A SELECTION OF LEGAL ISSUES RELATING TO PERSONS LIVING WITH ALBINISM

by

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PROMOTOR: PROF MN SLABBERT

28 February 2016
I, Mphoeng Maureen Mswela, declare that A selection of legal issues relating to persons living with albinism is my own work and that all the sources that I have used or cited have been indicated and acknowledged by means of complete references.

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

28th of February 2016

Mphoeng Maureen Mswela

DATE
DEDICATION

This thesis is dedicated to my sister, Ntombizodwa Mswela, who has been so supportive of my work and who has shared the many uncertainties, challenges and sacrifices in completing this thesis. I am indebted to her for her tireless assistance in taking care of my daughter and son throughout the period that I worked on the thesis. She never complained, even when my work continued deep into the night on a number of occasions. Words cannot express my gratitude for her help, support and concern. I was able to complete the thesis without worrying about my children because of her. I will always value her presence and love. My daughter, Tanyaradzwa Victoria Mzenda, has grown into an amazing five-year old and my son Atipatose Mzenda has also grown startlingly into a one year and four month old toddler, despite the many hours that their mum spent away from them because of this thesis.
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Mphoeng Maureen Mswela
February 2016
SUMMARY

Despite the fact that albinism affects several South Africans, it is a condition that remains deeply misunderstood. Albinism is steeped in myth and false notions, and is perceived by many as a curse and contamination. For years, persons living with albinism have been treated with doubt and suspicion. Also in schools and in the wider community, children with albinism are subjected to violence and ridicule. In certain areas on the African continent, including Southern Africa, persons living with albinism are killed for the trade in body parts for use as sacramental medicines, or sexually assaulted as a result of the belief that raping them may offer a cure for HIV/AIDS. All of this highlights the extreme vulnerability of persons living with albinism, not to mention the many violations of their fundamental rights that follow from the manner in which they are treated. Within the social context that frames the experience of persons living with albinism, the primary purpose of this study is to highlight some of the pertinent challenges faced by persons living with albinism in South Africa which compromise the full enjoyment of their fundamental rights as enshrined in the South African Constitution. The thesis makes a number of practical recommendations that will assist in promoting the legal position of this vulnerable group, while also contributing to a better understanding of albinism in general which will ultimately change negative perceptions and debunk the myths surrounding the condition.

Key terms: Albinism, albino, disability, discrimination, colourism, muti murder, myths, stereotypes, popular culture, the right to equality, the right to dignity, the right to life, the right to health care services, the right to education, the right to social assistance.
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CHAPTER 1: INTRODUCTION

“South Africa does not have a dedicated institution addressing the issues and rights of persons with albinism. There are also currently no projects or policies to sensitise persons and raise awareness on the rights of persons with albinism.”

PART I

1.1 Contextual background and significance of the topic

The notion that one person’s life can be easily exchanged for another’s good fortune is not new. From institutional slavery to aggressive imperialism, people have historically oppressed and even killed others for the sake of economic growth.

The killing of persons living with albinism, or albinos, as they are also referred to, was brought to the attention of the world a few years ago when CNN International World reported that approximately 10,000 albinos were hiding themselves in East Africa in fear of being murdered for their body parts. According to the report, a


3 The term “albino” refers to a person or an animal whose body does not generate the usual quantity of the pigment melanin, and hence has extraordinarily white hair or skin. The English word has its origin in the Spanish word “albino” which was originally used to describe albino people living in sub-Saharan Africa. The Spanish word “albino” is derived from “albo”, a poetic word for white. The Spanish word, “albo” comes from the Latin word for white “albus”, see American Heritage Dictionary Editors Spanish Word Histories and Mysteries: English words that come from Spanish (2007, Boston: Houghton Mifflin) at 9-10; Lotti TM “Regional Dermatological Centre” (2004) 43 (8) International Journal of Dermatology 618-621 at 619. This study will refer interchangeably to “albino”, “persons with albinism”, “persons living with albinism” and “people with albinism” in order to avoid monotonous repetition.

number of albinos fled to Tanzanian schools for the disabled or to emergency shelters set up by police in Burundi in order to escape possible attacks.\textsuperscript{5}

Following these reports, the United Nations Human Rights Council has since expressed grave concern about such attacks.\textsuperscript{6} The United Nations Office of the High Commissioner for Human Rights has acknowledged several forms of attacks against persons with albinism and stated that such attacks include, among others, ritual attacks; the killing of and attacks on persons with albinism for ritual purposes.\textsuperscript{7}

People have been seeking out persons living with albinism, murdering them and subsequently selling their body parts to witch doctors. Their body parts are allegedly used as ingredients in rituals, concoctions and potions with the claim that their magic will bring prosperity to the user.\textsuperscript{8} There is also the belief that their organs possess supernatural powers that can make a person very rich within a short time.\textsuperscript{9} For this reason, persons living with albinism have been persecuted, murdered and stripped


of their body parts and the graves of albinos dug up and desecrated. A recorded case in South Africa linked with albinism and muti is that of Sipho Lolwane, an albino who passed away in 2002 and whose grave has been defiled and robbed several times for his bones.

At the same time, albinos have been ostracised and even murdered for exactly the converse reason; because they are presumed to be a curse, bringing bad luck to the community. In South Africa, people are routinely murdered for their body parts, which are used as muti (magical charms). Such killings in South Africa are not aimed at persons living with albinism in particular. However, the fairly recent case of a missing albino child, reported early in June 2011, suggests that the problem may be more widespread than anticipated. It is also feared that this incident may prompt the behaviour to be copied.

The mysterious killing of albinos causes uneasiness among the albino community, as they feel very insecure under these circumstances. They are reluctant to stay, walk or travel alone due to the possible risks. Given their small numbers and vulnerability, they require social and legal protection in order to enjoy the full spectrum of fundamental rights, which include the right to life and freedom of movement.

____________________

16 Masanja et al 15; and Schühle 15.
The challenges affecting persons living with albinism do not end here. Besides their health concerns, they also deal with psychological and social challenges. They are often shunned, ridiculed and discriminated against. Some studies that rely on written accounts of people living with albinism demonstrate that albinos tend to be more withdrawn from social affairs in order to avoid being noticed. They are also inclined to be less stable emotionally and have less self-confidence than persons who do not have albinism. They also regard the rest of society as generally unfeeling and stigma-filled, although they may have close friends.

Of all the persons living with albinism, the position of the African albino is the worst. African albinos suffer overt discrimination that results from a fundamental and recurrent misunderstanding and general ignorance of the condition. There is growing evidence of social discrimination and stigmatisation directed towards this segment of the population. Their appearance, lack of knowledge about the condition itself and how it is viewed in communities serve to perpetuate the stigma associated with albinism. For example, the etiological beliefs about albinism are influenced by culture and superstition rather than by genetics. Stigma is one of the central aspects explored in this study. A stigmatised person is defined as somebody who represents unwanted features that are not present in the characteristics of the group to which he or she belongs. This person is viewed by society as a reduced person, from a "normal" person to one who is tainted and discounted. Normality is believed to be a corresponding counterpart to stigma.

To understand disability, one must revisit the concept of normality and the "normal" body. It is argued that societies establish categorisations where certain

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18 Hong et al 4.
19 Hong et al 4.
20 Braathen SH “Albinism in Malawi, A Qualitative Study on Attitudes and Beliefs” 2005 Thesis submitted as part of the Master of Philosophy Degree in International Community Health in the Faculty of Medicine at the University of Oslo 1-66 at 11-14. Also see Hong 4.
21 Cruz-Inigo AE et al “Albinism in Africa; Stigma, Slaughter and Awareness Campaigns” (2011) 29 (1) Dermatologic Clinics at 79-87. Also see Hong et al 4.
characteristics are considered “normal” within a group. The result of such categories can be referred to as social identity,\textsuperscript{27} based on appearance.\textsuperscript{28} It should be noted at the outset that albinism is viewed as a disability by some people, while seen as a condition by other people. In this study, the question of whether albinism is a disability will be addressed. This will facilitate a better understanding of whether persons stigmatise albinos as a result of their condition or the disability associated with their condition, or both.

It is sad to note that stigma does not only affect albinos in South Africa. The worldwide AIDS-related discrimination attached to this condition is an example of stigma. With respect to HIV/AIDS, such stigma can result in being shunned by family, peers and the wider community; psychological damage; poor treatment in healthcare and education settings;\textsuperscript{29} and an erosion of rights; and can negatively affect the success of testing and treatment.

