

THE RIGHTS OF PEOPLE WITH ALBINISM: A CONCEPTUAL AND RIGHTS BASED COMPARATIVE ANALYSIS.

A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF BACHELORS OF LAW [LLB] HONOURS DEGREE

BY

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My work is dedicated to:

- *My loving and devoted father, who believed in me when nobody else did, Mr Nikanor Natangwe Ntinda.*
- *My loving aunty and the best mother a girl can ever have, Mrs Suama Onwordi.*
- *My loving and encouraging uncle, God blessed me with a 2nd father Mr Isaac Onwordi.*
- *All the people living with albinism.*

SUPERVISOR'S CERTIFICATE

I, Ms Yvonne Dausab, hereby certify that research and writing of this dissertation was carried out under my supervision.

.....

Ms Yvonne Dausab

.....

Date

DECLARATION

I, the undersigned, hereby declare that the work contained in this dissertation for purposes of obtaining my honours degree of bachelors of laws, is my original work and that I have not used any other sources than those listed in the bibliography and/or quoted in the references.

.....

Ms Ruusa Nangula Ntinda

.....

Date

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The writing of this dissertation was one of my greatest academic challenges ever. The inspiration for doing this research came from the work done by Dr Oliver Ruppel on children's rights, in the book "*Children's rights in Namibia*", where he gave me the opportunity to write on customary practises and children with albinism.¹ This gave me the courage to write further on the rights people with albinism.

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¹ See Ntinda R. 2009. "*Customary practices and children with albinism in Namibia: a constitutional challenge?*" In Ruppel O. C. [eds]. "*Children's rights in Namibia*". Macmillan Education Namibia pp245.

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ABSTRACT

*“A very basic human need is to be “seen” by another person, to be known and accepted. This is poignantly true for the person with albinism who may be immediately “noticed” by many, but truly “seen” by few. This explains why it feels like a hidden condition despite its obviousness”.*²

The above quotation shows how the human rights of people with albinism get violated daily. These violations go unnoticed even if albinism is one of the obvious conditions. This is due to the skin and eyesight condition that people with albinism suffer from and all the stereotypes, cultural and modern beliefs and superstitions surrounding them. This dissertation will therefore investigate as to whether the rights of people with albinism are truly protected. Should people with albinism be regarded as vulnerable people and should they be classified as people with a disability.

The study is organised and presented in five main chapters. Chapter one will basically layout the introduction to the dissertation. The methodology for conducting this research findings and research ethics will also be discussed. Chapter two will look at the conceptual frame work on albinism. Here essential terms with regard to albinism shall be defined and discussed. A more detailed analysis will be made looking into the biological and cultural origin and developmental background on albinism. The second part of Chapter 2 shall lay out the social issues that affect people with albinism; this is due to the fact that issues such as gender imbalances, HIV/AIDS and violence contribute to the violation of human rights. In chapter three, people with albinism shall be placed within a human rights discourse within the national and international legal framework. A detailed research shall be done with regard to their rights, and to ascertain whether they are afforded the same protection? Furthermore this chapter will look at whether albinism should be categorised as a disability. Chapter four will provide a comparative analysis of Namibia to South Africa³ and Tanzania. Conclusions will be drawn in chapter five, where the recommendations shall also be made.

² See Sullivan J. 1998. Understanding albinism. Available at www.albinismfellowship.com . Accessed on 25 July 2011.

³ See chapter 4 on The Comparative Analysis as to why these countries were selected.

LIST OF ABBRIVIATIONS

| | |
|----------|---|
| ACHPR | African Charter on Human and People's Rights |
| CERD | Convention on the Elimination of all forms of Racial Discrimination |
| EFA | Education for All |
| HIV | Human Immunodeficiency Virus |
| ICCPR | International Covenant on Civil and Political Rights |
| ICESCR | International Convent on Economic Social and Cultural Rights |
| ICEAFRD | International Covenant on the elimination of all Forms of Racial Discrimination |
| ICF | International Classification of Functioning, Disability and Health |
| LAC | Legal Assistance Centre |
| MRC | Multi-disciplinary Research Centre |
| NAAT | Namibia Albino Association Trust |
| NNFPD | Namibia National Federation for Persons with Disabilities |
| NGO | Non-Governmental Organizations |
| NHRI | National Human Rights Institute |
| NOAH | National Organization for Albinism and Hypopigmentation |
| RoN | Republic of Namibia |
| SADC | Southern African Development Community |
| SINASTRA | Support in Namibia of Albino Sufferers Requiring Assistance |
| SPF | Sun Protection Factor |
| SSD | Social Sciences Division |
| UDHR | Universal Declaration of Human Rights |
| UN | United Nations |
| UNAM | University of Namibia |
| UNDF | United Nations Development Fund |
| UVR | Ultra-Violet Rays |
| WHO | World Health Organization |

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KEYWORDS

- *Albinism,*
- *Affirmative action,*
- *Disability,*
- *Discrimination,*
- *Human Rights and*
- *Stigma.*

CHAPTER 1: INTRODUCTION TO THE STUDY

1.1 Introduction

Albinism⁴ refers to a group of inherited genetic conditions that people with albinism have. It is a global phenomenon⁵ which can be found in people of all races. Albinism is surrounded by many cultural beliefs, superstitions and stereotypes. An individual with albinism stand out as a result of his/her whitish skin and hair due to a lack of the melanin⁶ pigment. Namibia, like other countries has an obligation to protect its minority population of people with albinism through the enforcement of human rights.

This study will look at whether the rights of people with albinism are protected; by using the human rights based approach. This will also be done from a sociological stand point. This is due to the fact that it is required of the by the research institution where she is currently employed⁷. And also because, one can never entirely talk about human rights separately from social issues in society, this is because human rights violations are a result of what happens in the society.

With the high emphasis on human rights in the world today, people with albinism are killed every day for purposes of witchcraft rituals⁸, abandoned at birth due to myths, taboos and cultural beliefs and even raped due to modern beliefs that having sex with a person with albinism will cure HIV/AIDS.⁹

1.2 Statement of problem

Namibia attained independence on the 21 March 1990 under a constitution that recognises human rights, in that it has an entrenched bill of rights in chapter 3.

⁴ See Chapter 2 on the Conceptual Framework on Albinism.

⁵ One person in 17000 in the United Kingdom has some type of albinism. See The National Organisation for Albinism and Hypopigmentation. What is albinism? Available at <http://www.albinism.org/html>. Accessed on 09 May 2011.

⁶ A natural occurring pigment in the hair and skin and one of its functions is to protect humans from harmful rays of the sun.

⁷ Currently working for the University of Namibia's Multi-Disciplinary Research Centre in the Social Science Division under the Gender Training and Research Programme as a Junior Researcher.

⁸ This happens especially in central and east Africa, for example; Tanzania. See Phitalis Were Masakhwe. 2009. Dispelling Africa's myths about albinism Urgent measures needed to protect people with albinism. 2009-09-10, Issue 447. Available at www.pambazuka.org. Accessed on 19 May 2011.

⁹ This is mostly done in Zimbabwe. See Ntinda R. 2009. "Customary practices and children with albinism in Namibia: a constitutional challenge?" In Ruppel O. C. [eds]. "Children's rights in Namibia". Macmillan Education Namibia pp245.

Despite an impressive human rights catalogue for all persons in Namibia, the problem is the exact position of the rights of people with albinism in Namibia. The research sets out to investigate what exactly is the position of the rights of people with albinism under our constitutional dispensation? And are they, or should they be categorised as people with disabilities? This investigation will be done in a comparative manner to other countries, such as Tanzania and South Africa.¹⁰

1.3 Research Questions

The dissertation will attempt to answer the following main questions.

1. What is albinism? This question will look on the biological background of albinism.
2. What is the position of the rights of people with albinism under a Namibian constitutional dispensation¹¹ and the international human rights framework?
3. Is albinism a disability? And if not, should it be categorised within the disability framework.

1.4 Significance of the study

This research is aimed at investigating the position of people with albinism within a human rights discourse. Its significance can be summed up in the following;

[1] There is no adequate research done on albinism and disability in Namibia. As a result no comprehensive and detailed analytical study has been undertaken. This study intends to address the existing vacuums and adds some volume to the limited literature available on albinism in general.

[2] The study will attempt to provide the policy makers and legislatures with the necessary information on the challenges, fears, expectations and opinions of people with albinism or parents having children with albinism.

[3] The study will also provide people with albinism or parents with children or family members with albinism information on what exactly are their rights in the Namibian

¹⁰ See Chapter 4 Comparative Analysis, as to why these countries were chosen.

¹¹ The rights of people with albinism are the same as everyone else. This question however will look at the constitutional verses society's interpretation of the rights of people with albinism.

legal system. Are they equal as everyone? Are they categorised under the category of people with disabilities or vulnerable people? In case of violations of their constitutionally entrenched rights, what remedies are available? The study is therefore conducted in order to assess the likely benefits that arise out of the subject.

[4] By comparing Namibia to other countries, the study may help our government to take the example from the approaches taken by other countries and in future improve the conditions and legal considerations of people with albinism.

[5] Finally, the research will also add significantly to the knowledge of the author on the subject.¹²

1.5 Methodology

A qualitative approach was applied in the conducting of this research. A number of respondents were consulted. In order to generate primary data, open ended questions for quantitative data collection and in-depth interviews for qualitative data collection were administered.¹³ In-depth interviews were used to support the dissertation with the help from the Namibian Albino Association. Open ended questioners and interviews were used based on the individual person. Aspects considered included; language barriers, the literate/illiterate and logistical issues.

In addition, black letter law inform of statutes, court cases etc. supported by commentaries, journal articles, internet and other literature were utilised¹⁴, especially on the human rights and comparative aspects of the dissertation in chapter 3 and 4.

Working as a gender, law and social science junior researcher at the Multi-disciplinary Research Centre [MRC] under the Gender Training and Research programme [GTRP], within the Social Sciences Division [SSD], it was required of author that aspects of social sciences are also covered. These aspects may include HIV/AIDS, gender and other social issues which will be discussed in chapter 2 and 3. This is due to the fact that most of these social issues result in the violation of human rights.

1.5.1 Limitation of the study

¹² The author is also a person living with albinism.

¹³ See field notes, interview questions and questioner in annexures 1 and 2.

¹⁴ See dissertation writing guidelines faculty of law University of Namibia.

The study had the following limitations:

Scope - The main limitation is that very little literature is available on albinism, disability and the law. Not much has been done on it, other than newspaper articles, journals and internet sources there is not much to use in literature review. As a result this dissertation is not entirely to a large extent desktop based. Another limitation includes the fact that people with albinism do not open up to strangers easily, and they saw this research as a sensitive issue.

Logistics and resources – Due to the fact that Namibia is a big country with a highly uneven population distribution, the author was not able to hear the views of all the people with albinism in Namibia due to transportation and financial constrain.

1.5.2 Research Findings Analysis

The result that was collected or attained under the study were recorded and analysed in order to see the views of society on the issue at hand. Data was analysed with the means of the **Content analysing system**¹⁵. This is a way of data analysing done manually. It is the preferred analysing technique because it is less complicated and easy to use. There will be no specific chapter on the research findings or literature review. The findings and literature will be worked into the different chapters accordingly.

1.5.3 Research Ethics

According to the guidelines for disability research set by the National Disability Authority [NDA], “*ethics*” is defined as a matter of principled sensitivity to the rights of others.¹⁶ What is important in ethical consideration is that the researcher obtained informed consent first from the respondents. The respondents are assured of confidentiality and had the right to stop the interview whenever they wished and none were forced to answer.

¹⁵ Is a data analysis method used in the analysing of documents by coding segments as instances of feature of interest, looking at content and analysing it as per interest of the study. See Gomm Palgrave R. 2009. *Key concepts in social research methods*. Hampshire, England.

¹⁶ See National disability authority 2005. Ethics in research. Available at <http://www.nda.ie/>. Accessed on 09 October 2011.

