 424.

World Health Organisation. (2004). Twenty five years of multi drug therapy for leprosy, *Weekly Epidemiological Record*, 27.

World Health Organisation. (2009). World Health Statistics.

World Health Organisation. (2010). World Health Statistics .

World Health Organisation. (2005). *Leprosy, WHO fact sheet no 101*, Revised October http://www.who.int/mediacentre/factsheet/fs101/en/print.html accessed 24/05/2007.

World Health Organisation. (2005). *Stigma and discrimination against mentally ill in Europe,* WHO European Ministerial Conference on Mental Health; Facing the Challenges, Building Solutions Helsinki, Finland 12-15 January.

World Health Organisation. (2010). *Global Leprosy Situation*, *Weekly Epidemiological Record*, 25.

World Health Organisation. (2007). *Fact Sheet 1 HIV/AIDS*: the infection, WHO http://www.who.int/hiv/abouthiv/en/fact_sheet_hiv.htm accessed 05/07/2007.

World Health Organisation.(2007). *Leprosy: the disease, WHO fact sheet* Retrieved from http://www.who.int/lep/leprosy/en/print.html.

World Health Organisation. (2005). *The leprosy burden at the end of 2005* Retrieved from http://www.who.int/lep/situation/se_asia/en/index.html.

World Health Organisation. (2007). *Transmission of leprosy*, WHO fact sheet Retrieved from http://www.who.int/lep/transmission/en/print.html.

World Health Organisation. (2013). *Third Symposium on Leprosy and Human Rights.* Leprosy and Human Rights: principles and guidelines for the elimination of discrimination against persons affected by and their family members.

World Health Organisation. (2016). Global Strategy on Leprosy Programme. Accelerating towards a leprosy – free World.

Withington, S., Joha, S., Baird, D., Brink, M. & Brink, J. (2003). *Assessing socio-economic factors in relation to stigmatization*, impairment status, and selection for socio-economic rehabilitation: a 1 year cohort of new leprosy patients in north Bangladesh', *Leprosy Review,* 2003; 74: 120-132.

Wong, M. (2004). *Can social marketing be applied to leprosy programmes?, Leprosy Review* 71, 308-318.

Wong, M. L. (2004). Designing programmes to address stigma in leprosy , issues and challenges. *Asia Pacific Disability Rehabilitation Journal*, 15, 2.

World Health Organization. (2008). Global Leprosy Situation 2008, *Weekly Epidemiological Record* 33, 333-340.

World Health Organization. (2006). Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities, (Planned Period 2006 – 2010), Operational Guidelines. Geneva: World Health Organization.

World Health Organization. (2005). Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities, (Planned Period 2006 – 2010). Geneva: World Health Organization.

World Health Organization . (2005). Global strategy for further reducing the burden of leprosy and sustaining leprosy control activities (plan period 2006–2010), 2005; http://www.ilep.org.uk/fileadmin/uploads/Documents/ WHO_Publications/gstrat130605.pdf.

World Health Organization. (2009). Global leprosy situation 2009. Switzerland: World Health Organization; Report No.:33.

Wragg, T. (2002). *Interviewing,* in Coleman, M. and Briggs, A. R. J. (Eds.), *Research Methods in Educational Leadership and Management.* London: Paul Chapman Publishing.

Yin, R. K. (2003). *Case Study Research: design and methods, Applied Social Research Methods Series,* 5, London: Sage Publications.

Zodpey, S. P., Rajnarayan, R., Tiwari, R. R., Salodkar, A. D. (2000). Gender differentials in the social and family life of leprosy patients, *Leprosy Review* 71, 505-51.

APPENDIX I

INTERVIEW GUIDE

(PERSONS AFFECTED BY LEPROSY (PAL)

- What brought you to the leprosarium?
- Why have you decided to live/ stay in the Leprosarium?
- What effects has the disease brought on your life?
- What challenges are you facing as a Person affected with leprosy?
- How are you treated by your family?
- How are you treated by the society?
- How is the treatment in the leprosarium different from treatment outside the camp (community/Church/ Mosque/ Market)?
- What are some of the difficulties you go through when accessing public institutions? (School/ Hospital/ Bank/ other offices)
- How are you treated by Nurses and Administrators in the leprosarium?
- In your own view, how do you want persons affected by leprosy to be treated in Ghana?