The appearance of albinism in the paleness of the albino skin makes it a condition that is loaded with symbolism and meaning in terms of racial difference.\textsuperscript{30} The deficiency of pigment that sets the albino apart in a superstitious Africa is often depicted as symbolic of his or her links to the world of spirits, or functions purely as an indicator of distinction and deviance.\textsuperscript{31} Underlying all such understanding is a failure to see albinism for what it is; a medical condition,\textsuperscript{32} an incredibly rare group of diseases and pigmentational variance in the skin, hair and/or eyes owing to hereditarily blocked melanin synthesis.\textsuperscript{33} This condition is often noticeable at birth from the symptoms of lack of pigmentation.\textsuperscript{34} Albinism can be confirmed with a deoxyribonucleic acid (DNA) test to verify the presence of an albinism gene.\textsuperscript{35}

\begin{itemize}
\item \textsuperscript{27} Braathen 12.
\item \textsuperscript{28} Braathen 12.
\item \textsuperscript{30} Twohig LP & Kalitzkus V Social Studies of Health, Illness and Diseases: Perspectives from the Social Sciences and Humanities (2008, New York: Editions Radobi BV) at 115.
\item \textsuperscript{31} Twohig & Kalitzkus 115.
\item \textsuperscript{32} Twohig & Kalitzkus 115.
\item \textsuperscript{33} Horobin W (ed) Diseases and Disorders (2008, New York: Marshal Cavendish Corporation) at 29.
\item \textsuperscript{34} Horobin 29.
\item \textsuperscript{35} Horobin 29.
\end{itemize}
In addition, persons living with albinism are at higher risk from sun damage. Pigmented growths and spots may develop in sun-exposed areas of the skin and “tanning” or exposure to the sun greatly increases the risk of skin cancer.

For those living with albinism in Africa, life may be particularly difficult. Poverty and a lack of knowledge about the condition deprive these individuals of protection against the burning sun. Many albinos die prematurely as a result of skin cancer. If they use proper skin protection, such as sunscreen lotion with a high protective factor and wear opaque clothing, albinos can participate in outdoor activities, even in summer. Above all, the treatment of eye conditions in albinism consists of visual rehabilitation. Surgery to correct the strabismus may improve the appearance of the eyes. Unfortunately surgery is expensive and requires substantial financing, which is not available to most African albinos. Access to healthcare services and disability grants is indispensable in such circumstances.

Apart from medical issues resulting from albinism, specific inadequacies are often attributed to albinos. This chapter will highlight some of the stereotypes, cultural beliefs and superstitions associated with albinism. Despite the anecdotal nature of these beliefs, they are necessary to inform the discussion of the legal issues in this thesis which focuses specifically on unfair discrimination and violation of protected fundamental rights.

This chapter is divided into four parts. Part I sketches the contextual background for this study, which has alluded to a brief description of the existing state of affairs of people with albinism. In Part II that follows, the research problem, approach, problem

37 Norman 39.
38 Norman 39.
39 Horobin 29. Also see Norman 39.
40 Norman 41.
42 Norman 41.
statement and methodology will be addressed. In Part III, specific cultural beliefs, myths and stereotypes associated with albinism are explored, with the objective of determining the extent to which these affect albinos’ exercise of the full spectrum of their fundamental rights. This same section, also gives a brief historical overview of albinism and epidemiological data on albinism. In the final part of this chapter (Part IV), the focus will turn to the present constitutional framework, with brief reference to the fundamental rights which will be explored in more detail later in the thesis. The framework for this context is provided by the Constitution of the Republic of South Africa, 1996, which places specific emphasis on the fundamental rights to equality and human dignity, amongst others.

PART II

1.2 Research problem and problem statement

The constitutional, medico-legal and clinical issues related to albinism set the framework for this thesis. The thesis is also informed by social, cultural and anthropological insights which assist in obtaining a better understanding of the legal challenges that affect albinos, specifically Black albinos, in South Africa.

The discussion will focus on an examination of selected legal issues relating to albinos. A further aim of this thesis is to identify shortcomings within the South African legal context, following from this investigation, and to propose recommendations aimed at improving the position of albinos in terms of the South African legal framework. The stigmatisation of and discrimination against albinos, are directly related to specific social perceptions, which in turn may exacerbate their marginalisation and exclusion. Albinism is a very unique example of how a specific medical condition has led to harmful and hurtful erroneous perceptions and stereotypes. For this reason, it is necessary to ensure that persons living with albinism also enjoy the full protection and benefit of the law and are not treated as second-class citizens.

The position of persons living with albinism in South Africa has not yet been the topic of any specific legal study, as compared to extensive studies on albinism in the fields
of medicine and the humanities. In 2013, delegates at the First National Albinism Conference in South Africa, attended by human rights and disability rights activists in Ekurhuleni, Gauteng, composed the Ekurhuleni Declaration on the Rights of Persons with Albinism which proposes a comprehensive research analysis into the incidence of human rights violence against persons with albinism in South Africa. Subsequent to this request, on 15 February 2015, the United Nations High Commissioner for Human Rights highlighted that, among other countries, South Africa is in need of a compact national legal document that addresses the human rights of people with albinism.


See Annexure B: Section 15 of the Ekurhuleni Declaration on the Rights of Persons with Albinism, 27 October 2013.

The need for an explorative legal study in order to identify and address the relevant constitutional, clinical and medico-legal issues relating to albinism cannot be emphasised enough.

Advisory Committee on the human rights situation of people with albinism to prepare a study on the global situation of human rights of persons living with albinism and to present a report thereon to the Council at its twenty-eighth session. In this connection, the Advisory Committee, in its preparation for the study, decided to seek views from respective member states. The drafting group drafted a questionnaire for states, national human rights institutions and non-governmental organisations from member states for inputs on the issue of the situation of human rights of persons living with albinism.


59 (a) "Limited knowledge of the issue and its impact on the enjoyment of human rights by persons with albinism;
(b) Limited knowledge and capacity of associations of persons with albinism around the world to engage with human rights mechanisms;
(c) Little information, scarce data and incomplete reports on cases of discrimination on specific grounds;
(d) Scarcity of reliable data on cases of killings of and attacks against persons with albinism in countries other than Burundi, Côte d'Ivoire or Tanzania, where there is a higher prevalence of albinism, but also a more active and better skilled civil society. The lack of information makes it difficult for potentially relevant special procedures mandate-holders to give attention to the issue within their respective mandates, including the Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment, on racism and related intolerance, education, disability, health, violence against women and violence against children. Similarly, the secrecy surrounding witchcraft and the underground nature of the market associated with the trafficking of persons and organs make it difficult to find evidence relevant to the mandates of the Special Rapporteur on the sale of children and the Special Rapporteur on trafficking in persons;
(e) Human rights challenges associated with albinism are multi-layered and are not currently being addressed in a comprehensive and sustainable manner by any human rights mechanism. In addition to the fact that they do not fall within the scope of the current definition of minorities, persons with albinism often suffer from poor eyesight and are prone to developing skin cancer, but cannot or would not want to be classified as persons with disabilities, as that would mean adding another layer of labelling and discrimination to which they may be subjected. They are attacked and tortured, and their body parts and organs are trafficked and sold owing to the myths and misconceptions surrounding albinism. Yet the protection afforded to persons with albinism by international human rights treaties does not cater for their special needs or the complexities they face, while existing special procedures can only partly address the situation of persons with albinism from a particular and limited angle to the extent that the scope of their mandates allows."

Following from the above it is apparent that the timing of this research is ideal. It is evident that there is a lack of an adequate legal document that addresses issues facing people living with albinism. This study therefore intends to address this gap. The study analyses medical and social problems facing people with albinism in South Africa from a new perspective; a human rights perspective.
Due to the multi-faceted focus of this work, it was necessary to consult not only relevant legal texts, but also, where required, relevant medical, sociological and anthropological sources, as stated already. Although not all of this discussion relates to South Africa specifically, as a result of the paucity of material on the subject, it is believed that in many African countries, similar perceptions regarding albinos prevail, especially in rural and uneducated communities.

As a first attempt to examine the position of persons with albinism from a legal perspective, it is submitted that this study will make an original contribution to the field of law. One of the primary objectives of this research is to deepen the existing understanding of the position of persons living with albinism, with respect to their rights to equality, life, dignity, privacy, education, health care services and freedom from any form of violence. For this purpose, this chapter attempts to contextualise the social issues that affect albinos generally. It is hoped that the thesis will assist in providing a first and tentative framework for further legal discussion regarding this topic.