CHAPTER 2: CONCEPTUAL FRAMEWORK ON ALBINISM

2.1 Introduction

In order to discuss the rights of people with albinism in depth, it is important to first look at what albinism is and to discuss the social issues people with albinism are faced with on the daily basis. In this chapter therefore, a closer look will be directed at what albinism is and the many social issues in society affecting the rights of people with albinism. These issues are of a wide range. They may however differ from society to society. They may include, gender stereotypes, traditional beliefs and practises, myths and taboos. These societal norms, beliefs and practises shape the way people live and treat others. It is to this regard, as pointed out earlier that, social issues and human rights go hand in hand.

2.2 Albinism: Biological Background

The term *albino*¹⁷ is commonly used in many languages all over the world. It is used to refer to a person or animal lacking colouring matter in their skin, hair or eyes.¹⁸ The term is of Latin origin 'albus', meaning white. Balthazar Tellez, a historian and missionary, coined the term albino around the 1660. He used the word to describe tribe members with this condition that he saw on the West African coast.¹⁹ The oldest records of albinism are found in Rome and Germany.²⁰

Albinism or medically known as congenital hypopigmentary disorder is a genetic condition that affects people from all races.²¹ Albinism refers to a group of inherited genetic conditions; it is passed from parents to their children. Both parents must carry an albinism gene to have a child with albinism. Parents may have normal

¹⁷ Due to the diverse cultural heritage in Namibia the following names are used to refer to people with albinism. These ranges from: *Ekihi [single]/ Omakihi [plural]*: among the Herero language. *Ekishi, ethithi, [single]/ Omakishi, omathithi*, [plural]: among the Ovambo. *Etokatoka/ litokatoka [single]/ Matokatoka/ vatokatoka [plural]*: among the Okavango people. *Otjihenyange*: among the Zemba community. *Tsirende*: in Damara Nama a native language in Namibia. See Ntinda R 2009 pp245.

¹⁸ See Merriam Webster's dictionary 2004 pp18.

¹⁹ See Beukes T. 200015230 Albinism in Namibia the sociological practice of discrimination. University of Namibia pp2.

²⁰ See Article Alley. 05th May 2010. A Short History of Albinism. Available at <http://taugeeruhassan.articlealley.com> Accessed on 12 June 2011.

²¹ See statistics for Oculocutaneous and Ocular Albinism. Available at www.thebrightesthub.com 7 July 2011. Accessed on 19 September 2011.

pigmentations but still carry the gene. There is a one in four chances at each pregnancy that the child will be born with albinism.²² There are three main types of albinisms. Namely:

- **Oculotaneous albinism;** this is a type of albinism that is a result of reduced pigmentation in the skin and eye due to a lack of the enzyme tyrosinase²³ and they have partial eyesight.²⁴
- **Oculocutaneous albinism;** This is a type of albinism as a result of a lack melanin pigmentation in the eyes, hair and skin where the enzyme tyrosinase is present, but other factors reduce the production of melanin.²⁵ These people are very sensitive to light and have no pigment. This is the most common and visible. It is the main focal area of this study.
- **Ocular albinism;** this is a type of albinism as a result of reduced melanin pigment in the eyes only. People with this condition have slightly lighter skin and hair compared with other family members.²⁶ An individual with this type of albinism lacks pigmentation in the irises and has vision problems.²⁷

Due to a lack of protection by the melanin pigment from ultraviolet rays [UVRs], people with albinism have to be careful by protecting themselves so that they are not exposed to too much sun, because they are highly prone to many different types of skin cancers.²⁸

Similarly to their hair and skin, their eyes too lack colour, their iris appears pinkish and they often have eye problems. First of all, people with albinism suffer from severe sensitivity of bright light. Secondly, they also experience cases of extreme near sightedness or farsightedness that cannot be completely corrected by glasses. They are not blind but their vision is impaired.²⁹ They sometimes demonstrate an

²² See Sullivan J. 1998. Understanding albinism. Available at www.albinismfellowship.com . Accessed on 25 July 2011.

²³ Tyrosinase is the major enzyme involved in the formation of the melanin pigment.

²⁴ See Sullivan J. 1998.

²⁵ See Sullivan J. 1998.

²⁶ Ibid Sullivan J. 1998.

²⁷ This type accounts for 10-15% of albinism cases. See statistics for Oculocutaneous and Ocular Albinism. Available at www.thebrightesthub.com 7 July 2011. Accessed on 19 September 2011.

²⁸ See statistics for Oculocutaneous and Ocular Albinism. Available at www.thebrightesthub.com 7 July 2011. Accessed on 19 September 2011.

²⁹ See Andrew Gray. What role does experience play in the development of vision? Available at <http://www.andrewgray.com/essays/vision.htm> Accessed on 10 September 2011.

involuntary back and forth or sometimes up and down movement of the eyes, called **nystagimus**. However if a person with albinism learn to use a head tilt or to turn, it will reduce this involuntary eye movement and may improve sight.³⁰

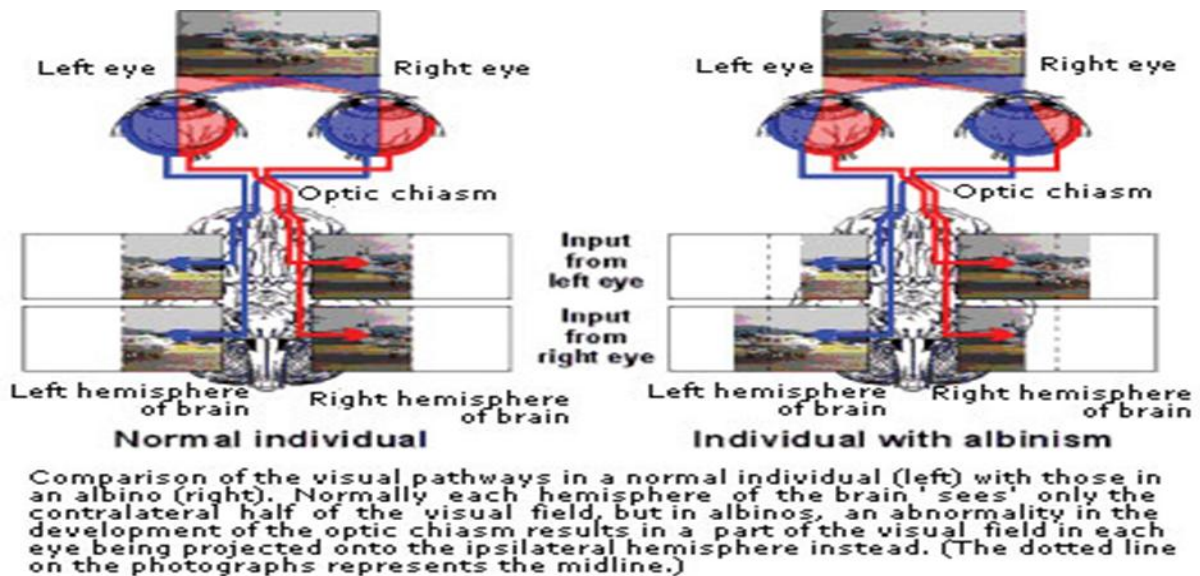


Figure 1 A comparison of the visual pathway of a person without albinism and a person with albinism³¹.

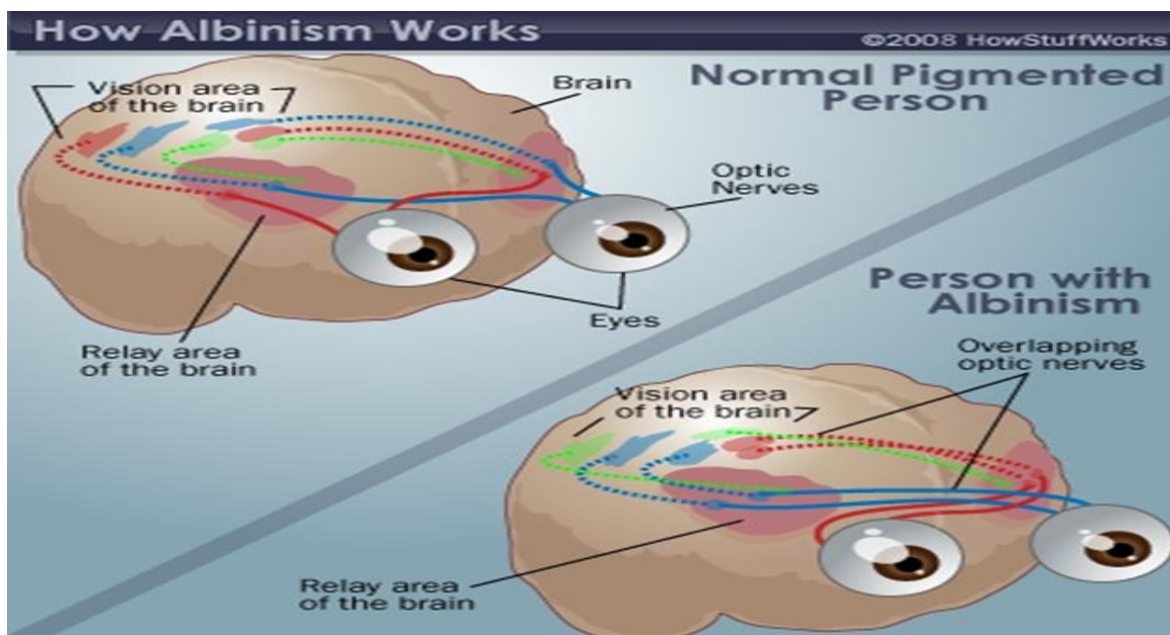


Figure 2 The nerves that connect the retina to the brain of a person without albinism and a person with albinism.³²

³⁰ See Beukes T. 200015230 Albinism in Namibia the sociological practice of discrimination. University of Namibia pp22.

³¹ See Andrew Gray 10 September 2011.

As shown by figure 1, the eyes of people with albinism do not fixate and track together. One of the major abnormalities of the eyes of people with albinism is the development of the nerves that connect the retina to the brain as shown by figure 2. These people have an unusual pattern for sending nerve signals from the eyes to the brain. The nerve connection from the eyes to the vision area of the brain is organized differently. As a result it prevents the eyes from working together properly and this causes a reduced depth perception.³³

People with albinism also experiences a condition referred to as **Strabismus**, which is a muscle imbalance within the eyes causing the person to squint and also to use each eye separately rather than together. Thus people with albinism do not have binocular vision; which is the ability to use both eyes at the same time, however most people adapt and so there is not a sense of double vision.³⁴

From the above it is evident that albinism is a very unique condition that may require special measures. However this is based on the medical definition of what albinism is. It is therefore imperative that societal views on what albinism is should also be considered.

2.3 Albinism: Views on what it is?

Many people both in Namibia and all over the world have their own views, believes or theories as to what albinism really is. These views may include the following:

2.3.1 View No 1: Albinism is a Curse or a Bewitchment

Similar to many other things in our diverse cultures, albinism is surrounded by many beliefs, superstitions and stereotypes. In some communities, it is a taboo to give birth to a child with albinism. It is believed that such a child is a result of bewitchment in the family, or the child is a curse³⁵ or it is punishment by an angry god for some

³² See Nasr S. how albinism works? Available at <http://health.howstuffworks.com/skin-care/problems/medical/albinism2.htm> . Accessed on 10 September 2011.

³³ See Beukes T. 200015230 pp24.

³⁴ See National Organisation for Albinism and Hypopigmentation NOAH. What is albinism? Available at www.albinism.org/. Accessed on 09 May 2011.

³⁵ In Jamaica people with albinism are regarded as cursed and therefore degraded. See Ntinda R. 2009 pp244.

wrong done by the family or that the woman slept with a tokolosh.³⁶ As a result, many children with albinism are either killed or abundant.³⁷

In a book of oral literature from Malawi, an old myth has been described, that also view albinism as a punishment. This myth shows that the concept of albinism has long been in existence in the Malawian culture, associated with an element of fear and negativity.³⁸

*The myth is called '**The origin of albinos**', it is a story of two people who are about to be married, but before they are lawfully wed, they have sexual intercourse. As a result they have four children born without a body and limbs, just a head. This was seen as a punishment from the Gods for the sin they have committed before they were married. The first three children were thrown into the river and eaten by the crocodiles, but the fourth child the mother insisted on keeping. She raised this child and as he grew older he spoke of his desire to be married. It was not easy for the mother to find a woman to marry 'head'. After they were married, while asleep at midnight the head broke open and out came an albino. When the wife saw that her husband now had a body and limbs, she embraced him, and she too turned into an albino. They had many albino children and they were happy, but other people kept away from them. The myth says that people with albinism today are still a punishment from the Gods for the sin that the first pair committed before they were married.³⁹*

2.3.2 View No 2: Albinism is a Good Luck Charm or a Blessing

In other parts of Africa, people with albinism are perceived as sacrificial lambs, wanted for their head or their genitals which are considered as the body's strongest parts.⁴⁰ People with albinism are killed for their parts to be used in making fetish

³⁶ A tokolosh is a malevolent spirit in Shona folklore which can be called upon to cause trouble for other people. See Baker C, Lund P, Nyathi R and Taylor J 2010. "The myths surrounding people with albinism in South Africa and Zimbabwe". Journal of African cultural studies. 22: 2 pp 172.