APPENDIX II

(NURSE)

- How long have you been working on Persons affected with Leprosy?
- How different is providing healthcare to Persons affected by leprosy as compared to other diseases?
- What are some of the challenges in providing health care to persons affected by leprosy?
- In your opinion, how has caring for persons affected by leprosy affected your social, professional and personal life?
- How do you assess the relationship between persons affected by leprosy and their families?
- How do you assess the relationship between nurses and persons affected by leprosy?
- Explain how persons affected by leprosy are treated in Ghana?
- What effects has the disease brought on your patients?
- Explain some difficulties persons affected by leprosy faces when accessing public institutions?
- In your own view, how do you expect persons affected by leprosy to be treated in Ghana?

APPENDIX III

(ADMINISTRATOR)

- How many years have you been working here as an administrator?
- How have been affected socially, professionally and personally as an administrator in the leprosarium?
- In your own view, how do you assess the relationship between administrator(s) and persons affected by leprosy (PAL)?
- Explain the reasons for establishing the leprosarium?
- What are the effects of the disease on the inmates?
- What are some of the challenges they go through as persons affected by leprosy?
- How is the relationship between family members and persons affected by leprosy?
- Explain how persons affected by leprosy are treated in Ghana?
- Explain some of the challenges persons affected by leprosy go through when accessing public institutions?
- In your own view, how do you expect persons affected by leprosy to be treated in Ghana?

APPENDIX IV

(FAMILY MEMBER)

- Why did you bring your family member to the leprosarium?
- What effects has the disease brought on the family?
- How is the relationship between the family and person affected by leprosy?
- What effects has the disease brought on the family member who is affected by leprosy?
- How are persons affected by leprosy treated in Ghana?
- Explain the relationship between nurses, administrators and persons affected by leprosy?
- What are some of the challenges persons affected by leprosy go through when accessing public institutions?
- In your own view, how do you expect persons affected by leprosy to be treated in Ghana?

APPENDIX V

The Rights of the Disabled Person (Vienna Declaration of Action)

In Part II, paragraph 63, the VDAP reaffirms that all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities. Every person is born equal and has the same rights to life and welfare, education and work, living independently and active participation in all aspects of society. Any direct discrimination or other negative discriminatory treatment of a disabled person is therefore a violation of his or her rights. Paragraph 64 of the VDAP affirms that the place of disabled person is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society.

United Nations and the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members

Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

I. Principles

1. Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights, as well as in other relevant international human rights instruments to which their respective States are parties, including the International Covenant on Economic, Social and Cultural Rights, the

International Covenant on Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.

2. Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.
3. Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood. To this end: (a) No one should be denied the right to marry on the grounds of leprosy; (b) Leprosy should not constitute a ground for divorce; (c) A child should not be separated from his or her parents on the grounds of leprosy.
4. Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.
5. Persons affected by leprosy and their family members should have the right to serve the public, on an equal basis with others, including the right to stand for elections and to hold office at all levels of government.
6. Persons affected by leprosy and their family members should have the right to work in an environment that is inclusive and to be treated on an equal basis with others in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.
7. Persons affected by leprosy and their family members should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.
8. Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth. Persons affected by leprosy and their family members who have

been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.

9. Persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.

II. Guidelines

1. General

1. States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy. To this end, States should: (a) Take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members, or that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy in the context of such discrimination; (b) Ensure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise.
2. States should take all appropriate measures to achieve for persons affected by leprosy and their family members the full realization of all the rights enshrined in the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.

3. In the development and implementation of legislation and policies and in other decision-making processes concerning issues relating to persons affected by leprosy and their family members, States should consult closely with and actively involve persons affected by leprosy and their family members, individually or through their respective local and national organizations.

2. Equality and non-discrimination

1. States should recognize that all persons are equal before and under the law and are entitled, without any discrimination, to the equal protection and equal benefit of the law.
2. States should prohibit all discrimination on the grounds of a person having or having had leprosy, and should guarantee equal and effective legal protection to persons affected by leprosy and their family members.
3. Specific measures which are necessary to achieve de facto equality of persons affected by leprosy and their family members shall not be considered as discrimination.

3. Women, children and other vulnerable groups

1. In many societies, leprosy has a significantly adverse impact on women, children and other vulnerable groups. States should therefore pay special attention to the promotion and protection of the human rights of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.
2. States should promote the full development, advancement and empowerment of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.

4. Home and family

States should, where possible, support the reunification of families separated in the past as a result of policies and practices relating to persons diagnosed with leprosy.