1.3 Research approach and methodology

The research method of this thesis will be a document-based literature study, consisting of a review of existing legal and other relevant sources concerning the topic, including scholarly books, legislation, case law, journals, newspaper reports and internet sources. The thesis will also inevitably rely heavily on recent internet sources, particularly media and other social reports, which, in the absence of verified formal studies regarding the myths and stereotypes surrounding albinism, for reasons explained elsewhere in this chapter, are reservedly accepted for the purpose of the contextualisation of the research problem.

1.4 Choice of legal systems

1.4.1 South Africa

Against the social context that frames the experience of persons living with albinism, the primary purpose of this study is to highlight some of the pertinent challenges faced by persons living with albinism in South Africa, which compromise the full enjoyment of their fundamental rights as enshrined in the South African Constitution.
This thesis reviews current legislation, case law and other relevant materials in as far as they relate to the interpretation of human rights of persons with albinism.

1.4.2 Tanzania

Although the focus of this study is primarily on South African law, occasional references to the position in Tanzania will be made for the purpose of illustrating the gravity and extent of the violation of human rights among persons with albinism. Tanzania is singled out for this comparison for the reason that several gross human rights violations on persons with albinism have been reported in that country and the largest percentage of albinos on the African continent are found there. 47

1.4.3 Kenya

In Kenya there has been an effort to have the Persons with Disability Act 2003 amended in order to include albinos in the disability class. The Amendment Bill stems from advocacy work carried out by the Albino Society of Kenya and comes at a time when there are global uncertainties on whether albinism is classified as a disability or not. This thesis examines this development.

1.4.4 United States of America

Colourism generally is a phenomenon which continues to affect many South Africans, although the Constitution provides protection against unfair discrimination

47 Lotti 618-621.
48 Colourism is the social meaning associated with one’s colour that establishes one’s status, while in the case of racism, the social meaning attached to one’s race establishes one’s position. Colourism, also known as skin tone discrimination, may be interracial or intra-racial. Intra-racial skin colour discrimination takes place when an affiliate of a particular racial group makes a distinction on the basis of skin colour between persons of the same racial group, while interracial colourism takes place when an affiliate of a particular racial group makes a distinction on the basis of skin colour between persons of another racial group. See Mswela M & Nóthling-Slabbert MN “Colour Discrimination against People with Albinism in South Africa” (2013) 6 (1) South African Journal on Bioethics and Law 25-27. Also see Scott SA “New Category of Color: Analyzing Albinism Under the Title VII and the Americans with Disabilities Act” (1999) 2 The Journal of Gender, Race and Justice 493-522; Banks TL “Multilayered Racism, Courts Continued Resistance to Colorism Claims” at http://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=1821&context=fac_pubs (visited 10 June 2012). Also see Jones T “Shades of Brown: The Law of Skin Color” (2000) 49 (6) Duke Law Journal 1487-1557 and Gabriel D Layers of Blackness: Colourism in the African Diaspora (2007, London: Imani Media Ltd) at 11.
based on skin colour.\footnote{Section 9 (3) (4) of the Constitution of the Republic of South Africa, 1996 (hereinafter referred to as the Constitution of 1996), reads as follows:
(3) “The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.
(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3)”.}

In South Africa, scant legal attention has been paid to persons living with albinism and the many forms of discrimination which they may be subjected. Even though colour as grounds for discrimination is prohibited in the equality clause of the Constitution, it is conventionally grouped with race and ethnicity when unfair discrimination is interpreted.\footnote{Currie I & De Waal J The Bill of Rights Handbook (2013, Cape Town: Juta) at 227.} At the writing of this thesis, South Africa has no local precedents to resolve jurisprudential issues on colourism in the context of albinism, whereas this issue has been at the centre of court cases in the United States of America. American case law examples show the complexities associated with establishing colour as a new basis for action, autonomous of race. In this regard the thesis refers to case law from the United States of America for the purpose of finding a basis for a proper investigative framework relevant to colourism issues.

Observing America’s strong history and the sound amount of studies on colourism, America is the country that stands out as relevant for a foreign comparative analysis on colourism. Foreign case law may help South African courts to develop the right to equality and discrimination based on colour, particularly in the context of albinism, where the grounds of unfair discrimination become blurred.

The existing literature on albinism in South Africa contains uncertainties regarding whether albinism should be classified as a disability or not, whereas this has already been addressed in court cases in the United States of America. This thesis will hopefully fill the uncertainty gap in South Africa by evaluating the existing legal interpretations in the United States of America with the aim of providing some clarification on this legal issue.

1.5 Framework of the thesis

This study consists of five chapters which are structured as follows:
Chapter one (Introduction) presents a general introduction to the study. It addresses the contextual background to the research problem, the problem statement and limitations, the research approach and methodology as well as an outline of selected constitutional rights relevant to the topic. Specific cultural beliefs, myths and stereotypes associated with albinism are also explored, with the objective of determining the extent to which these affect albinos’ exercise of the full spectrum of their fundamental rights.

Chapter two (Clinical overview of albinism) provides an overview of the clinical issues relating to albinism. Amongst others, this chapter explores what albinism is; how the condition is passed from one person to the next; the diagnosis of the condition and specific health challenges relating to the condition, to name but a few.

Chapter three (The constitutional framework relevant to persons living with albinism) examines the fundamental rights framework relevant to persons with albinism. The chapter provides a detailed analysis of the constitutional rights relevant to this study and further discusses the general limitation clause contained in section 36 of the Constitution. The key focus of this chapter is to demonstrate that the mystification of albinism as portrayed in cultural beliefs, popular culture, myths and false perceptions, challenges the rights to equality, life, dignity, privacy, access to healthcare services, education as well as the right to freedom and security of persons with albinism.

Chapter four (The limitation analysis) discusses section 36 of the Constitution, the limitations clause, in as far as it stipulates a test which a limitation of rights must meet to be considered reasonable and justifiable.

Chapter five (Albinism and disability: a comparative analysis) explores whether albinism is a disability or not against the backdrop of the Employment Equity Act51 and the Social Assistance Act.52 The objective of such an analysis is to understand whether people with albinism qualify for

52 Social Assistance Act 13 of 2004.
the protection which is afforded to people with disabilities, namely eligibility for government programmes and eligibility for protection by legislation. The comparative analysis offers an in-depth legal analysis of how the United States of America has tackled the question of whether albinism is a disability or not. The chapter is also geared towards exploring the mandate of the Convention on the Rights of Persons with Disability in as far as it relates to the social construction of disability.

- Chapter six (The international human rights framework with regard to albinism) discusses some of the international human rights instruments relevant to this study.

- Chapter seven (Conclusion and recommendations) concludes the study with a summary and specific recommendations, legal and social, aimed at improving the position of persons living with albinism in South Africa.

1.6 Limitations

The topic of this thesis invariably spans a wide range of legal issues relating to albinism that belong to the domains of public law, health law, social security law and equity law, all embedded within a constitutional law framework. It would be impracticable to traverse all of these issues in detail. The focus will be on persons affected by albinism specifically, as persons affected by albinism stand among other groups of people who have traditionally suffered the most in terms of discrimination, intolerance and violence. In addition, reference will also be made to selective medical, cultural and social issues linked to albinism. It is submitted that a discussion of these issues is important in coming to terms with and understanding the challenges that face persons living with albinism in South Africa. As stated earlier, although reference is made to albinos in general, most of the prejudice and stereotypes referred to in the study relate to African albinos. In the absence of formal studies detailing the prejudice and myths surrounding albinism, reliance on a range of anecdotal evidence regarding these is inevitable.
PART III

1.7 The socio-cultural and historical context of albinism

1.7.1 Cultural beliefs, superstitions and myths associated with albinism

In Africa, an understanding of albinism is deeply influenced by specific cultural beliefs, superstitions and myths. Most, if not all, of these beliefs and practices are erroneous and harmful to the emotional, physical and psychological state of both children and adults with albinism. As pointed out above, these beliefs are not openly discussed due to their superstitious nature.

Some of these beliefs and superstitions are the following:

- Persons with albinism always have red eyes.
- Persons with albinism are totally blind.
- Some see albino children as a gift or a blessing because these children are believed to have magical powers or are able to tell the future.
- Others believe that albino children are a curse. They are perceived as a punishment to a woman, man or family that is wicked and the result of angering the gods or as the result of a bewitchment in the family.
- In some parts of Africa, persons with albinism are not perceived as human beings, but as sacrificial lambs, wanted for their hands or their genitals which are considered the strongest body parts.