³⁷ See Ntinda R. 2009 pp244.

³⁸ See Stine Hellum Braathen and Benedicte Ingstad. October 2006. "Albinism in Malawi: knowledge and beliefs from an African setting". University of Oslo, Norway and SINTEF Health Research, Norway Disability and society Vol.21, no 6, pp599-611.

³⁹ Ibid Stine Hellum Braathen and Benedicte Ingstad. October 2006 pp599-611.

⁴⁰ See Ntinda R. 2009 pp244.

potions that the witchdoctors allegedly advise their clients to drink in order to obtain wealth.⁴¹ On the other hand some believe that people with albinism are a blessing from God.⁴² I lack the knowledge of whether people with albinism in Namibia are also hunted and killed for their body parts.

2.3.3 View No 3: Albinism is a contagious condition or disease⁴³

Albinism is believed by some to be a very contagious disease. If you eat, sit, sleep next to, drink from the same cup or any other physical contact with a person with albinism you will also become a person with albinism or you will smell like them or have a child with albinism.⁴⁴

2.3.4 View No 4: Albinism is a Disability

Albinism is viewed by some as a disability. This is due to the fact that people with albinism have serious eyesight problem and a skin condition that makes them prone to cancer and social stereotypes. They are not able to do certain work that involve them being in the sun. These are disabilities and people with albinism should be regarded as people with disabilities. This view is main focus of the dissertation⁴⁵.

2.3.5 View No 5: Albinism Is a sign of infidelity

Suspicious of interracial relationships may also come into play. Men tend to believe that the woman was having an affair with a white man that's why the baby looks white, these women are accused of infidelity and sometimes abundant.⁴⁶ Nyathi recalls the accusation faced by his own mother, commenting that

⁴¹ As done in east central African countries especially in Tanzania. Each part is allegedly used for in these fetishes portions, e.g. if eyes were used then you partner will never cheat on you. See Ntinda R. 2009 pp244 -245.

⁴² In some cultures, people with albinism are thought to have magical powers, or are able to tell the future. See Ntinda R. 2009 pp245.

⁴³ Sometimes the words genetic condition and disease are used inter-changeably.

⁴⁴ See Stine Hellum Braathen and Benedicte Ingstad. October 2006. "Albinism in Malawi: knowledge and beliefs from an African setting". University of Oslo, Norway and SINTEF Health Research, Norway Disability and society Vol.21, no 6, pp599-611.

⁴⁵ See Chapter 4 below.

⁴⁶ See Ntinda R pp245.

*“She was accused of infidelity and of being cursed because of her children with albinism. The consequences of this accusation by members of her husband’s family were that she suffered abuse throughout her married life”.*⁴⁷

Lund also observed that when a young boy with albinism asked his father what had caused his albinism, the father replied that his mother’s people were responsible.⁴⁸

2.3.6 View No 6: Albinism is a cure to HIV/AIDS

In addition to the beliefs which have long surrounded people with albinism, a number of modern myths also exist. For instance in Zimbabwe, it is believed that having sex with a woman with albinism will cure a man of HIV.⁴⁹ And as result many woman with albinism have been raped. This believe is however very wrong. Raping a woman with albinism will not cure a man of his HIV statutes; this practise just spreads the disease.⁵⁰ A man with albinism in Zimbabwe acknowledges this

*“To be an albino is a terrible thing, but to be a girl albino is the worst of all. You know that the AIDS pandemic, they say the cure is to sleep with a virgin, but if you sleep with a virgin who is albino then even better. There are many rapes; because people with albinism are so hidden already they do not come forward, and now because of this we also are dying of AIDS.”*⁵¹

2.4 From a Sociological Stand Point

From the views above on what albinism is, it is evident that albinism is a debilitating condition that causes embarrassment and stigma. This is due to the very visible difference of a person with albinism. It has a profound effect on the personal identity of that individual.⁵² A young man with albinism in Bulawayo comments that,

⁴⁷ See Baker C. et al October 2011 pp172.

⁴⁸ See Phitalis Were Masakhwe. 2009. Dispelling Africa’s myths about albinism Urgent measures needed to protect people with albinism. 2009-09-10, Issue 447. Available at www.pambazuka.org. Accessed on 19 May 2011.

⁴⁹ See Ntinda R pp245.

⁵⁰ Ibid Ntinda R pp245.

⁵¹ See Baker C. et al October 2010 pp176.

⁵² Ibid Baker C. et al October 2010 pp176.

*“Nowhere can an albino be his self socially, at work, at school, at home, nowhere. It is a living nightmare.”*⁵³

This is due to the problematic whiteness of the body of the person with albinism. In his description of people out walking in the sun, Owen Sheers stated that:⁵⁴

*On the first street, department-store dummies look out onto the lunchtime workers sitting in the sun. White dummies looking onto black people (....) albinos, walking down the street in wide brimmed hats to protect their sensitive skin, blinking the fair lashes of their pink rimmed eyes. Unlucky, a rixi taxi driver tells me. I would not like to be one he laughs ‘You are black but you are white, so you belong nowhere. Nobody likes you.’*⁵⁵

One of the most common misconceptions about albinism is the notion that is contagious. Like people with leprosy or physical disabilities, people with albinism were and are segregated in the fear their disease will spread.⁵⁶ Some people with albinism even find their own family members keeping them at a distance.⁵⁷

The notion of contagious, lead to a development of number of different actions to avoid ‘catching’ the condition. For instance, spitting in response to seeing a person with albinism as a way of warding off contagion.⁵⁸ The immediate consequence of such beliefs or actions, is the social isolation of people with albinism, citing reclusive behaviour, withdrawal from society and inferiority complexes among others.⁵⁹ This makes them vulnerable to human rights violations.

The second common misconception is the language used with regard to people with albinism. Language can shape ideas and create reality.⁶⁰ Some people are comfortable with the word and prefer being called an albino. However the word

⁵³ Ibid Baker C. et al October 2010 pp173.

⁵⁴ Ibid Baker C. et al October 2010 pp173.

⁵⁵ Ibid Baker C. et al October 2010 pp173.

⁵⁶ See Baker C. et al October 2010 pp174.

⁵⁷ Ibid Baker C. et al October 2010 pp174.

⁵⁸ In Zimbabwe an albinism activist reports that pregnant woman spit on their stomachs when they meet a person with albinism in the belief that the act will prevent their unborn child from being born with albinism. In the Venda region of South Africa, splitting inside your shirt is suggested as a way of warding off contagion, as is holding your hair and turning away from the person with albinism. Ibid Baker C. et al October 2010 pp174.

⁵⁹ Ibid Baker C. et al October 2010 pp174.

⁶⁰ See Waugh J. 09 May 2011.

“albino” is sometimes used hurtfully. Many feel it is dehumanizing to refer to a person in terms of a condition. Although slightly cumbersome, the terms “person with albinism” and “people with albinism” put the person first and the condition second⁶¹ placing emphases on the person not the condition. Teasing and name calling⁶² are other ways in which language can be very dehumanizing.⁶³

The media, including literature and film, have also contributed to stereotypes of albinism by the character which albinism is often portrayed as villainous, deviant, supernatural or sadistic.⁶⁴ This makes it difficult for the public to know what is true and untrue about albinism.⁶⁵

As a result of this embarrassment and stigma, People with albinism are at risk of isolation. Social stigmatization can occur, especially within communities of colour, where the race or paternity of a person with albinism may be questioned⁶⁶ and their rights are violated, because they are often viewed “differently” by people in the society.⁶⁷

2.5 Conclusion

In conclusion, albinism is a very unique condition which is associated with social and traditional beliefs and practices that are very wrong and can be very harmful to both the emotional, physical and psychological state of people with albinism, resulting in the violation of their human rights. These practises and beliefs should be done away

⁶¹ “We do not like to be called albinos. We are not a separate category of humanity. We are simply people with albinism” says Nomasonto Mazibuko [founder of the albinism society of South Africa] see Beukes T. pp1.

⁶² **Nambalakata, Nghixupulasha, Ndoumbekutu and Neyoo lile** which means long tooth. These terms are derogative Oshiwambo terms, they originating from folktales. In folk tales, people with albinism are portrayed to be men eaters. See Ntinda R. 2009 pp245.

⁶³ See Waugh J. Social and economic aspects of albinism. Available at <http://www.tsbvi.edu>. reprinted with permission from the National Organisation for albinism and Hypopigmentation (NOAH). Accessed 09 May 2011.

⁶⁴ For example, Silas, the evil monk in The Da Vinci Code, or the nefarious blond twins in the matrix reloaded. See Ballantyne C. 18 February 2009. What causes albinism? Available at www.scientificamerican.com accessed on 7 July 2011.

⁶⁵ Some news reports and encyclopaedia articles have included false or incomplete information about albinism. See Sullivan J. 1998. Understanding albinism. Available at www.albinismfellowship.com . Accessed on 25 July 2011.

⁶⁶ See The National Organisation for Albinism and Hypopigmentation. What is albinism? Available at <http://www.albinism.org/html>. Accessed on 09 May 2011.

⁶⁷ Fortunately, there are people with albinism who gained fame by showcasing their talents to the public. See statistics for Oculocutaneous and Ocular Albinism. Available at www.thebrightesthub.com 7 July 2011. Accessed on 19 September 2011.

with in order to fully protect the rights of these people with albinism.⁶⁸ In order for the rights people with albinism to be protected, it is important that they are specifically pointed out as a disability group within the disability framework.

⁶⁸ See the albinism fellowship advice and support group. Available at www.albinism.org.uk accessed on 05 June 2011. See also Ntinda R 2009 pp252.

CHAPTER 3: PLACING ALBINISM WITHIN A HUMAN RIGHTS DISCOURSE

3.1 Introduction

Is disability a human rights issue and will it improve the situation of people with albinism? Looking at albinism from a human rights framework we argue that if people with albinism are specifically pointed or grouped as a disability, their rights will be better protected. This will be substantiated by looking at various instrument of protection to enhance the argument. In this chapter,

3.2 Albinism and Disability

3.2.1 Disability: A closer look

Disability is a complex phenomenon with no static state. It can be conceptualized in many ways, including at the level of the body, the person or the society.⁶⁹ Disability is a global phenomenon and does not only happen to a minority of the population. As a result, what is regarded as a disability depends to a greater extent on individual, societal, cultural and medical perceptions of what is normal and this depend very much on the point of comparison⁷⁰. This often happens because there is a comparator. Due to the obviousness of oculocutaneous albinism, the comparator is the person not living with albinism, regardless of their colour.

The objective of locating albinism with a general human rights paradigm and specifically arguing that it be regarded as a disability that requires increased protection; is a conundrum. In order to establish whether or not it can be, there is a need for a closer look at the defined framework of disability.

The most commonly cited definition of disability is that of the World Health Organization [WHO]⁷¹, which draws a three-fold distinction between impairment, disability and handicap.

- *'An impairment is defined as any loss or abnormality of psychological, physiological or anatomical structure or function,*

⁶⁹ See Haihambo C. K. Student Number: 3625-906-3. 2010. *Inclusive Education: Challenges of Students with Disabilities in Institutions of Higher Education in Namibia*. Submitted in accordance with the requirements for the degree of doctor of education in the subject of inclusive education at the University of South Africa. Promoter: Professor Hugo J. A. pp4.

⁷⁰ See Degener T. et al Human rights and disabled persons 1995 pp13.