5. Living in the community and housing

1. States should promote the enjoyment of the same rights for persons affected by leprosy and their family members as for everyone else, allowing their full inclusion and participation in the community.
2. States should identify persons affected by leprosy and their family members living in isolation or segregated from their community because of their disease, and should give them social support.
3. States should enable persons affected by leprosy and their family members to choose their place of residence and should ensure that they are not obliged to accept a particular living arrangement because of their disease.
4. States should allow any persons affected by leprosy and their family members who were once forcibly isolated by State policies in effect at the time to continue to live in the leprosarium's and hospitals that have become their homes, if they so desire. In the event that relocation is unavoidable, the residents of these places should be active participants in decisions concerning their future. States should, however, improve living conditions in those leprosaria and hospitals. With due regard to the wishes of the persons affected by leprosy and their family members, and with their full participation, States should also design, promote and implement plans for the gradual integration of the residents of such places in the community and for the gradual phasing out of such leprosaria and hospitals.

6. Participation in political life

States should ensure that persons affected by leprosy, and their family members, enjoy voting rights, the right to stand for election and the right to hold public office at all levels of government, on an equal basis with others. Voting procedures must be accessible, easy to use and adapted to accommodate any individual who is physically affected by leprosy.

7. Occupation

States should encourage and support opportunities for self-employment, the formation of cooperatives and vocational training for persons affected by leprosy and their family members, as well as their employment in regular labour markets.

8. Education

States should promote equal access to education for persons affected by leprosy and their family members.

9. Discriminatory language

States should remove discriminatory language, including the derogatory use of the term “leper” or its equivalent in any language or dialect, from governmental publications and should revise expeditiously, where possible, existing publications containing such language.

10. Participation in public, cultural and recreational activities

2. States should promote the equal enjoyment of the rights and freedoms of persons affected by leprosy and their family members, as enshrined in the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including, the International Covenant on

Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.

3. States should promote access on an equal basis with others to public places, including hotels, restaurants and buses, trains and other forms of public transport for persons affected by leprosy and their family members.
4. States should promote access on an equal basis with others to cultural and recreational facilities for persons affected by leprosy and their family members.
5. States should promote access on an equal basis with others to places of worship for persons affected by leprosy and their family members.

11. Health care

2. States should provide persons affected by leprosy at least with the same range, quality and standard of free or affordable health care as that provided for persons with other diseases. In addition, States should provide for early detection programmes and ensure prompt treatment of leprosy, including treatment for any reactions and nerve damage that may occur, in order to prevent the development of stigmatic consequences.
3. States should include psychological and social counselling as standard care offered to persons affected by leprosy who are undergoing diagnosis and treatment, and as needed after the completion of treatment.
4. States should ensure that persons affected by leprosy have access to free medication for leprosy, as well as appropriate health care.

12. Standard of living

2. States should recognise the right of persons affected by leprosy and their family members to an adequate standard of living, and should take appropriate steps to safeguard and promote that right, without discrimination on the grounds of leprosy, with regard to food, clothing, housing, drinking water, sewage systems and other living conditions. States should:
    a. Promote collaborative programmes involving the Government, civil society and private institutions to raise funds and develop programmes to improve the standard of living;
    b. Provide or ensure the provision of education to children whose families are living in poverty by means of scholarships and other programmes sponsored by the Government and/or civil society;
    c. Ensure that persons living in poverty have access to vocational training programmes, microcredit and other means to improve their standard of living.

3. **States should promote the realization of this right through financial measures, such as the following:**
    a. Persons affected by leprosy and their family members who are not able to work because of their age, illness or disability should be provided with a government pension;
    b. Persons affected by leprosy and their family members who are living in poverty should be provided with financial assistance for housing and health care.

4. Awareness-raising

States, working with human rights institutions, non-governmental organizations, civil society and the media, should formulate policies and plans of action to raise awareness throughout society and to foster respect for the rights and dignity of persons affected by leprosy and their family members. These policies and plans of action may include the following goals:

a. To provide information about leprosy at all levels of the education system, beginning with early childhood education affirming, inter alia, that leprosy is curable and should not be used as grounds for discrimination against persons who have or have had leprosy and their families;

b. To promote the production and dissemination of "know your rights" material to give to all persons recently diagnosed with leprosy;

c. To encourage the media to portray persons affected by leprosy and their family members with dignified images and terminology;

d. To recognize the skills, merits and abilities of persons affected by leprosy and their contribution to society and, where possible, to support exhibitions of their artistic, cultural and scientific talents;

e. To encourage creative persons, including artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, to make a contribution to awareness-raising through their specific talents;