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53 Gaigher et al 5.
56 Salewi 15.
57 Lund & Gaigher 370.
• Albinos are killed for their body parts to make fetishes or potions that witch doctors allegedly advise their clients to drink to obtain wealth.\textsuperscript{60}

• Marriage to an albino may bring good luck or fortune to the marriage partner.\textsuperscript{61}

• In some cultures, albinos are believed to be cannibals.\textsuperscript{62} In many folk tales, albinos are often portrayed as evil cannibals.\textsuperscript{63} Children who misbehave are told that if they continue their naughtiness, they will be devoured by an albino.\textsuperscript{64}

• Some believe that albino children are the result of inbreeding or racial mixing. For example, many believe that the child is white because the mother had sex with a white man. The woman could be accused of infidelity and be abandoned.\textsuperscript{65}

• Albinism is thought to be very contagious.\textsuperscript{66} Some people believe that if one eats, sits or sleeps next to, drinks from the same cup or has any other physical contact with a person with albinism, one will also become an albino or smell like them.\textsuperscript{67} In Venda, in Limpopo Province, spattering in one’s shirt is advised as a way of warding off the contagion of albinism, as well as holding your hair and moving away from the person with albinism.\textsuperscript{68}

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\textsuperscript{59} Phatoli et al 2.
\textsuperscript{61} Ntinda RN \textit{Customary Practices and Children with Albinism} in Ruppel QC \textit{Childrens Rights in Namibia} (2009, Windhoek: McMillian Education Namibia) 244-245 at 244.
\textsuperscript{62} Williamson R \textit{Tavua the white Cannibal} (2007, Ludwigshafen: Verlag Angelika Hoernig) at 51.
\textsuperscript{63} Also see Ntinda 244-245.
\textsuperscript{64} Ntinda 244-245.
\textsuperscript{65} Ntinda 244-245. Also see Mswela & Nöthling-Slabbert 25.
\textsuperscript{66} Baker C et al “The Myths Surrounding People with Albinism in South Africa and Zimbabwe” (2010) 22 (2) \textit{Journal of Cultural Studies} at 7: “As a consequence of the reluctance to accept genetic inheritance as the sole explanation for the birth of a child with albinism, other reasons for such a birth are sought. A young woman in northern South Africa describes how her mother explained the cause of her albinism to her as something she had ‘caught’ by touching a child with albinism. The mother attended a party while pregnant and saw a mother with a baby precariously strapped to her back in a blanket. Fearing the baby was about to fall she went forward to help tighten the blanket. She then saw to her fright that the baby had albinism. She believed that, as a direct result of this encounter, she had given birth to a child affected with the same condition.”
\textsuperscript{67} Ntinda 244-245.
\textsuperscript{68} Baker 7.
\end{flushleft}
The immediate consequence of this myth is the social isolation of albinos. At the University of Venda students with albinism testified that other students did not sit close to them in lecture rooms and avoided them at during events. Clearly this is unfounded; albinism is a genetic condition and can only be passed on to another person by genetic means, namely from parents to their offspring.

- Some people believe that people with albinism do not die in the presence of other people with albinism; they go into hiding and die elsewhere. A man in a rural area of Venda, South Africa, reported that he invited the whole village to the funeral of his relative with albinism, with the intention that each person would be convinced of the deceased albino’s death.

- In Zimbabwe it is believed that having sex with an albino woman will cure a man of HIV. As a result, many women with albinism in the area have been raped. This is another fallacy; having sex with an albino will not cure an HIV-positive person.

- Some believe that people with albinism are sterile.

- Many also believe that albinos have a short life expectancy. This could perhaps explain why some albino children in Namibia are killed at birth.

- Albinism is seen as a sign of failure or weakness in the family with an albino member.

The above beliefs and superstitions clearly illustrate ignorance of what albinism is. Unfortunately, these beliefs have a profound impact on the freedom of persons living with albinism to enjoy the spectrum of fundamental rights in a variety of contexts.

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69 Baker 7.
70 Baker 8.
71 Ntinda 244-245.
72 Lund & Gaigher 370.
73 Baker 10.
74 Ntinda 244-245.
75 McElroy RJ Simple Man (2008, New York: SHS Publications) at 39. Also see Ntinda 244-245.
76 Ntinda 244-245.
77 Ntinda 244-245.
1.7.2 Stereotypes relating to albinism as portrayed in the media and literature

The powerful effect of the negative perceptions and beliefs highlighted above also resonates in the mainly negative portrayal of albinism in popular culture, and more so in the portrayal of albinos in film and fiction. This portrayal, referred to as the “evil albino bias”, perpetuates societal intolerance, stereotypes and discrimination against this group of vulnerable people by manipulating the attitudes and opinions of the respective audience. It is realistic that attitudes and opinions change radically in consequence of what is seen or heard. There are indications of selective perception of what is viewed, namely that audiences tend to identify with that which reinforces their existing beliefs. Some speculation is in order, however; attention needs to be drawn to the effect of negative stereotyping of a particular group, especially where vulnerable members of society are concerned. Self-identity is shaped by what is communicated through the media, as well as by inter-personal acts. To see oneself labelled and cast at all times in the role of a criminal, vulnerable dependent or victim, to mention but a few popular portrayals, is not a desirable fate. There is no doubt that such stereotypes help to strengthen the stigmatisation and discrimination that accompany albinism.


Mswela 79-93.


The media plays a central role in creating stereotypes.\textsuperscript{87} If the media characterise particular groups of people in certain ways, their viewers are likely to do the same.\textsuperscript{88} If the motion picture industry portrays a group of people negatively, they are likely to bring about negative stereotypes which could bear piteous results. Stereotypes in books also have negative effects and will noticeably perpetuate stereotypes from one generation to the next, causing suspicion against albinos for many years to come. Negative media and literary representation of a particular group of people has further detrimental effects on the manner in which these people are treated. These stereotypes create profound inequality in our society. These hurtful stereotypes not only afflict those most affected (albinos) by it, but also harm society in general.

The next section will very briefly explore the origin of the stereotype of the “\textit{evil albino}”. Unjust discrimination and stereotyping can only effectively be addressed once one has a clear understanding of the origin of the prejudice or stereotyping.

\textbf{1.7.3 History of the “evil albino” stereotype}

The "evil albino" stereotype perhaps has its origin in Neolithic Eastern Europe, where some cultures portrayed death as a “pallid woman with light hair”.\textsuperscript{89} The fear of vampires and other legendary “undead” with a “deathly pallor”, more so in European folklore, could also have played a role in fuelling the albino bias.\textsuperscript{90}

The National Organisation for Albinism and Hypopigmentation, a non-profit advocacy group for people living with albinism, identified sixty-eight films which have been released since 1960, featuring negative portrayals of albinos.\textsuperscript{91} The scope of this study only permits reference to a few of these films.

One of the oldest literary examples of albino bias can be traced to H.G. Wells’ setting of the central character in his 1897 science-fiction novel, \textit{The Invisible Man}, the latter

\textsuperscript{88} Mehta 90.
\textsuperscript{90} Adcock at http://www.bloodsprayer.com/uncategorized/power-was-given-unto-them-the-evil-albino-stereotype-in-horror-fiction/ (visited 10 May 2011).
capable of becoming invisible by employing his scientific invention for the sole reason that he is already pigmentless. Already peculiar prior to his experimentation, he eventually becomes totally deranged, an "albino villain." 92 Once invisible, he finds that the usual societal restrictions are no longer applicable to him. In particular, the law can no longer be applied to an invisible man since he cannot be arrested and be brought to trial either. He plots a "Reign of Terror," dreaming about a novel master race of Invisible Men. 93

Albino bias is also seen in modern times. In the film, *The Da Vinci Code*, the character Silas is conceivably the most remarkable current example of the "evil albino" character in fiction. Silas, an albino monk in the service of the *Opus Dei* organisation, comes from a background of confusion, fear, and hatred. He eventually murders his father and embraces a life of crime. 94 An apparent miracle frees him from prison, causing him to go into the Catholic Church. In the novel and the film adaptation, he is used by *Opus Dei* as an assassin, killing those who threaten the version of historical facts preferred by the Church. Primarily uncomfortable with the idea of murder, recognising it as a sin, Silas is ultimately convinced by the argument that it is for the Church's good.