⁷¹ This was laid out in 1976 by the world health organisation.

- **a disability** is defined as any restriction or lack that results from an impairment of the ability to perform an activity in the manner or within the range considered normal for a human being, while
- **A handicap** is defined as a disadvantage for a given individual, resulting from impairment or a disability, which prevents the fulfilment of a role that is considered normal for that individual'.⁷²

However according to activists in the disability movement, the World Health Organization confused between the terms 'Disability' and 'Impairment'. They maintain that

*"Impairment refers to physical or cognitive limitations that an individual may have, such as the inability to walk or speak, whereas, disability refers to socially imposed restrictions, that is, the system of social constraints that are imposed on those with impairments by the discriminatory practices of society".*⁷³

Based on this definition of disability, albinism should be categorised as a disability. However, according to the United Nations Standard Rules on the equalization of Opportunities for Persons with Disabilities;

*"The term "Disability" summarizes a great number of different functional limitations occurring in any population, in any country of the world. While the term "Handicap" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others; it describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasize the focus on shortcomings in the environment and in many organized activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms."*⁷⁴

⁷² See The UN definition of disability. Available at <http://www.aarogya.com> Accessed on 02 October 2011. This applies to people with albinism see chapter 2 on the sociological stand point.

⁷³ Ibid The UN definition of disability. 02 October 2011.

⁷⁴ See Hill country disable group. What is disability? Available at <http://hcdg.org>. accessed on 16 October 2011.

It is therefore evident that there are many definitions on what “disability” is. As a result the World Health Organization (WHO) moved toward a new international classification system, namely the International Classification of Functioning, Disability and Health (ICF). This new classification emphasizes functional status over diagnoses in that it looks at the functional abilities of the person instead of just the medical diagnoses. The new system focuses on analysing the relationship between capacity and performance. If capacity is greater than performance then that gap should be addressed by removing barriers.⁷⁵ The current terminology defining disability recognises the necessity to address both individual needs and the shortcomings or perceptions of society.⁷⁶ WHO now defines disability as a contextual variable, dynamic over time and in relation to circumstances. One is more or less disabled based on the interaction between the person and the individual, institutional and social environments.⁷⁷

Within Namibia however, the term disability refers to or is associated with an individualistic and impairment-base understanding.⁷⁸ Is based on the traditional definition of disability. According to the National Disability Council Act “disability” is defined to means

*“A physical, mental or sensory impairment that alone, or in combination with social or environmental barriers, affects the ability of the person concerned to take part in educational, vocational, or recreational activities”.*⁷⁹

This definition is not quite in accordance with the WHO’s new definition on what disability refers to. The policy makers need to re-work the Namibian disability so as to conform to the international standard and move away from antiquity to new developments.

3.2.2 Placing Albinism as a Disability within the legal framework

When placing albinism as a disability, neither the general public nor those with the condition agree whether or not to identify albinism as a disability. This ambiguity

⁷⁵ See Scott. October 8, 2007 10:21 PM. The World Health Organization's New Definition of Disability. Available at www.rollinggrains.com. Accessed on 11 October 2011.

⁷⁶ See Hill country disable group. 16 October 2011

⁷⁷ See Scott October 8, 2007.

⁷⁸ See the National Disability Council Act, No. 26 of 2004.

⁷⁹ See Section 1 of the National Disability Council Act, No. 26 of 2004.

creates a problem in the language used to talk about albinism.⁸⁰ It also makes it difficult for those with albinism to identify themselves as a group.⁸¹ For many reasons albinism can be seen as a very unique condition. Its uniqueness, however, has led to separation and isolation.⁸² There are a few reasons as to whether albinism is a disability or not.

The reasons as to why some argue that albinism is a disability; is based on firstly on the skin condition that lacks pigmentation and are prone to cancer. This limits their ability to engage in certain activities.

The second reason is based on their visual impairment⁸³ that people with albinism suffer and in this light, people with albinism should fall within the category of those with a visual disability.⁸⁴ As shown by these statistics in table 1 below, visual impairment is very high and amounts to 35% of all disability statistics in Namibia. Could it be maybe because people with albinism are included? This is however, not quite clear.

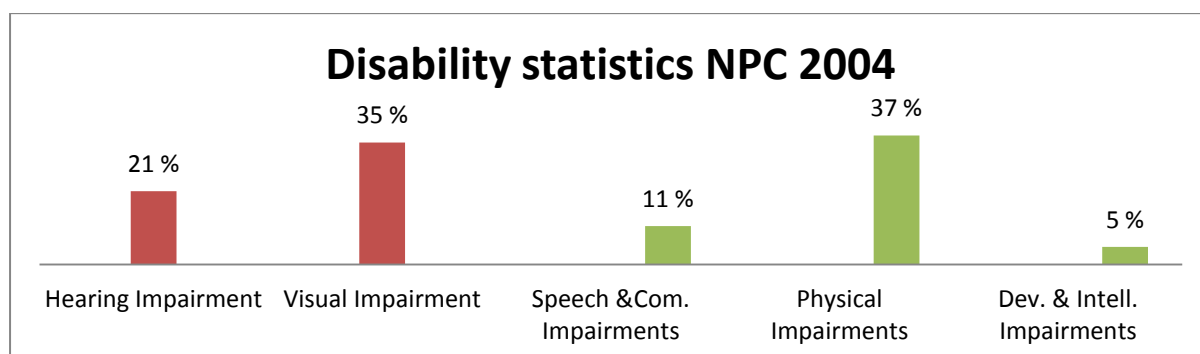


Figure 3 Disability statistics in Namibia 2004.⁸⁵

The identification of albinism with regard to vision as a disability is complicated by the concept of legal blindness. Legal blindness is defined by a visual acuity of 20/200 or higher in the better eye with correction. However by this standard some with

⁸⁰ See Waugh J. Social and economic aspects of albinism. Available at <http://www.tsbvi.edu>. reprinted with permission from the National Organisation for albinism and Hypopigmentation (NOAH). Accessed 09 May 2011.

⁸¹ See annexure 3 were Dr Libertine Amadhila specifically stated that, even if they require special treatment with regard to health, people with albinism are not a distinctive group.

⁸² See Waugh J. Accessed 09 May 2011.

⁸³ As laid out in Chapter 2 that people with albinism have eyesight problems which cannot be corrected with eyeglasses. They are either too farsighted or too near-sighted.

⁸⁴ See Waugh J. Accessed 09 May 2011.

⁸⁵ See Haihambo C. K. Student Number: 3625-906-3. pp4.

albinism fit the legal category of visual impairment and some do not.⁸⁶ This leads to the question “if some people with albinism fall within the legal blindness category and others do not, should they be consider visually impaired? The answer is yes they should. However, does such a question matter? Regardless of whether or not some people with albinism experience extreme farsightedness while others experience extreme near sightedness, the fact is that they are visually impaired and this impairment cannot be corrected by glasses. There are various optical aids that are helpful to people with albinism. It should be stressed however that “*they are only helpful*”, they cannot correct the visual impairment. The choice of an optical aid should depend on how a person uses his or her eyes in their daily activities.⁸⁷

However, according to EgonKochonke, Ambassador of Germany to Namibia, albinism is not a handicap.⁸⁸ Beukes⁸⁹ also pointed out that albinism is not a disability in general.⁹⁰ However, she contradicted herself by saying that albinism is a disability due to the vision of people with albinism.⁹¹

Notionally, there is an assumption that people with disabilities have a poor quality of life, and are therefore exposed to a great deal of stigmatization and discrimination. Consequent to this notion, people with albinism have difficulties with that type of stereotyping. In fact, it may be seen as reason for increased discrimination and stigmatation⁹². This is due to the fact that social attitudes toward albinism are often similar to those experienced by other disability and minority groups. These attitudes include a lack of understanding, fear of the unknown, and prejudice based on

⁸⁶ See Waugh J. Accessed 09 May 2011.

⁸⁷ Some people do well using bifocals which have a strong reading lens, prescription reading glasses, or contact lenses. Other use hand-held magnifiers or special small telescopes and some prefer to use screen magnification products on computers or software which converts what is displayed on the computer into speech. Some use bioptic glasses which have a small telescopes mounted on, in or behind their regular lenses, so that one can look through either the regular lens or telescope. See Waugh J. Accessed 09 May 2011.

⁸⁸ See Economist. 21 April 2011. Albinism not a handicap-German Ambassador. Available at www.allAfrica.com. Accessed on 7 July 2011.

⁸⁹ See Beukes pp30.

⁹⁰ Ibid Beukes pp31.

⁹¹ Ibid Beukes pp16.

⁹² **Stigmatation or stigma** can be defined as a special kind of relationship between attribute and stereotype. It is a social process under constant change and that it is constructed and must be understood, through interaction. Interaction differs in different settings and so does stigma. Stigma as a social process operates in relation to different and to social and structural inequalities”. See Waugh J. Accessed 09 May 2011.

appearance of people with albinism.⁹³ Discrimination and stigma can therefore only be addressed through a human rights based approach.

3.3 Placing Albinism as a Disability within the Human Rights Discourse

The placing of albinism as a disability within the human rights discourse will be divided into two main levels. Firstly, the international and regional human rights framework and secondly, the national level with regard to the approaches, implementation and protection of human rights of people with disabilities.

3.3.1 Albinism within the International and Regional Human Rights Framework

In the past few decades efforts have been made on the international agenda to improve the situation for people with disabilities.⁹⁴ These efforts range from the International year of Disabled persons in 1981, the world programme of action concerning disabled persons in 1982, and the development of the Standard Rules on the equalization of opportunities for persons with disabilities⁹⁵. In addition, there are international agreements and instruments in place that make provision for the rights of people with disabilities.⁹⁶ These are as follows:

❖ The Universal Declaration of Human Rights [UDHR].⁹⁷

The Universal Declaration of Human Rights was adopted by the United Nations General Assembly on the 10th of December 1948. The Charter serves as a road map to guarantee the rights of every individual everywhere.⁹⁸ According to Article 1⁹⁹

“All human beings are born free and equal in Dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood”.

⁹³ See Waugh J. Accessed 09 May 2011.

⁹⁴ See Baker C. et al 2010 pp175.

⁹⁵ Ibid Baker C. et al 2010 pp175.

⁹⁶ See Dausab Y. 2009. *International law vis-à-vis municipal law: an appraisal of article 144 of the Namibian constitution from a human rights perspective*. Bosl A et al editors'. *Constitutional democracy in Namibia: a critical analysis after two decades*. Macmillan Namibia p271.

⁹⁷ Also referred to as the UN Charter on human rights.

⁹⁸ See The Universal Declaration of Human Rights. Available at <http://www.un.org>. accessed on 25 October 2011.

⁹⁹ Ibid The Universal Declaration of Human Rights [1948].

Article 7¹⁰⁰ further states that

“All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination”.

People with disabilities including people with albinism are equal to, and form part of the human family. Therefore they are entitled to equal protection provided for in this charter.

❖ Convention on the Rights of Persons with Disabilities

Nearly half a century later,¹⁰¹ the international community came up with the Convention on the Rights of Persons with Disabilities in 2006 in order to specifically provide for the rights of people with disabilities. Article 1 state that the purpose of this Convention is

“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.”

In terms of its preamble, persons with disabilities in this case people with albinism should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.¹⁰² The convention is further concerned about the difficult conditions faced by these people who are subject to multiple or aggravated forms of discrimination, recognizing that any discrimination against any person on the basis of disability¹⁰³ is a violation of the inherent dignity and worth of the human person.¹⁰⁴

The convention therefore defines "Discrimination on the basis of disability" to mean

“any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or

¹⁰⁰ See The Universal Declaration of Human Rights [1948].

¹⁰¹ About 58 years to be specific.

¹⁰² See The Convention on the Rights of Persons with Disabilities [2006].

¹⁰³ For example on the bases of the skin and eye condition of people with albinism.

¹⁰⁴ Ibid the Convention on the Rights of Persons with Disabilities [2006]. Article 5.

*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. It includes all forms of discrimination”.*¹⁰⁵

It is evident that the most important human right is the elimination of all forms of discrimination in line with article 2[1] International Covenant on Civil and Political Rights [ICCPR]¹⁰⁶, article 2[2] of the Convention on the Elimination of all forms of Racial Discrimination [ICERD]¹⁰⁷ and article 7 of the Universal Declaration of Human Rights [UDHR]¹⁰⁸. Therefore once people with albinism are placed within the disability framework, their rights will be better protected.