f. To provide information to social leaders, including religious leaders, on how addressing leprosy in their teachings or written materials may contribute to the elimination of discrimination against persons affected by the disease and their family members;

g. To encourage higher education institutions, including medical schools and nursing schools, to include information about leprosy in their curricula, and to develop and implement a "train the trainer" programme and targeted educational materials;

h. To promote implementation of the World Programme for Human Rights Education and to incorporate the human rights of persons affected by leprosy and their family members into the national human rights education programme of each State;

i. To identify ways to recognize, honour and learn from the lives of individuals forcibly isolated by their Governments for having been diagnosed with leprosy, including oral history programmes, museums, monuments and publications;

j. To support grass-roots awareness efforts to reach communities without access to traditional media.

5. Development, implementation and follow-up to States' activities

1. States should consider creating or designating a committee to address activities relating to the human rights of persons affected by leprosy and their family members. The committee should ideally include individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from the human rights field and related fields, and representatives of government.
2. States are encouraged to include in their State party reports to the relevant treaty bodies the policies and measures that they have adopted and/or implemented with regard to the elimination of discrimination against persons affected by leprosy and their family members.

6. The Constitution of the Republic Ghana (1992) and Disability Rights

The 1992 Constitution of Ghana has devoted Chapter Five of its provisions for enjoyment of fundamental human rights and freedoms for Ghanaians in general. Article 29 of the constitution has made specific provisions to persons with disability. The article has made provisions to promote and protect the lives of persons with disability in Ghana; from discrimination, ensure participation, special incentives (social security), legal aid, ensure accessibility to public places and empower Parliament to enact laws for full realization of Article 29. The provisions in the article are listed below;

1. Disabled person have the right to live with their families or with foster parents and to participate in social, creative or recreational activities.
2. A disabled person shall not be subjected to differential treatment in respect to residence other than that required by his or her condition or by the improvement which may derive from the treatment.
3. If the stay of a disabled person in a specialised establishment is indispensable, the environment and the living conditions there shall be as close as possible to those of the normal life of a person of his age.
4. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.
5. In judicial proceedings in which disable person is a party, the legal procedure applied shall take his physical and mental condition into account.
6. As far as practicable, every place to which the public have access shall have appropriate facilities for disabled persons.

7. Special incentives shall be given to disabled persons engaged in business and also to business organisations that employ disabled persons in significant numbers.
8. Parliament shall enact such laws as are necessary to ensure the enforcement of the provisions of this article.

2.8 Ghana's Disability Act (Act 715)

Persons with Disability Act (Act 715), has provided a legal framework for persons with disability in Ghana to enjoy their fundamental rights. By passing the Act 715, Ghana seeks to do the following; fulfill a constitutional obligation of enacting laws to protect and promote the rights of people with disabilities and her international obligations. The Act 715 is made up of 60 clauses in eight (8) sections. The sections and their respective clauses are ; Rights of persons with disability (clauses 1 – 8), Employment of persons with disability (clauses 9 – 15), Education of persons with disability (Clauses 16 – 22), Transportation (clauses 23 – 30), Health-care facilities (clauses 31 – 35), Miscellaneous provisions (clauses 36 – 40) , Establishment and functions of National Council on Persons with Disability (clauses 41 – 50) and Administrative and Financial provisions (clauses 51 – 60). The Disability Act has made provision for the people with disability to enjoy the following rights; right to a family life and right to participate in social, creative or recreational activities; the prohibition of differential treatment for residential purposes, the right to the same living conditions as persons without disability when persons with disability are placed in special institutions; no exploitation, abuse, discrimination or disrespect to persons with disability, appropriate facilities when involved in court proceedings; and access to public places. The Act has established a National Council on Persons with Disability which main objective is to propose and evolve policies and strategies to enable persons with disability enter and participate in the mainstream of the national development process. Despite these provisions of the Disability Act, it is not consistent with the CRPD. . The goal of the UNCPRD is expected to significantly redress the profound social disadvantage of PWDs and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities. However, the Act in its current form, required some amendment to fill in the gaps and put it in total conformity to the UNCRPD .The Act did not make provision to take into account the rights of "women with disabilities", the rights of "children with disabilities", the inherent "right to life," and the right to protection and safety in "situations of risk and humanitarian emergencies. The Act is not very clear on whether all persons with disability can apply for a driving license. It says that persons who have a hearing disability may own a driving license if they pass a driving test and satisfy VELD conditions.