The dermatologist, Dr Vail Reese, on his website www.skinema.com, refers to twelve motion pictures that were released in the 1980s featuring an "evil albino", twenty in the 1990s, as well as twenty-four after 2000. 95 Dr Reese theorises that the albino bias may perhaps be part of a broader Hollywood model of connecting skin disorders and appearance problems with villainy. 96 The majority of movies that feature skin disease use it to represent evil in some or other form. 97

The writers and directors of films which portray the "evil albino" could well have been influenced by various other beliefs and myths that exist not only in other parts of the world, but also in the African culture. In Africa, as mentioned above, albinism goes

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94 Schiappa 6.
hand in hand with specific cultural beliefs, superstitions and stereotypes.98 Most if not all of these beliefs and practices are erroneous and detrimental to the emotional, physical and psychological state of children and adults with albinism. More importantly, these beliefs and practices have the effect of undermining the fundamental rights of albinos or persons living with albinism, as will be discussed in more detail in this thesis.

1.7.3.1 Exceptions to the negative stereotyping of albinism

During the period of the Middle Ages and the Renaissance, and even in ancient times in Europe, fair skin was considered exceptionally attractive since it was thought to be a sign of wealth along with high social status. A sunburnt skin meant that a person had to work in the fields for an income, in other words, was a labourer or a peasant.99

In the same way, the powdered white wigs worn during the American colonial era indicated the wearer’s wealth or privileged education.100 However, in nineteenth-century America, albinism was regarded as such an unusual feature, that persons with albinism were exhibited in circus sideshows.101 During the 1870s to the 1890s, with the advent of the camera, albinos were portrayed on postcards which were widely distributed and collected.102 Photo studios, for example those of Charles Eisenmann, Obermuller and Son, and that of Matthew Brady, specialised in photographing what were regarded as human oddities.103 A number of pictures of albinos appear on their website.104

Several Native American and South Pacific ethnic groups believed that persons and animals living with albinism were heralds from divine entities.105 Some recognised

98 Ntinda 243-254.
102 Norman 39.
103 Norman 39.
105 Norman 39.
them as good omens and treated them respectfully, whereas others saw their presence as a sign of transgressions within the tribe.\textsuperscript{106}

Positive portrayals of albinos in mass culture are, as expected, rare. One example of a positively portrayed albino is found in the 1995 film, \textit{Powder}, which portrays an extraordinarily gifted albino youth, and the cruelty he has to face as a result of being “different” from “normal” people.

\subsection*{1.8 Epidemiology and the prevalence rate of albinism}

The occurrence of albinism differs across the world. Globally one in 20,000 people are albinos.\textsuperscript{107} In the United States of America the frequency of albinism is reported to be 1 in 17,000.\textsuperscript{108} It is estimated that there are currently approximately 1,400 Negro albinos in America.\textsuperscript{109}

The occurrence in parts of Africa is far higher than the worldwide average.\textsuperscript{110} However, there are very few and outdated statistics regarding the occurrence and prevalence of albinism in Africa,\textsuperscript{111} to the extent that the Office of the High Commissioner for Human Rights noted that the lack of sufficient registration of important statistics, such as information on birth and death of people with albinism, increases the prospect of cases going unreported and failing to be investigated.\textsuperscript{112}

In South Africa, albinos make up about 1 in every 4,000 people.\textsuperscript{113} The genetic condition of albinism in South Africa\textsuperscript{114} has a high frequency among the Sotho people of Northern South Africa. One study, carried out in 1982, of the incidence of oculocutaneous albinism amongst the South African black population determined

\begin{itemize}
  \item \textsuperscript{106} National Organisation for Albinism and Hypopigmentation at http://www.albinism.org/popcult/intro.htm (visited 15 May 2011).
  \item \textsuperscript{108} Russell PJ \textit{Fundamentals of Genetics} (2000, London: Longman Publishing Group) at 45.
  \item \textsuperscript{109} Burns B Jet \textit{The weekly News Magazine} 1 (9) at 62.
  \item \textsuperscript{110} Uromi 324.
  \item \textsuperscript{111} John P “Strategies to Address Vulnerable Populations” at http://hir.harvard.edu/archives/3018 (visited 10 June 2015).
  \item \textsuperscript{112} The Special Representative’s submission of the Office of the High Commissioner for Human Rights noted that the lack of sufficient registration of important statistics, such as information on birth and death increases the prospect of cases going unreported and failing to be investigated, see the United Nations, General Assembly, \textit{Report on Persons with Albinism}, 12 September 2013, A/HRC/24/57 at 8.
  \item \textsuperscript{113} Sacharowitz 45. Also see John at http://hir.harvard.edu/archives/3018 (visited 11 March 2015)
  \item \textsuperscript{114} Lund & Gaigher 365.
\end{itemize}
seven diverse ways of establishing who was affected by the disorder.\textsuperscript{115} Among the 126 families that had members who were affected by albinism, 113 were males and 93 females. At the time, the Black population of Soweto was more or less 803,511.\textsuperscript{116} Based on these statistics, the incidence of albinism was found to be 1 per 3,900. The carrier rate of the albinism gene is around 1 in every 32 persons.\textsuperscript{117} The number of persons living with albinism was estimated to be 1 per 2,254 amongst the Southern Sotho, 1 per 4,700 amongst the Xhosa, 1 per 9,700 amongst the Pedi and 1 per 28,614 among the Shangaan inhabitants of South Africa.\textsuperscript{118}

In Nigeria the occurrence of albinism is approximately one in 5,000.\textsuperscript{119} A 2006 review published in the journal *BMC Public Health*, gives the occurrence in Tanzania as 1 in 1,400.\textsuperscript{120} Considering that Tanzania’s total population is more than 40 million, this implies a community of about 30,000 albinos.\textsuperscript{121}

The table below, referred to by Hong in 2006, provides an overview of the estimated prevalence of albinism by country:\textsuperscript{122}

\begin{table}[h]
\begin{tabular}{|c|c|}
\hline
Country & Estimated Prevalence \\
\hline
Nigeria & 1 in 5,000 \\
Tanzania & 1 in 1,400 \\
South Africa & 1 in 3,900 \\
\hline
\end{tabular}
\end{table}

\textsuperscript{115} Kromberg & Jenkins 386.
\textsuperscript{116} Kromberg & Jenkins 386.
\textsuperscript{117} Kromberg & Jenkins 386.
\textsuperscript{118} Kromberg & Jenkins 386.
\textsuperscript{119} Robins AH *Cambridge studies in Biological Anthropology, Biological Perspectives on Human Pigmentation* (2005, Cambridge: Cambridge University Press) at 140. Robins derives these statistics from Kromberg & Jenkins at 383.
\textsuperscript{120} Hong et al 2.
\textsuperscript{121} Hong et al 2.
\textsuperscript{122} Hong et al 2.
<table>
<thead>
<tr>
<th>Author</th>
<th>Country/Population*</th>
<th>Study details</th>
<th>Prevalence</th>
<th>Estimated number in country**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kromberg et al. (11)</td>
<td>South Africa /45,026,000</td>
<td>Cross-sectional study. Subjects were ascertained through all 120 schools, 6 health clinics and 2 hospitals in Soweto and interviewed; 213 albinism cases found; 206 interviewed</td>
<td>1/3,900</td>
<td>11,545</td>
</tr>
<tr>
<td>Kagore et al. (14)</td>
<td>Zimbabwe /12,835,000</td>
<td>Postal survey of all secondary schools within the Harare regional office area; second mailing in 3 months; visited, if there was no response</td>
<td>1/2,833</td>
<td>4,531</td>
</tr>
<tr>
<td>Lund (13)</td>
<td>Zimbabwe /12,835,000</td>
<td>Nationwide survey to schools; age range of 6–23 yrs; 278 albinism cases</td>
<td>1/4,728</td>
<td>2,715</td>
</tr>
<tr>
<td>Lund et al. (9)</td>
<td>Zimbabwe /12,835,000</td>
<td>Follow up on the above study which identified a cluster of OCA2* in Tonga community; 11 albinism cases; 5 adults and 1 school girl were interviewed</td>
<td>1/1,000</td>
<td>---</td>
</tr>
<tr>
<td>Luande et al. (17)</td>
<td>Tanzania /36,977,000</td>
<td>Cross-sectional study. Questionnaire to 350 registered people with albinism in Tanzania Tumor Centre</td>
<td>1/1,400</td>
<td>---</td>
</tr>
<tr>
<td>Okoro (8)</td>
<td>Nigeria /124,009,000</td>
<td>Cross-sectional study. Questionnaires distributed to people with albinism who came to the hospital; expanded the study to educational, health, religious institutions and markets in East Central state; 517 albinism cases</td>
<td>1/15,000</td>
<td>8,267</td>
</tr>
</tbody>
</table>

This table, although dated and only providing a rough estimate, shows that countries on the African continent are disproportionately affected by the condition, with Tanzania showing the highest occurrence of albinism. It is also no coincidence that discrimination against and intolerance of persons with albinism are more prevalent in Tanzania.
PART IV

1.9 Living with albinism during apartheid

The question arising is what the position of albinos on the local front is, and to what extent South Africa’s apartheid history may have contributed to present perceptions regarding albinos. The racial classification of the apartheid era affected Black persons with albinism in a very specific way, as will be considered elsewhere in the thesis. In terms of the Population Registration Act, all South Africans had to be racially classified into one of the three categories, White, Black, or Coloured. Black persons with albinism defied some of these classifications, which made them vulnerable to additional hardship and unfair discrimination. Traces of this effect amongst Black albinos are still prevalent in the present South African context.