❖ The African Charter of Human and People’s Rights [ACHPR]

Within the borders of the African continent, after most of the African states gained independence from their colonial masters, African leaders came up with a bill of rights to promote and protect the human rights of people within the African horizon. This bill of rights was called the African Charter on Human and Peoples’ Rights.¹⁰⁹ It is also referred to as the Banjul Charter. It was adopted by the Assembly of Heads of States and Governments of the OAU in 1981 and entered into force five years later.¹¹⁰

According to Article 2 of the Charter, one of its goals is the elimination of all forms of discrimination and to ensure equality among all human beings.¹¹¹ Furthermore, Article 19 provides that,

*“All peoples shall be equal; they shall enjoy the same respect and shall have the same rights. Nothing shall justify the domination of a people by another.”*¹¹²

¹⁰⁵ See Article 2 on definitions.

¹⁰⁶ See the International Covenant on Civil and Political Rights [1966].

¹⁰⁷ See the Convention on the Elimination of all forms of Racial Discrimination [1969].

¹⁰⁸ See The Universal Declaration of Human Rights [1948].

¹⁰⁹ See the African Charter on Human and Peoples’ Rights [1986].

¹¹⁰ See Pamphlet No. 6 of the UN Guide for Minorities Minority Rights Under The African Charter On Human And Peoples' Rights.

¹¹¹ See the African Charter on Human and Peoples’ Rights [1986].

¹¹² Pamphlet No. 6 of the UN Guide for Minorities Minority Rights Under The African Charter On Human And Peoples' Rights.

The term “domination” is not defined; however allegations of "domination" have been dealt with under the non-discrimination provision in Article 2.¹¹³ The charter couples non-discrimination with the duty of mutual respect and tolerance for all fellow beings¹¹⁴ by providing that

*“Every individual shall have the duty to respect and consider his fellow beings without discrimination, and to maintain relations aimed at promoting, safeguarding and reinforcing mutual respect and tolerance.”*¹¹⁵

Therefore people with albinism have a right to be respected as human beings without discrimination, they should be provided with special measures of protection as provided for in Article 18[4] of the Charter that states that,

*“Disable [people with disabilities] shall have the right to special measures of protection in keeping with their physical and moral needs.”*¹¹⁶

At the 48th Ordinary Session of the African Commission on Human and People's Rights (ACHPR) in Banjul it was warned that efforts to protect the rights of people with disabilities could become meaningless unless all African nations put their hands on deck and agree to an inclusive Disability Protocol.¹¹⁷ This warning did not fall on deaf ears, currently there is a draft in place on the rights of people with disabilities in Africa. This draft protocol should provide as to what is considered as disabilities, the rights of people with disabilities and remedies in case of violation. Albinism should also be included as a disability in this protocol.

In relation to the above, it is evident that a norm of non-discrimination features in both the UN Charter, the Convention on the rights of people with disabilities and the African Charter¹¹⁸. In terms of these human rights instruments, states are obliged, inter alia, to remove the stigma associated to people with albinism. The vulnerability

¹¹³ Ibid Pamphlet No. 6.

¹¹⁴ See Article 28. See Hubbard D. 2009. *The paradigm of equality in the Namibian constitution: concepts, contours and concerns*. Bosl A et al editors'. *Constitutional democracy in Namibia: a critical analysis after two decades*. Macmillan Namibia pp244.

¹¹⁵ See Pamphlet No. 6 of the UN Guide for Minorities Minority Rights Under The African Charter On Human And Peoples' Rights.

¹¹⁶ Ibid Pamphlet No 6.

¹¹⁷ See Call for an inclusive disability protocol in Africa Sunday, 21 November 2010 00:46 By JollofNews Correspondent. Available at www.jollofnews.com accessed 23 September 2011.

¹¹⁸ See Article 2[1] of the UN Convention and article 3 of the African Charter.

of these people to stigma and discrimination should be the source of various special provisions aimed at preventing their mal-treatment.¹¹⁹

However, even if Africa has human rights laws in place, Africa is still far from being a beacon of human rights conduct due to a lack of knowledge and information and it prevents African people from claiming and exercising their human rights.¹²⁰ These barriers should therefore be removed in order for the rights of people with albinism and people with disabilities in general to be protected.

3.3.2 Albinism within the National Human Rights Framework

Namibia has a physical landscape that covers 824 292 square kilometres housing a population of 2.04 million¹²¹ in terms of the 2001 Population and Housing Census, approximately 5% of Namibians have a disability.¹²² In an attempt to make provisions for the citizens with disabilities, Namibia rectified a number of international treaties and agreements, such as the Continental Plan of Action concerning People with Disabilities; the signature and subsequent ratification during 2007 of the UN Convention on the Rights of People with Disabilities¹²³ amongst others.

By acceding or ratifying these international instruments, Namibia is liable to ensure that they are effectively implemented in the municipal laws¹²⁴ Within Namibia the implementation of rights basically refers to the promotion and protection of human rights at the national level. In order for the state to protect and guarantee the rights of individuals and to create an atmosphere conducive to both the individuals and society as a whole, the following statutes and other legal provisions have been put in place.

❖ The Namibian Constitution

¹¹⁹ See Horn N. 2010. Human rights education in Africa. Bosl A et al editors. *Human rights in Africa: legal perspective on their protection and promotion*. pp60

¹²⁰ Ibid Horn N. 2010 pp60.

¹²¹ See Haihambo 2010 pp4.

¹²² See Haihambo C. K. and Lightfoot E. 2010. Cultural beliefs regarding people with disabilities in Namibia: implications for the inclusion of people with disabilities. *International journal of special education*. Vol 25 No 3.

¹²³ See the Republic of Namibia Speech By Dr Richard Nchabi Kamwi, MP Minister of Health and Social Services During the Opening of the Workshop to Sensitize Namibian Parliamentarians on Disability as Human rights, Social and Development issue 22 October 2008

¹²⁴ See Dausab Y. pp262.

The Namibian Constitution¹²⁵ came in force on the independence day of Namibia, the 21st March 1990. In terms of its preamble the constitution

*“Proclaims the equal and inalienable rights of all members of the human family, in a democratic society where the government is responsible to the people”.*¹²⁶

Chapter 3 contains entrenched fundamental rights and freedoms which are protected and enforceable in terms of articles 5¹²⁷ and 25[2].¹²⁸ In the conducting of the research, some respondents were of the view that the rights provided for in our Namibian law does not equally apply to people with albinism. In terms of Article 10 of the Namibian constitution it is recognised that:

[1] All persons shall be equal before the law.

[2] No person shall be discriminated against on the grounds of sex, race, colour, ethnic origin, religion, greed or social or economic status.

Even if this is a general principle, that people should enjoy their rights equally and be provided equal opportunities, it seems as this principle does not apply to people with albinism all the time. The right of people with albinism to equality and freedom from discrimination is one of the most important rights. However they are discriminated all the time. The term ‘discrimination’ should be understood to imply

“any distinction, exclusion, restriction or preference which is based on any grounds such as race, colour, sex, language, religious political or other opinion, national or social origin, property, birth or other status and which has

¹²⁵ See the Namibian Constitution Act No 1 of 1990.

¹²⁶ See Wiechers M. 2009. *The Namibian constitution: reconciling legality and legitimacy*. Bosl A et al editors’ *Constitutional democracy in Namibia: a critical analysis after two decades*. Macmillan Namibia pp54.

¹²⁷ Article 5 states that: *“The fundamental rights and freedoms enshrined in this chapter shall be respected and upheld by...all organs of the government and its agencies, and where applicable to them, by all natural and legal persons in Namibia, and shall be enforceable by the courts in the manner herein prescribed”*. See the Namibian Constitution Act No 1 of 1990.

¹²⁸ Article 25[2] *“aggrieved persons who claims that a fundamental right or freedom guaranteed by this constitution has been infringed or threatened shall be entitled to approach a competent court to enforce or protect such a right or freedom may approach the ombudsman to provide them with such legal assistance or advise as they require...”* See the Namibian Constitution Act No 1 of 1990.

*the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.”*¹²⁹

People with albinism in Namibia are still discriminated against on the bases of their lack of pigment.¹³⁰ This goes against the foundation behind the human rights norm. As a result of this discrimination, all the other rights are pushed aside.

This is due to a lack of understanding of albinism as a condition. It plays a significant role in the problems faced by people with albinism. For instance when seeking employment. The physical appearance and visual impairment of people with albinism influence the ways in which employers regard them.¹³¹ People with albinism find that many employers prefer to stress their limitations while overlooking their abilities. The beliefs already mentioned and practical problems faced in the workplace makes it very difficult for many people with albinism to find work.¹³² If this trend continues, people with albinism will largely be unemployed on the basis of their condition.

In order to deal with discrimination faced by people with albinism, one should apply the four steps that were laid down in *Muller v President of the Republic of Namibia & Another*¹³³ in terms of article 10[2] of the Namibian constitution.

i. Whether there exist a difference between people or categories of people

The difference is the skin condition due to a lack of pigmentation and the extreme eyesight problem experienced by people with albinism. It should however be pointed out that, in the case of albinism, colour will referred to “pigment”. This is due to the fact that in Namibia, discrimination is based on colour which usually means black, white and coloured people. This connotation of what colour means in Namibia is as a result of the colonial and apartheid era.

ii. Whether such differentiation is based on one of the enumerated grounds set in the sub article

¹²⁹ See Implementation handbook for Convention on the Rights of the Child. 2007 UNICEF pp17.

¹³⁰ See Ntinda R 2009 pp249.

¹³¹ See Baker C. et al 2010 pp175.

¹³² Ibid Baker C. et al 2010 pp175.

¹³³ 1999 NR 190[SC]. See Hubbard D. 2009. The paradigm of equality in the Namibian constitution: concepts, contours and concerns. Bosl A et al editors'. Constitutional democracy in Namibia: a critical analysis after two decades. Macmillan Namibia p228.

It is based on pigmentation which falls under the ground of colour.¹³⁴ This is due to the fact that the discrimination is based on the fact that people with albinism lack pigment in their skin,¹³⁵ their colour looks different from others and as a result are ridiculed and discriminated.

iii. Whether such differentiation amounts to discrimination against such people or categories of people

Due to the lack of pigment and extremely poor eyesight people are teased, isolated, killed at birth, abundant and discriminated against in employment and education. Their rights are violated daily.

iv. Once it is determined that the differentiation amounts to discrimination, it is unconstitutional unless it is covered by the provisions of article 23.

The court in this case held further that, an element of unjust and unfair treatment was inherent in the meaning of the word ‘discriminate’, a court should look at among others....the impact of the discrimination on the victim...and whether the discrimination had the effect of impairing the victim’s human dignity.¹³⁶ This is in line with Article 8[1] of the Namibian constitution that states that the dignity of all persons shall be inviolable, and [2][b] no one shall be subjected to torture or to cruel, inhuman or degrading treatment...¹³⁷ People with albinism have a right to be protected against torture and inhuman degrading treatment that might surface as a result of discrimination.¹³⁸

Furthermore, in the Fourie case¹³⁹ it was concluded that an egalitarian society “embraces everyone and accepts people for who they are”, saying that equality

¹³⁴ This argument is based on pigmentation and not colour as per apartheid definition of what colour may mean.

¹³⁵ See Chapter 2 what albinism is and the misconceptions surrounding this condition.

¹³⁶ See Hubbard D 2009 pp228.

¹³⁷ See *Exparte Attorney General Namibia: in re corporal punishment by organs of state* 1991 NR 178[SC] 1991 [3] SA 76 [Nms], see also *S v Tcoeb* 1996 [1] SACR 390 [Nms], *S v Likuwa* 199 [2] SACR 44 [Nm] and *Namundjepo and Others v Commanding officer, Windhoek prison and Another* 2000 [6] BCLR 671 [NmS] see also the Namibian Children Act No 33 of 1960.

¹³⁸ See Chapter 2, as pointed out in the sociological stand point, discrimination experienced by people with albinism affects them both severely.

¹³⁹ See *Minister of Home Affairs & Another v Fourie & Another* 2006 [1] SA 524 [CC].

means “equal concern and respect across difference” rather than “the elimination or suppression of difference”:¹⁴⁰

“At the very least, equality affirms that difference should not be the bases of exclusion, marginalization and stigma. At best it celebrates the vitality that difference brings to any society... the constitution thus acknowledges the variability of human beings [genetics and socio-culture], affirms the right to be different.....at issue is the need to affirm the very character of our society as one based on tolerance and mutual respect. The test of tolerance is not how one finds space for people with whom, and a practice with which one feels comfortable, but how one accommodates the expression of what is comforting.”

Finally, people with albinism have a right to think for themselves and to expression of their views and needs as guaranteed by article 21 of the Namibian constitution. They have a right to be heard and their views to be taken seriously. In order to know what exactly is in the best interest of people with albinism, it is only logical to listen them. In addition they have a right to participate in the decision making processes, that maybe relevant in their lives, and to influence decision taken on their behalf, within the family setup and the community”.¹⁴¹

❖ The National policy on disability 2004¹⁴²

In 1997, a national policy on disability was formulated and adopted by the cabinet¹⁴³ in order to accept the principles of participation, integration and equalisation of opportunities, defined by the United Nations in the World Programme of Action Concerning Disabled Persons and The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.¹⁴⁴ These principles served as leading guidelines and also form the basis for the implementation of the National Policy on Disability.¹⁴⁵ The Namibian government expresses its focus on the abilities and

¹⁴⁰ See Hubbard D 2009 pp228.

¹⁴¹ See Article 12 on the Convention on the Rights of the Child [1989].

¹⁴² See the Schedule of the National disability Council Act 26 of 2004.

¹⁴³ See Haihambo 2010 pp7.

¹⁴⁴ See National Disability Council Act 26 of 2004 Schedule National Policy on Disability.

¹⁴⁵ The National Policy also represents the policy referred to in Article 2 of ILO Convention No. 159 on the Vocational Rehabilitation and Employment of Disabled Persons. Ibid National Disability Council Act 26 of 2004 Schedule National Policy on Disability.

potential of people with disabilities to be full and active members of our society who as equal citizens should be able to contribute to national development at every level they may choose, focusing not on their disabilities, but instead on their abilities. This commitment to people with disabilities translates to provide equal education and employment opportunities, to ensure that we built environments, including the public transport system, information, health services are accessible to all.¹⁴⁶

This policy really made provision for issues in relation to people with disability. It only lacks specific indications or outline of the different types of disabilities within Namibia. As a result of this lack, one cannot make out whether albinism falls within this policy as a disability.

❖ National disability council Act No 26 of 2004

The act expressly points out that persons with disabilities do not form a uniform group of people all needing the same assistance. Therefore, definitions and classifications should not have the effect of separating or excluding them from society, but point to their individual needs and to ways in which they can gain access to services to enable them to fully participate in society.¹⁴⁷ The Namibian government has ensured the development and supply of support services for disabled people in order to minimise the consequences of the disability and to increase their level of independence¹⁴⁸ by paving the way for persons with disabilities to be included at all levels of the Namibian society.

With the establishment of the National Disability Council, it meant that line Ministries would be required to report annually to the Council on activities related to disability programs.¹⁴⁹ Programs, at whatever level that are aimed at social, economic and political development will include, proportionally at least, people with disabilities. This will increase their visibility at all levels from decision making to implementation.

¹⁴⁶ See Speech By Dr Richard Nchabi Kamwi 22 October 2008.

¹⁴⁷ See National Disability Council Act 26 of 2004 Schedule National Policy on Disability.

¹⁴⁸ See National Disability Council Act 26 of 2004 Schedule National Policy on Disability.

¹⁴⁹ See the Republic of Namibia Speech By Dr Richard Nchabi Kamwi, MP Minister of Health and Social Services During the Opening of the Workshop to Sensitize Namibian Parliamentarians on Disability as Human rights, Social and Development issue 22 October 2008.

Monitoring and evaluation is crucial in order to ensure that their needs and interests are addressed on an equal basis with the rest of Society.¹⁵⁰

In addition, according to section 16(3)¹⁵¹ of the Namibia Disability Council Act, the Council may run programmes or conduct campaigns to inform the public to raise the awareness of the public concerning an issue relating to disability. Some of the people with albinism are against the idea of the public being educated about them and their needs, because they believe this puts them in the open and so they will be discriminated against more than before. This shows that some of the roles provided for in this act are not welcomed by everyone. In contrast however, an educational, human rights and development approach to disability would face a better chance of creating equal opportunities and do away with discrimination.¹⁵²

❖ The policy of Education for All

At independence in 1990, Namibia adopted the policy of Education for All in accordance to Article 20 of the Namibian Constitution, “*which states that all persons shall have the right to education.*”¹⁵³ This is also in accordance to the Jomtien Conference that states that

*“Every person, shall be able to benefit from educational opportunities designed to meet their basic needs. This constitutes a common and universal human responsibility.”*¹⁵⁴

The government therefore redefined access to education to mean:

*“Providing education for, and to, all by bringing into the system learners who had been deprived of educational opportunities, through eradicating physical and psychological barriers that hinder learners from attending school.”*¹⁵⁵

Efforts to implement this policy of education for all, led to the formulation of the National Policy Guidelines for Educationally Marginalized Children (2002) and recently the formulation of the National Policy on Inclusive Education [2009] provide

¹⁵⁰ See Speech By Dr Richard Nchabi Kamwi 22 October 2008.

¹⁵¹ See the Namibia Disability Council Act 26 of 2004.

¹⁵² See National Disability Council Act 26 of 2004 Schedule National Policy on Disability.

¹⁵³ See Haihambo pp8.

¹⁵⁴ Ibid Haihambo pp8.

¹⁵⁵ Ibid Haihambo pp9.

evidence of the prioritization of the education of children with disabilities.¹⁵⁶ The National Federation for Persons with Disabilities in Namibia (NFPDN) has also served as a pressure group for students with disabilities to gain access to education.¹⁵⁷

Regardless of the above, people with albinism still face challenges. Firstly, people with albinism in schools are neglected and suffer at the hands of the teachers who call them names, or just completely ignore them as they view them as a burden. This destroys the person's confidence to ask for clarity or for help if they do not understand.¹⁵⁸ In addition parents leave their children with albinism at home alone hidden in fear of what society will say. These children end up not going to school.¹⁵⁹

Secondly, as a result of poor vision, students with albinism may require longer than others to complete assignments or to do wood work or practical agricultural courses under a shade. Measures can be put in place to facilitate their learning, such as allowing them to sit in the front row of the class near the chalkboard and positioning them away from direct light entering the room.¹⁶⁰

The right to education will only apply to people with albinism ones these issues are addressed. People with albinism should be well intergraded in the available schools, as separate ones will just promote more discrimination.¹⁶¹

In addition to the above, people with albinism have a right to the enjoyment of the highest attainable standard of health. According to Dr Haihambo¹⁶² the Namibian government has made provision for free access to health in all public hospitals. The elderly, OVCs and people with disabilities are not required to pay for services if unable to.

However, a lot more need to be done. Firstly, even if the government has distributed clinics all over the country, not all with albinism have access to them, as some distances are too far for people with albinism to walk in the hot sun where transport

¹⁵⁶ Ibid Haihambo pp8-9.

¹⁵⁷ Ibid Haihambo pp8.

¹⁵⁸ See Ntinda R 2009 pp49.

¹⁵⁹ See Baker C. et al 2010 pp175.

¹⁶⁰ Ibid Baker C. et al 2010 pp175.

¹⁶¹ See Ntinda R. 2009 pp245.

¹⁶² Dr Haihambo interview on the 30 august 2011 in her office university of Namibia.

is not available. In addition the enduring beliefs surrounding albinism mean that nurses fear it is contagious and will often refuse to touch patients with albinism.¹⁶³

Secondly, the sun block lotion distributed is not always enough.¹⁶⁴ Namibia is a semi desert and as a result, the sun is very strong and the lotion provided is not a near match for it. People with albinism are therefore requesting the state and other nongovernmental organizations to maybe provide sun block with higher SPF.

Based on the above therefore it is evident that persons with disabilities are particularly vulnerable to abuse, violence, discrimination and stigmatation within the family, community and institutions. The state should ensure that measures are put in place to protect people with albinism.

However, the protection of people with albinism is only the first step, as this vulnerable group needs special protection from the state and society. This will require specific stronger protection of certain human rights as compared to those without albinism.¹⁶⁵

It is a generally belief that groups made vulnerable by social exclusion and inequality are best protected through the implementation of social, economic and cultural rights and the right to development.¹⁶⁶ This vulnerability is caused by the exclusion and marginalisation of certain groups,¹⁶⁷ thus strategies for addressing vulnerability and exclusion should include integrated, multi-sectorial and multi-disciplinary approaches, and should have the following elements among others:

- *“Be right based: this approach promotes, protects and defend the rights of the most vulnerable and marginalised as being integral to sustainable development.”¹⁶⁸*

¹⁶³ See Baker C. et al 2010 pp174.

¹⁶⁴ See Annexure 4.

¹⁶⁵ See Nowak M and Suntinger W. *The rights of disabled persons not to be subjected to torture, inhuman and degrading treatment or punishment*. In Degener T. editor. *Human rights and disabled persons* pp117.

¹⁶⁶ See Gawanas B. 2009. *The African Union concepts and implementation mechanisms relating to human rights*. Bosl A et al editors. *Human rights in Africa: legal perspective on their protection and promotion* pp149.

¹⁶⁷ Ibid Gawanas B pp149.

¹⁶⁸ Ibid Gawanas B pp159-160.

- *Focus on people's realities: this will require their active involvement and participation.*¹⁶⁹
- *Change social norms: this can be done through effective awareness raising campaigns, civic and human rights education, and the involvement of traditional and community leaders, in order to address harmful traditional practises and...inequality.*¹⁷⁰

Therefore affirmative action should come into play. Affirmative action is necessary to translate goals of equality from empty theory into concrete realities. It recognises the impact of patterns of discrimination and the way in which they disadvantage whole groups of people.¹⁷¹ It is provided for in Article 23[2] of the Namibian constitution which empowers parliament¹⁷² to enact legislation aimed at redressing the imbalances in the Namibian society arising out of discriminatory practises.¹⁷³

Within this provision however, no particular group are identified, although article 23[3] recognises the special discrimination traditionally experienced by women and people with disabilities. What about people with albinism? Since no specific group was identified, people with albinism should fall under the category of those discriminated, vulnerable and disadvantaged due to disabilities. Affirmative action should be utilised to bring about beneficial changes and the rights of people with albinism will be given the recognition it deserve.¹⁷⁴

However, affirmative action can sometimes have unintended effect on the very people whose interest it's meant to promote. In the sense that to help these people some time they have to be singled out so that they can be able to be assisted efficiently.

It should be noted that, affirmative action is a process not an end. It brings with it no guarantees. Changes to bring about equality cannot be bought about simply by the stroke of a legislative pen.¹⁷⁵ It's a temporary measure to be used until equality is

¹⁶⁹ Ibid Gawanas B pp159-160.

¹⁷⁰ Ibid Gawanas B pp159-160.

¹⁷¹ See Ntinda R 2009 pp251.

¹⁷² See article 44 of the Namibian constitution that states that the legislative power shall be vested in the national assembly...

¹⁷³ See Namibia affirmative action in employment: an assessment 2000-1004, February 2005 pp9.

¹⁷⁴ See Ntinda R 2009 pp251.

¹⁷⁵ Ibid Ntinda R 2009 pp251.

achieved. But we must be sure what we need and mean by equality, so that we know it has in fact been achieved.¹⁷⁶

3.4 Conclusion

In conclusion it is clear that the Namibian Government has committed itself to accept persons with disabilities as an integral part of its population. This is evident from the Constitution and the various international instruments which create a conducive environment that fosters the equalization of opportunities for people with disabilities.¹⁷⁷ The current policy environment must therefore be used to the benefit of people with disabilities.¹⁷⁸ Attention should be given to the national policy on disabilities with regard to the fact that, this policy does not outline the different types of disabilities it provides for. If the policy places albinism as a distinct disability group, then the rights of people with albinism can be better protected.