1.10 Albinism in the era of the new constitutional democracy

This section provides a brief contextualisation of the constitutional framework, with emphasis on selected fundamental rights at threat as a result of the manner in which persons living with albinism are treated, which will be explored in more detail in a subsequent chapter.

The stigmatisation of persons with albinism often leads to discrimination and other violations of human rights which affect their well-being. Mention was made above of the fact that there is still much ignorance amongst the general public and certain communities regarding the subject of albinism and persons affected by the condition. Sadly, this phenomenon does not only affect albinos, but also those suffering from other genetic conditions.

Besides popular culture, myths and various cultural beliefs regarding albinos influence the way in which people perceive them. One of the most devastating consequences of adhering to such beliefs, myths and stereotyping of albinos is the possibility of stigma. Stigma prompts a noteworthy loss of self-esteem in particular,

123 Population Registration Act 30 of 1950.
so that albinos may possibly conclude that they are worthless. Stigma is likely to have an effect on people through mechanisms of direct discrimination, such as reluctance to employ the person; structural discrimination, such as the availability of a smaller number of resources for research and treatment; or socio-psychological processes, which encompass the stigmatised person’s perceptions.\textsuperscript{125}

In order to identify possible solutions to albinism-related stigma and discrimination, it is essential to know what is meant by stigma and discrimination, to analyse the relationships between these two phenomena, to explain how they are apparent among albinos, as well as to highlight the most important, yet applicable laws that aim to eliminate the practice of stigma and discrimination among vulnerable members of communities in South Africa.

The word “stigma” relates to an active course of action of depreciation which “significantly discredits” an individual in the eyes of others.\textsuperscript{126} The traits to which stigma most often relate may be very subjective, for example, skin colour, manner of speaking or sexual preference, amongst others.\textsuperscript{127}

Through such associations, stigma is linked to the vulnerable members of society, thereby generating and strengthening inequalities in the sense that some groups are made to feel superior and others devalued. The association of film stereotypes regarding the “evil albino”, with already existing cultural beliefs, myths and superstitions about albinos, as discussed above, reinforces pre-existing differences, generating the creation as well as re-creation of unbalanced relations between groups of people. Stigmatisation may have the result that albinos internalise the harmful reactions that are generated by ignorance, cultural beliefs and myths. Self-stigmatisation concludes the vicious cycle created by this prejudice, because its primary consequence is that it impinges on an individual’s or affected community’s self-esteem and worth,\textsuperscript{128} leading to feelings of shame, self-blame and

\begin{itemize}
\item \textsuperscript{125} Bruce G \textit{et al} “Stigma as a Barrier to Recovery: The Consequences of Stigma for the Self-Esteem of People with Mental Illnesses” (2001) 52 (12) \textit{Psychiatric Services} 1621-1626 at 1622.
\item \textsuperscript{126} Aggleton P \textit{et al} \textit{HIV-Related Stigma, Discrimination and Human Rights Violations} (2005, Geneva: UNAIDS) at 7.
\item \textsuperscript{127} Aggleton \textit{et al} 7.
\item \textsuperscript{128} Aggleton \textit{et al} 9.
\end{itemize}
worthlessness, as well as isolation from society as a whole, depression, self-imposed withdrawal and suicidal thoughts.

The most obvious result of stigmatisation is discrimination.\textsuperscript{129} Discrimination consists of actions or omissions that result from stigma and is aimed at persons who are stigmatised.\textsuperscript{130} The Joint United Nations Programme on HIV/AIDS (UNAIDS) 2000, in the \textit{Protocol for Identification of Discrimination against People Living with HIV}, defines discrimination as

\begin{quote}
any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic […] belonging to a particular group […] irrespective of whether or not there is any justification for these measures.\textsuperscript{131}
\end{quote}

Besides dealing with issues such as photophobia, decreased visual acuity, extreme sun sensitivity and skin cancer, albinos on the African continent may face discrimination in a social and legal context.\textsuperscript{132} A great deal of the social discrimination emerges from lack of education or ignorance regarding the etiology of albinism.\textsuperscript{133} The discrimination against albinos ranges from the contexts of health care to education, the family and employment.\textsuperscript{134} Even in South Africa, whose Constitution and Bill of Rights are heralded as one of the most progressive in the world, the marginalisation of specifically Black albinos continues.

Stigma and discrimination are closely connected, supporting and legitimising each other.\textsuperscript{135} Stigma lies at the root of discriminatory actions, making people engage in actions or omissions that damage or refute services or entitlements to others.\textsuperscript{136}

\textbf{1.10.1 The right to equality}

Unfair discrimination is a violation of fundamental rights. The principle of non-discrimination, based on recognition of the equality of all people, is enshrined in the

\begin{itemize}
\item \textsuperscript{129} Aggleton \textit{et al} 9.
\item \textsuperscript{130} Aggleton \textit{et al} 9.
\item \textsuperscript{131} UN Joint Programme on HIV/AIDS (UNAIDS), \textit{Protocol for the Identification of Discrimination Against People Living With HIV}, May 2000, UNAIDS/00.05E.
\item \textsuperscript{132} Hong \textit{et al} 2.
\item \textsuperscript{133} Hong \textit{et al} 2.
\item \textsuperscript{134} Phatholi 1-10.
\item \textsuperscript{135} Aggleton \textit{et al} 13.
\item \textsuperscript{136} Aggleton \textit{et al} 13.
\end{itemize}
South African Constitution.\textsuperscript{137} It may be argued that in the South African Constitution, equality rights hold a position of pre-eminence. Although the sequence of rights in a bill of rights does not generally determine their significance in relation to one another, the drafters of Chapter 2 of the Constitution, which contains the Bill of Rights, listed equality first in order to stress its primary significance. The crucial nature of equality, especially racial, gender and sex equality, becomes clear from a contextual reading of section 9.

The preamble states that one of the objectives of creating a new order in South Africa is to ensure that there is equality between men and women and people of all races so that all citizens can enjoy their fundamental rights and freedom. Despite the predominantly vertical operation of section 9, section 9(2) authorises measures designed to prohibit unfair discrimination.\textsuperscript{138} Stigmatising and discriminatory actions, as a result, infringe upon the elementary human right to freedom from discrimination.\textsuperscript{139}

Several watershed cases\textsuperscript{140} relating to equality have been heard before the South African courts, each with a unique contribution to the analysis and interpretation of the equality clause. Some of these cases will be explored in a subsequent chapter of

\textsuperscript{137} Section 9 of the Constitution of 1996 reads as follows:
9(1) “Everyone is equal before the law and has the right to equal protection and benefit of the law. (2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken. (3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth. (4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination. (5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.”

\textsuperscript{138} Currie & De Waal 242-243. Also see National Coalition for Gay and Lesbian Equality v Minister of Home Affairs 2000 (1) BCLR 39 (CC) at paragraph 62.

\textsuperscript{139} Aggleton et al 11.