¹⁷⁶ Ibid Ntinda R 2009 pp251. This can be drawn in formal or substantive equality. Formal equality refers to when the law treats everyone the same no matter the circumstances, in accordance the same “neutral” norm or standard of measure. It does not take in account social and economic inequalities or conditions between groups and individuals in account. Substantive equality is when circumstances are taken into account and the law has to ensure equality of the outcome. It requires the examination of the actual social and economic conditions between the groups or individuals in order to determine whether constitutional commitments are upheld. The result or effects of a particular rule are emphasised rather than its mere form. A formal understanding of equality therefore neglects the deepest commitments of the constitution while a substantive approach is supportive of the fundamental values of the Namibian constitution. See De Waal J. Currie I. and Erasmus G. 2000 3rd edition. The Bill of Rights Hand book JUTA & co Ltd pp184.

¹⁷⁷ See Speech By Dr Richard Nchabi Kamwi 22 October 2008.

¹⁷⁸ See Speech By Dr Richard Nchabi Kamwi 22 October 2008.

CHAPTER 4: COMPARATIVE ANALYSIS

3.1 Introduction

In this chapter, a comparative analysis will be done in order to determine as to how the chosen countries differ or are the same to Namibia with regard to the measures in place for the promotion of human rights of people with albinism and as to what Namibia could learn from them in order to effectively protect the rights of people with albinism. The comparative analysis will be done in relation to Namibia, South Africa and Tanzania. These nations were chosen on the following bases:

- **Tanzania:** this country experienced very brutal murders and trafficking of people with albinism in world history. It is currently trying to turn this situation around by putting protective measures in place to make people with albinism within its borders to feel safe and come out of hiding.
- **South Africa:** was chosen as a neighbouring country within the SADC region. Its cultural beliefs and the legal system is in most cases similar.
- **Namibia:** is the main subject of this dissertation. The comparison of Namibia to the above two countries is done in order to help Namibia take example as to how the rights of people with albinism are protected in other countries in order to improve and strengthen its approach.

3.2 Tanzania

Tanzania has an estimated 200,000 population of people with albinism. From 2006-2008, more than 57 Tanzanian people with albinism were attacked, mutilated, or killed for their highly priced body parts used by witch doctors to make “magical portions”¹⁷⁹

Sometimes family members look on in horror as groups of machete-wielding men chop off the legs, heads, and genitals of albinos. Among the dead: is a seven-month-old baby, a cassava farmer with two children and a child murdered by his own father, according to reports by the BBC.¹⁸⁰ The brutal killings are fuelled by rumours that

¹⁷⁹ See statistics for Oculocutaneous and Ocular Albinism. Available at www.thebrightesthub.com 7 July 2011. Accessed on 19 September 2011.

¹⁸⁰ See Ballantyne C. 18 February 2009. What causes albinism? Available at www.scientificamerican.com accessed on 7 July 2011. The times reports in a story profiling Canadian albinos peter Ash, founder of

albino blood, skin, and hair have magical powers. People are actually wearing albino hair into fishing nets and fashioning amulets with albino body parts, hoping that these devices will bring them riches.¹⁸¹

In 2009, the government embarked on a campaign against the killers of people with albinism, particularly in the Lake Victoria region in the northwest part of the country. In a secret vote conducted by the government last year, several suspects were arraigned and convicted of murder. Some were sentenced to death.¹⁸² President Kikwete of Tanzania has shown great leadership on the issue not only through regular advocacy, he has equally appointed a woman with albinism as nominated Member of Parliament to give enhanced visibility to the cause.¹⁸³

Now that there is a representative in the National Assembly with Albinism, people with albinism hope to propose a law to ensure that the government guarantees their welfare and security.¹⁸⁴ In addition, the regional chairman for the Tanzania Albino society said, the association will put more pressure on the country's law making body to see that stern laws are enacted to secure their lives and to ensure that they get good jobs, homes and education¹⁸⁵ and since Albinism involves a visual impairment, they are legally categorised as disabled in Tanzania. This is specifically because of their poor vision.¹⁸⁶

In addition in order to create awareness, the Tanzanian Albino Association in partnership with the German technical assistance group came up with a booklet ***“questions and answers about for albinos, their families and friends.”***

According to Ernest Kimaya the Chairperson of the Tanzania Albino Society (TAS), *“the booklet is just one of the many efforts being undertaken by different players aiming at giving correct information on people living with Albinism. It is anticipated that correct information and knowledge will make people recognize people with*

Under the same Sun, an albinism advocacy organization aimed at shaming the Tanzanian government into stopping the murders.

¹⁸¹ Ibid Ballantyne C. 18 February 2009.

¹⁸² See Mfanga 03 November 2010. Albinos see hope for protective law in Tanzania. Available at <http://articles.cnn.com>. Accessed on 7 July 2011.

¹⁸³ See Phitalis Were Masakhwe. 2009.

¹⁸⁴ See Mfanga 03 November 2010.

¹⁸⁵ Ibid Mfanga 03 November 2010.

¹⁸⁶ See Questions & Answers Booklet for Albinos, their Families and Friends. This booklet was developed in collaboration with Tanzanian Albino Adolescents and TGPSH – GTZ pp15.

*albinism as normal people with equal rights, feelings and needs and highly capable if given the same chance in a friendly and supportive environment.*¹⁸⁷

There is no specific law that supports people living with Albinism. However, the Constitution and other sector specific laws prohibit discrimination of any kind. Furthermore, the National Disability Policy defines disability as

“the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors”.¹⁸⁸

Furthermore, the policy calls for equal opportunities for the disabled in receiving education and information, employment, care, health services, and mobility and accessibility in daily life.¹⁸⁹ Tanzania is also the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities of 2006.¹⁹⁰

3.3 South Africa

Although prevalence rates vary considerably throughout the world, the frequency of oculocutaneous albinism is high throughout sub-Saharan Africa, Up to 10 times the world figure. In Northern South Africa about one in 2000 people have this type of albinism.¹⁹¹ In specific groups such as the Tswana where marriage between cousins has been encouraged for generations, the prevalence rate is particularly high especially in some geographically isolated communities.¹⁹²

The myths and beliefs surrounding albinism in Southern Africa are often found to compensate for such a lack of knowledge that leads to the violation of the rights of people with albinism.¹⁹³

¹⁸⁷ Ibid Questions & Answers Booklet for Albinos, their Families and Friends pp20.

¹⁸⁸ Ibid Questions & Answers Booklet for Albinos, their Families and Friends pp25

¹⁸⁹ Ibid Questions & Answers Booklet for Albinos, their Families and Friends pp25.

¹⁹⁰ Ibid Questions & Answers Booklet for Albinos, their Families and Friends pp24.

¹⁹¹ Compared with one in 4000 in Zimbabwe.

¹⁹² See Baker C. et al 2010 pp169. Such as the Tonga people of the Zambezi Valley in Zimbabwe, where 1 in 1000 have this condition.

¹⁹³ For instance the right to life. The killing of children with albinism in southern Africa was first documented in the nineteenth century by Livingstone, who gave an account of a young boy with albinism who is killed by his mother.

In South Africa, albinism is not a disability, although most people with albinism are identify with other disabled people due to the nature of discrimination they experience, they are not classified as such.¹⁹⁴ People with albinism are therefore, only protected and provided for under the laws in place such as the constitution etc.

In an attempt to place emphases on the protection and recognition of the rights of people with albinism, the albinism society of South Africa has a training role in raising awareness of albinism and lobbying the government for the recognition of the plight of people affected by the condition. These are government-funded information leaflets available in the vernacular languages, providing genetic and management information about albinism and detailing the support available, which includes sunscreen preparations, eye care and counselling.¹⁹⁵

In addition, several publications allow people with albinism to write about their own experiences, challenging many of the misconceptions surrounding the condition. Ngizi's book, *black or white, does it matter? : My journey with albinism* is one of most recent of these publications amongst others.¹⁹⁶

3.4 Namibia

Namibia commemorates "*Albinism day*" each year on October 21st and there are many measures set in place to assist people with albinism and protect the rights of people with albinism.

For instance, Namibian, like Tanzania also have a member of parliament who is a person with albinism, Mr Samuel Ankama, he is currently the deputy minister of Works and Transport. In addition, Bishop Dr Zephania Kameeta of the Evangelical Lutheran Church in the Republic of Namibia (ELCRN) is also a person with albinism.

"During the time I resided at Mabotsa, a woman came to the station with a fine boy, an Albino. The father had ordered her to throw him away, but she clung to her offspring for many years. He was remarkably intelligent for his age. The pupil of the eye was of a pink colour, and the eye itself was unsteady in vision. The hair, or father wool, was yellow and the features were those most common among the Bechuanas. After I left the place the mother is said to have become tired of living apart from the father, who refused to have her while she retained the son. She took him out one day and killed him close to the village of Mabotsa and nothing was done to her by the authorities". Ibid Baker C. et al 2010 pp172.

¹⁹⁴ DISABLED PEOPLE SOUTH AFRICA D P S A Pocket Guide On Disability Equity. AN EMPOWERMENT TOOL. In support of The Africa Decade of Disabled Persons 1st of January 1999 - 31st of December 2009 Published by the DPSA Parliamentary Office On behalf of DPSA.

¹⁹⁵ Ibid Baker C. et al 2010 pp172-173.

¹⁹⁶ Ibid Baker C. et al 2010 pp178.

This indicates that people with albinism are given a platform to be heard and be involved in the decision making process.

Moreover the Namibian government under the Ministry of Health and Social Services provides sun block/sun screen to people with albinism for free in all health care centres, clinic and hospitals. Free big hats and sunglasses are also given to these people to protect themselves from the harmful ultraviolet rays.¹⁹⁷ Efforts are also made to provide them with eye glasses.¹⁹⁸

According to Dr Peggy Mwula there are also pension grants available for people with albinism, but only by application. The ministry of gender and child welfare provides grants for children below the age of -12 while the ministry of health and social services provides grants for those over the age of +12.¹⁹⁹ It is however not clear if this grant is given on the bases of disability. This is due to the fact that, some people with albinism are not provided these grants, even on application. Some claim that the reason they were given is that their skin still looks good. This begs the question as to whether they should wait until the skin is highly damaged.

Furthermore, the **Namibian Albino Association Trust [NAAT]** was established to give information and educate the nation about what albinism is and provide support services to this regard. Mr Joseph Ndinomupya is currently president and Mr Wacade Werner Well Kambabi as the vice president. There are views however that this organisation is not carrying out its mandate and should be restructured.

In addition to the above organisation, there are other non-governmental organisations. For instance in November 2001 the **Support in Namibia of Albinism Sufferers Requiring Assistance [SINASRA]** organization was established, with the aims of providing professional eye testing and protection, board rim hats and protective clothing, sun block cream to cancer patients and people with albinism and to educate and create public awareness. This organization has a multi-disciplinary board that is comprised of Rotary together with optometrists, state oncology doctors, the Namibian Albino association trust, people with albinism, and parents to children

¹⁹⁷ See Annexure 4.

¹⁹⁸ See Economist. 21 April 2011. Albinism not a handicap-German Ambassador. Available at www.allAfrica.com. Accessed on 7 July 2011.

¹⁹⁹ Interview at her office at the Dr Bernard may cancer care centre, Windhoek central hospital 28 July 2011.

with albinism as well as a social worker. It meets every 3rd month to discuss what they have achieved, what should still be achieved, to look at their budget, donations and how many hats, sunscreen, sunglasses and protective clothes have been distributed. The main priorities of this organization are to, sustain the lives of the people with albinism, and assist with their vision, to provide information to both the public and to educate the nation and create awareness about albinism and to do research.²⁰⁰

With regard to the above, therefore, it is thus evident that Namibia has set in place measures to protect, promote and recognise the rights of people with albinism. Similar to South Africa and Tanzania, people with albinism are not regarded as people with a disability in Namibia.

3.5 Conclusion

Despite the various measures that Namibia has put in place to make provision for people with albinism a lot more needs to be done. Among the three countries compared above, none of them have specific laws with regard to people with albinism. People with albinism are protected under the existing legal framework. However, even if Tanzania recognises people with albinism as people with disabilities due to their visual impairments, they are not specifically categorised as a distinct disability group. This is similar to South Africa and Namibia. Therefore, Namibia should take a further step and recognise people with albinism as a distinct disability group within the disability framework.²⁰¹ Then only can the human rights of people with albinism be effectively protected.

²⁰⁰ Ibid Dr Peggy Mvula Interview 28 July 2011.

²⁰¹ Even if Namibia does not per se characterise people with albinism as people with disabilities, some sports organisations such as special Olympic Namibia and disability sports Namibia view people with albinism as people with disabilities due to the visual impairment and the lack of protective pigment from harmful rays.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

In conclusion, it should be pointed out that Namibia has a long way to go to be able to say that its entire population knows that their rights are recognised and protected equally. This is due to the fact that some of its citizens such as people with albinism do not know their rights and if they do, they believe that it's not the benefit of everyone.

Being a person with albinism myself, I fully understand the feeling of not being accepted as expressed by the people with albinism. Even if I was fortunate enough to be born to a loving father that supports and guide me all the way, I had gone through some things in my life that made me wish I was not different. For example, at school if I drank from a tap no one else will use it again, until maybe they wash it. If I sit in a certain area of a class no one will sit there. I use to be bullied and hurt by other kids with the aim of seeing how my blood and tears look like; I guess they presumed my tears and blood will be as different as my skin. I hated school because of the fear of being tortured by the kids at school.

Currently, being a student at the University of Namibia, the author want to thank the University for helping people with albinism were assistance is needed. By putting in place the disability unit, which provides assistance to students with albinism and any other disability. People with albinism are given some extra time during exams and providing with a larger font size due to the fact that they cannot see well and lose a lot of time trying to read the paper as a result do not finish at the end of the day and this puts them back.

However, even if the university has put up measures to make sure that people with albinism have access to tertiary education, a lot more needs to be done especially at the taxi rank. The taxi drivers' call students with albinism names; ridicule them and even go to the extent of spiting on them, especially the female students with albinism. Management should therefore, find a way to do away with these practices.

People with albinism are highly valued members of the Namibian society and the government has made provisions to ensure that their interests are firmly protected by law. However, even if a lot has been done, a lot more still needs to be done.

Strategies are needed in particular to challenge traditional and other discriminatory attitudes and customs. It's the state's responsibility to raise awareness to challenge discrimination against people with albinism in order to preserve and ensure protection and dignified life for people with albinism, robust and extensive awareness and public education programmes particularly at the grassroots' are sorely called for.²⁰²

It is also vital that the family members have accurate information about albinism. This is due to the fact that, there is no single force greater than the family in helping a person understands and accepts his or her self.²⁰³

Counselling has also been shown to be very successful in particular cases, although further research needs to be undertaken into the impact of the counselling services.²⁰⁴

The state must therefore increase its efforts to adopt a proactive and comprehensive strategy to eliminate the discrimination directed against these people, by introducing legislation to protecting the equal rights to life and protection from all forms of violence and discrimination by placing albinism as a distinct disability group falling within the disability framework.

Other recommendations include the following:

- Discrimination happens but nothing gets done, Dr Haihambo is of the opinion that if there are consequences for discrimination then maybe the situations will change.²⁰⁵ Mr Kambabi vice president of the Namibia albino associations trust says' there should be additional law supporting people with albinism.
- Proper implementation monitoring and evaluation of the laws in place to protect the rights of people with disabilities.
- Development of policies that offer a better understanding of albinism as a disability and may promote the inclusion of people with albinism in the drafting of such policies.

²⁰² Such as "in my genes", a film produced by Lupita Nyong'o, is highly encouraged. See *Dispelling Africa's myths about albinism Urgent measures needed to protect people with albinism*. See Phitalis Were Masakhwe 2009-09.

²⁰³ See Sullivan J. 1998.

²⁰⁴ See Sullivan J. 1998.

²⁰⁵ Interview on the 30 august 2011 in her office university of Namibia.

- Outreach programmes on sanitation and awareness creation on albinism in general and community sensitisation, but this is long process it needs incentives and continuant monitoring.²⁰⁶

However to deal with all the challenges faced by people with albinism will not be easy, because of the fact that discrimination is a multi-layered phenomenon. Thus making the application of human rights guarantees very difficult: When a layer of discrimination has been peeled off, another one appears below. It can be frustrating! However, how gloomy or bright the future of people with albinism, will depend on the extent to which we are getting ourselves involved today. The decisions we take every day, the laws we promulgate, the programs we are designing, in short all our actions on a daily basis have direct or indirect bearing.

People with albinism are equal to everyone. They should however, be considered a vulnerable group that shall be included within the disability framework for better protection. However, change does not happen overnight and for it to come about we must meet each other half way.

²⁰⁶ Dr Haihambo interview on the 30 august 2011 in her office university of Namibia.

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LIST OF FIELD NOTES

Field note 1. - 28 July 2011 Dr Peggy Mwula. Dr Bernard may cancer care centre, Windhoek central hospital.

Field note 2. - 30 August Dr C K Haihambo ya Otto lecturer faculty of education university of Namibia.

Field note 3. – 08 September 2011 Dr Ute Graz occupational therapy.

ANNEXES

Annexure 1: Interview questions²⁰⁷

Preamble

This questionnaire is devised to be used to conduct research and gather information on *The Rights of People with Albinism: A Conceptual and Rights Based Comparative Analysis*. A Dissertation Submitted In partial fulfilment of the requirements for the Bachelors of Law [LLB] Honours Degree of the University Of Namibia. All the information that you provide in this questionnaire, shall remain confidential and be used for research purposes only.

General

- *What is albinism?*

Legal

- *Are people affected by albinism viewed as equal before the law?*
- *Is the law fair or unfair to those people with albinism?*
- *Should changes be done to the current legal system with regard to people with albinism? And why?*
- *What measures have the governmental and nongovernmental organization have set in place to help protect the rights of people with albinism?*
- *Are people with albinism categories as people with disabilities? Should they be categories as such or not?*

Health

- *Do these people have enough access to health care?*
- *What have the government done to ensure that people with albinism have access to health care? And do you think enough has been done?*
- *If you were the minister of health, what changes or improvements will you come up with and put in force to this regard?*
- *What nongovernmental organizations do you know of, that try to help these people?*

²⁰⁷

These interview questions and the questioner below in annexure 1 was used in the conducting of the research that lead to the publication of Ntinda R. 2009. "*Customary practices and children with albinism in Namibia: a constitutional challenge?*" In Ruppel O. C. [eds]. "*Children's rights in Namibia*". Macmillan Education Namibia pp245. But in this research it was to a large extend altered in certain areas to fit the current research.

Educational

- *Do they have access to education?*
- *What measures have been set in place to help them in terms of their educational needs?*
- *People with albinism have poor eyesight, what have the ministry of education advised schools to do in order to help them?*

Customary practices

- *Are there certain names used to refer to these children in your culture or their families?*
- *How does your community treat these children or their families?*
- *Are they accepted in society? If not what advice will you give to society?*
- *In Tanzania their body parts are in high demand by witchdoctors, as a result they are murdered to supply this demand, is it the same in Namibia? Or have you heard of anything close to this? What about in the past, what was done then?*
- *Any suggestions or anything you would like to add?*

Thank you for you cooperation!!!!!!!!!!

Annexure 2: Questionnaire²⁰⁸

Preamble

This questionnaire is devised to be used to conduct research and gather information on *The Rights of People with Albinism: A Conceptual and Rights Based Comparative Analysis*. A Dissertation Submitted In partial fulfilment of the requirements for the Bachelors of Law [LLB] Honours Degree of the University Of Namibia. All the information that you provide in this questionnaire, shall remain confidential and be used for research purposes only.

1. Personal data [optional]

- 1[a] Name 1[b] gender: male [] Female []
1[c] Nationality..... 1[d] age 0-10 [] 11-20 [] 21-3 [] 31-40+ []
1[e] Are you a person with albinism? Yes [] No []
1[f] Educational level: Primary..... Secondary..... Tertiary.....
1[g] Occupation.....

2. General

- 2[a] Albinism is a: 1. Disease [] 2. A disability []. 3. Curse [].
4. A genetic condition []. 5. None of the above []

2[b] How many people with albinism do you know of?

- 0-4 [] 5-10 [] 11-20 [] 21-30 [] 40+ []

2[c] What causes albinism?

.....
.....

3. Education

3[a] Do people with albinism have access to education?

Yes [] No []

Reasons.....
.....
.....

3[b] people with albinism have poor eyesight, do you know of any measures in place in the educational sector to help them?

²⁰⁸ Ibid.

Yes [] No []

If yes explain

.....
.....
.....

3[c] Do they need special schools? Or must they just be integrated in the schools available?

Yes [] No [] Explain why

.....
.....
.....

4. Customary practices

4[a] How are people with albinism treated in your community and why?

.....
.....
.....

4[b] What must be done to make society more acceptable of people with albinism?

.....
.....
.....

Health

5[a] Do people with albinism have access to health care in Namibia? Explain please

.....
.....
.....

5[b] What are the measures set in place by the government and nongovernmental organizations to help people with albinism?

.....
.....
.....

5[c] What nongovernmental organizations do you know of that helps people with albinism?

.....
.....

5[d] Do you think enough has been done? If not, what more do you suggest must be done both by the community, the government and other stakeholders?

.....
.....
.....

Legal

6[a] The rights of people with albinism are the same to all Namibian citizens.

Yes [] No [] Explain why?

.....
.....
.....

6[b] Do you have any comments or suggestions with regard to the research?

.....
.....
.....
.....
.....

6[c] should albinism be categorised as a disability?

Yes [] No [] explain why

.....
.....
.....

Thank you!!!!

Annexure 3: Ministry of Health and Social Services on the establishment of SINASRA.



9-0/0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
WINDHOEK

Ministerial Building
Harvey Street

Tel 264 61 203 2802
Fax 264 61 231784

Enquiries Ms L Krüger

Date 5 December 2001

OFFICE OF THE MINISTER

Dr PAP Emvula
SINARA
P O Box 1739
WINDHOEK

Tel Fax (061) 225637

Dear Dr Emvula

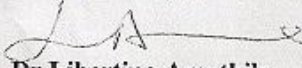
THE NEWLY ESTABLISHED SINARA

I have received your letter and took note of your organisation lending a helping hand to the Albinos and the information is appreciated very much.

In my opinion Albinos are not a special grouping in itself. Yes they have special need as you rightly observed.

I would therefore suggest that they receive treatment as required.

Yours sincerely


Dr Libertina Amathila
MINISTER



Forward with Health for all Namibians by the Year 2000!

Annexure 4: Ministry of Health and Social Services on provision of sunblock.



9 - 0 / 0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13366
Windhoek
Namibia
Enquiries: Mr. J. #Gaeseb

Ministerial Building
Harvey Street
Windhoek
Ref. No. :

Telephone: (061) 203 2350
Telefax: (061) 203 2349
International: 264 - 61 -
Date: 28 April 2004

PEGGY EMVULA
THE SECRETARY
SINASRA
P.O. BOX 1739
WINDHOEK

RE: PROVISION OF SUNBLOCK BY THE MINISTRY OF HEALTH AND SOCIAL SERVICES

Thank you for your letter on the above-mentioned subject matter.

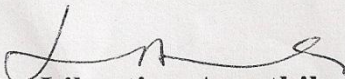
I would like to inform you that my Ministry is as concerned of albinism suffers as your organization is. In recognition of their plight we have added, in our latest edition of the Namibia Essential Medicines List (NEMLIST), **Mexenone cream** (a sunscreen cream) to be widely available.

In the past we did not make provision for such a cream and that is why, as rightly pointed out in your letter, clinics and health centers did not have stock of any sunscreen products. However this is a thing of the past as the Mexenone cream is now available at the lowest level of the primary health care chain, i.e. the clinics.

Let me make use of this opportunity to show our appreciation of the important role played by organizations, such as yours, in complementing my Ministry to achieve the objective of "Health for all Namibians".

Thank you for your understanding.

Yours Sincerely


Dr. Libertina Amathila
Minister of Health and Social Services



Forward with Health for all Namibians by the Year 2005!