\textsuperscript{140} Among others, these cases include; In re Certification of the Constitution of the Republic of South Africa 1996 (10) BCLR 1253 (CC); Mthemba v Letsela and Another 1998 (2) SA 675 (T); Hoffman v South African Airways 2000 (2) SA 628 (W); Government of the Republic of South Africa and Others v Grootboom and Others 2000 (11) BCLR 1169; South African Human Rights Commission and Another v President of the Republic of South Africa and Another 2005 (1) SA 580 (CC); Woolworths (Pty) Ltd v Whitehead (Women’s Legal Centre Intervening) 2000 (3) SA 529 (LAC); Carmichele v Minister of Safety and Security 2001 (10) BCLR 995 (CC); S v Jordan (Sex Workers Education & Advocacy Task Force as Amicus Curiae) 2002 (11) BCLR 1117 (CC); Standard Bank of South Africa v Commission for Conciliation, Mediation and Arbitration and Others 2008 (4) BLLR 356 (LC); and IMATU & Another v City of Cape Town 2005 (11) BLLR 1084 (LC) 1091.
this thesis. Relevant international human rights instruments\textsuperscript{141} that prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, property, birth or other status will also be explored.

Stigmatisation of and unfair discrimination against persons with albinism may be addressed by raising awareness of and ensuring compliance with the fundamental rights protection afforded by the Constitution and other existing human rights instruments.

Some of the fundamental rights contained in the South African Bill of Rights that will be explored in more detail later in the study are the rights to life, access to health care services, human dignity, freedom and security of the person, social security, education and privacy. These rights will briefly be contextualised below.

1.10.2 The right to life

Section 11 of the South African Constitution recognises that everyone has the right to life. It was emphasised in the \textit{Carmichele} case\textsuperscript{142} that the constitutional guarantees of the right to life, the right to dignity as well as the right to freedom and security of the person impose an obligation on the state, as well as all its organs, to refrain from infringing on such rights. In certain situations, this guarantee also entails a positive duty to afford proper protection to every person through the laws and organisations intended to give such protection.\textsuperscript{143}

In Tanzania, where discrimination against albinos is rife, the right to life is regarded as one of the most important of all the entrenched rights.\textsuperscript{144} The right to life is

\begin{footnotesize}
\begin{enumerate}
  \item \textit{Carmichele v Minister of Safety and Security} (2001) 4 SA 938 (CC) at paragraph 29. Also see Westmarland N & Gangoli D \textit{International Approaches to rape} (2011, Bristol: The Policy Press) at 173.
  \item Westmarland & Gangoli 173.
  \item Uromi 331.
\end{enumerate}
\end{footnotesize}
guaranteed in the Tanzanian Constitution under article 14. The violation of the right to life in Tanzania carries the death penalty.

Other relevant provisions in international conventions, as well as regional African treaties designed to promote the right to life of persons living with albinism, will also be explored elsewhere in this study. For example, the African Charter on Human and Peoples’ Rights stipulates in Article 4 that

> [h]uman beings are inviolable. Every human being shall be entitled to respect for his life and integrity of his person. No one may be arbitrarily deprived of this right […].

Article 3 of the Universal Declaration of Human Rights declares the right to life in absolute terms, by stating that [e]veryone has the right to life, liberty and security of person. Article 6 of the International Covenant on Civil and Political Rights provides that

> [e]very human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

These are just a few examples that emphasise the importance of the right to life in a broader context, discussed in more detail later.

1.10.2.1 Albino murders

The murdering of albinos and disabled children is widely documented in anthropological literature on albinism. Fuelled by some of the myths and stereotypes, some discussed above, albino murders are shrouded in secrecy. This is reflected in fictional representation of the killing of albinos, portrayed as a mysterious act that is carried out discreetly. Witches are involved in an illegal trade in albinoskin, bones and hair that are used in potions and charms to pass good luck and

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145 Article 14 of the Constitution of Tanzania reads as follows: “Every person has the right to live and to the protection of his life by the society in accordance with the law”.
147 Article 3 of the Universal Declaration of Human Rights of 1948.
148 Article 6 of the international Covenant on Civil and Political Rights of 1976.
149 Twohig & Kalitzkus 121.
150 Twohig & Kalitzkus 122.
make people rich.¹⁵¹ As mentioned above, the graves of albinos are often opened up and pillaged for body parts.¹⁵²

The phenomenon of albino murders has been analysed through a range of lenses that are often at odds with each other.¹⁵³ One lens positions itself as a neo-functionalist and occult economic argument; another is based on a shared depiction of rumour and gossip where people tell and retell about the albino killings, while the final lens is based on exploitation of ethical hierarchies to maintain legitimate authority and power.¹⁵⁴ The neo-liberal theory acknowledges that there is a localised belief in witchcraft which perseveres as a solution to the failures in Tanzania’s economics and politics.¹⁵⁵ The political elite, who every so often play a part in occult practices, place themselves at the uppermost of a moral hierarchy with the intention of gaining support from the international community.¹⁵⁶ Rumours permit the social elite to retain positions of power and authority in the international arena for the reason that they are able to place themselves in a situation of power by being agents of modernity and opponents to tradition; precisely the kind of thought international

¹⁵² Schnoebelen 17.
¹⁵⁵ Bryceson et al 354,365 and 374. Also see Sanders 1-83.
¹⁵⁶ “Witchcraft belief is abundant among politicians who are believed to use the belief to bring them luck needed to win in elections at all levels”. See Masanja MM “Albinos’ Plight: Will Legal Methods be Powerful Enough to Eradicate Albinos’ Scourge?” (2015) 3 (5) International Journal of Education and Research 231-244 at 234. “The killings are known to peak during election times as demand increases for magical portions by politicians seeking election or re-election. Killings have been reported in Kenya, Uganda, Congo and Burundi possibly to sell the organs in Tanzania. The trend has now hit southern African countries with killings reported in Swaziland and Zimbabwe. Similar cases have been reported in Mali, West Africa. Also, people in Benin believe that blood of persons with albinism has magical properties and that it brings prosperity and luck. The fingers of persons with albinism are worn on necklaces around people’s necks as amulets”. See Uromi 328. Ackely at http://www.underthesamesun.com/sites/default/files/The%20Fetishization%20of%20Albinos%20in%20Tanzania.pdf (visited 15 June 2015).
humanitarian organisations want to hear so as to provide more aid money.\textsuperscript{157} For the purpose of this study, the brief reference to these arguments serves to illustrate the complexity of albino stereotypes and beliefs which feed the vicious cycle of the prejudice against and fear of albinos in general. Any approach that aims to analyse and understand the multi-faceted and complex issue of albino prejudice should clearly be a multi-, inter- and trans-disciplinary one.

The albino murders are inevitably linked to an understanding of these myths and stereotypes, such as, for example, the belief that a potion for wealth and good fortune can be prepared with the blood, limbs and hair of a person living with albinism.\textsuperscript{158} Witch doctors are alleged to be the source of such fallacies.\textsuperscript{159} In Tanzania, the problem is so severe that even the Tanzanian Minister of Home Affairs has referred to Tanzania as the capital of witchcraft and albino murders.\textsuperscript{160}

The majority of reported murders have taken place in the northern Lake Region in Tanzania, although there have also been reports of murders in countries sharing its borders.\textsuperscript{161} These murders have taken place in remote regions where the inhabitants are rooted in traditional beliefs and more inclined to comply with the authorities of witchdoctors in enlightening the causes of their hardships or misfortunes.\textsuperscript{162} Witch doctors who reside in these villages are revered and respected.\textsuperscript{163} Such fear has led some villagers to kill a family member purely for the reason that a witch doctor has instructed such a murder.\textsuperscript{164} Prices vary from witch doctor to witch doctor depending on their suppliers.\textsuperscript{165} The starting price for a potion is approximately $2,000, but a witch doctor could easily earn up to $30,000 for an entire albino body.\textsuperscript{166} A full set of

\begin{thebibliography}{99}
\item Bryceson \textit{et al} 355.
\item Uromi 327.
\item Uromi 327. Also see Masanja 231
\item Alum \textit{A et al} "Hocus Pocus, Witchcraft, and Murder: The Plight of Tanzanian Albinos" International Team Project, December (2009)1-59 at 10.
\item Uromi 327.
\item Schühle 3-4.
\item Dave-Odigie 68.
\item Ackely at http://www.underthesamesun.com/sites/default/files/The%20Fetishization%20of%20Albinos%20in%20Tanzania.pdf (visited 15 June 2015). Also see Dave-Odigie 71.
\item Schühle 14.
\item Alum \textit{A et al} 11. The Tanzanian Shilling is the currency of Tanzania. Reference to $ refers to United States dollars.
\end{thebibliography}
albino body parts comprising of all four limbs, genitals, ears, the tongue and nose was priced to the equivalent of $75,000.\textsuperscript{167}

Some fishermen in the fishing industry believe that weaving the golden hair of an Albino into the fishing nets will attract more fish and result in a bigger catch.\textsuperscript{168} It is widespread practice to sprinkle the ground-up hair and bones of an albino over the nets.\textsuperscript{169} However, despite the prevalence of this practice, local fishermen in Dar es Salaam claim that it is difficult to engage in these practices as a result of the constant patrolling of fishing grounds by regional police.\textsuperscript{170} Also in the mining industries, the legs, bones and blood of albinos are sought for use in potions.\textsuperscript{171} These potions are sprinkled over the mining sites in anticipation of extracting precious minerals.\textsuperscript{172} These miners occasionally place the blood of an albino in an amulet that they wear for the rest of their lives.\textsuperscript{173}

Closer to home, the murder of albinos is not as common as appears to be the case elsewhere in Africa.\textsuperscript{174} Muti murders, however, do take place from time to time. A recent case, reported in July 2011 in South Africa, referred to an albino boy who went missing on his way home from school and was believed to have been snatched with the intent of using the child for the purpose of a tribal sacrifice.\textsuperscript{175} The recent disappearance of the 14-year old albino adolescent, Sibususo Nhatave, led to an extensive investigation in the eastern province of KwaZulu-Natal, as he was feared to have been a victim of witchcraft and murder for his body parts.\textsuperscript{176}

\begin{footnotesize}
\begin{itemize}
    \item \textsuperscript{167} International Federation of Red Cross and Red Cross Crescent Societies, Advocacy Report, 5.
    \item \textsuperscript{168} Ackely at http://www.underthesamesun.com/sites/default/files/The%20Fetishization%20of%20Albinos%20in%20Tanzania.pdf (visited 15 June 2015). Also see Uromi 327.
    \item \textsuperscript{169} Uromi 323.
    \item \textsuperscript{170} Alum \textit{et al} 12.
    \item \textsuperscript{171} Schühle 3, 5 and 17-22.
    \item \textsuperscript{172} Alum \textit{et al} 12. Also see Schühle 15.
    \item \textsuperscript{173} Alum \textit{et al} 12.
    \item \textsuperscript{175} Hlongwane at http://www.iol.co.za/news/south-africa/kwazulu-natal/fear-as-albino-boy-vanishes-1.1092451#.VYkfCvmqqko (visited 15 June 2015). Sibusiso Nhatave, a 14-year-old boy with albinism, was last seen talking to a man outside his school, Ikhandela Junior Secondary in ESikhawini, on the north coast of KwaZulu-Natal, where he was in Grade 8.
\end{itemize}
\end{footnotesize}
Another recorded scandalous case in South Africa associated with albinism and muti was that of Sipho Lolwane, an albino who passed on in 2002 and whose grave was defiled and robbed a number of times for the remains of his bones.\textsuperscript{177} Police spokesperson, Captain Amanda Funani, stated that a sangoma and his driver had been apprehended with the bones of Sipho Lolwane, discovered by the police while patrolling the Moletsamongwe cemetery in Modimola.\textsuperscript{178} The police guarding the area noticed the sangoma and his driver departing from the cemetery with a bag.\textsuperscript{179} The forensic department took the bones for pathology tests and a case of desecration of a grave was opened.\textsuperscript{180} The family indicated that the suspects besieged the grave for the reason that it belonged to an albino, stating that this fuelled existing myths that albino bones can be used for muti purposes.\textsuperscript{181} The deceased’s younger brother, Willie Lolwane, also an albino, noted that

\begin{quote}
We are not safe, people see us as muti ingredients instead of ordinary people.\textsuperscript{182}
\end{quote}

Despite these reported cases specific to albinism, muti murder still happens with alarming regularity in South Africa. The manifestation of muti murder and witchcraft murder in South Africa is considered next.\textsuperscript{183}

\begin{flushright}
\textsuperscript{180} Tlape O “Sangoma Bust with Bones at Graveyard” at http://152.111.1.87/argief/berigte/dailysun/2012/10/08/DK/5/DK%20ALBINO.html (visited 15 June 2015).
\textsuperscript{182} Tshehle at http://www.sowetanlive.co.za/news/2012/10/08/sangoma-nabbed-for-bones-dug-up-in-grave (visited 15 June 2015). For a more detailed discussion on the occurrences of muti murder in South Africa, see the discussion under Chapter 3 on the limitation of the right to life among persons with albinism under Constitutional scrutiny.
\end{flushright}
1.10.2.2 Witchcraft and muti murder in South Africa

Muti murder has become ritualised, as a certain procedure is followed, but it is not in itself a sacrificial act in the sense of appeasing a god or deity. Muti murder takes place when someone is murdered and parts of the body are used as ingredients for medicinal purposes. The term “ritual murder” is frequently used synonymously with sacrificial murder, in other words, where the intention is to offer the life of a human being to appease a divine being.

Witchcraft, generally seen as the ability to cause damage or accumulate illicit wealth and power by mystical means, is a vital feature of African life in South Africa. Ever since the first independent elections in South Africa, witchcraft has been rapidly increasing. Witchcraft is not presently on the political agenda of South Africa as the state is being reconstructed in the image of a contemporary open-minded democracy. South Africa is at this time governed as a contemporary liberal democratic state, in the process of reintegrating itself into the international community with its universal circuits of people, capital and cultures. Principal discourses of jurisprudence, public management, and political and economic administration globally leave little room for concerns about witchcraft as anything other than an ancient system of beliefs caught up in lack of knowledge and backwardness. Witchcraft, however, even in the modern cities of the new South

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185 Scholtz et al 117.
186 Labuschagne 193.
187 Labuschagne 193.
189 Ashforth 505.
190 Ashforth 505.
192 Ashforth 505.
Africa, remains a lively concomitant of everyday life.\textsuperscript{193} Life is lived on the supposition that the powers of witches are existent, undeniably true and vast.\textsuperscript{194}

Witches are characteristically understood to be engaged in actions akin to violence by bringing harm to innocent citizens.\textsuperscript{195} They are perpetrators of a form of crime and a threat to the community as a whole.\textsuperscript{196} Underpinning this study is an analysis of alleged reports of how witches hire people to kill the innocent (including albinos) for the purpose of using parts of their bodies for muti. The aim of this investigation is to question and challenge the legitimacy of such an act in a democratic regime like South Africa, particularly against the background of the Bill of Rights. This issue is discussed in more detail in a subsequent chapter.

1.10.3 Access to health care

Chapter 2 of the study investigates some of the health problems related to albinism. The major disabilities of people living with albinism are poor vision and skin cancer.\textsuperscript{197} Some of the eye problems are improved, for example, by the wearing of tinted or dark glasses to help reduce glare, and prescriptions to improve refractive errors.\textsuperscript{198} Above all, treatment of eye conditions in albinism consists of visual rehabilitation.\textsuperscript{199} Surgical treatment to correct the strabismus may possibly mend the appearance of the eyes.\textsuperscript{200}

Apart from the visual handicaps affiliated with albinism, sun exposure is highly detrimental to the hypopigmented skin. Lack of melanin exposes albinos to extreme

\textsuperscript{193} Ally Y "Witchcraft Accusations in South Africa: A Feminist Psychological Exploration" 2013 Thesis Submitted in Accordance with the Requirements for the Degree of Doctor of Literature and Philosophy in the subject Psychology at the University of South Africa 1-82 at 5.

\textsuperscript{194} Ashforth 505.

\textsuperscript{195} Ashforth 505.

\textsuperscript{196} Ashforth 505.


\textsuperscript{198} Brodsky MC Pediatric Ophthalmology (2010, New York: Springer) at 405. Also see Enderle JD Horizontal Eye Movements Early Models of Saccades and Smooth Pursuits (2010, San Raelaf: Morgan & Claypool) at 164; and Norman 41.


\textsuperscript{200} Rosenbaum AL & Santiago AP Clinical Strabismus Management: Principles and Surgical Techniques (1999, New York: Elsevier Health Sciences). Also see Norman 41.
skin damage, subsequently resulting in skin cancer.\textsuperscript{201} The majority of these lesions are in the most sun-exposed parts of the body such as the face, ears, neck and shoulders.\textsuperscript{202} Skin lesions include sunburns, blisters, solar elastosis or keratosis, ephelides, lentiginosis and superficial ulcers.\textsuperscript{203} Ultimately, squamous cell and, less frequently, basal cell carcinomas may occur.\textsuperscript{204}

In Africa, life is difficult for many marginalised groups, but even more so for people with albinism.\textsuperscript{205} Poverty and lack of knowledge about the condition, for example, lead to lack of protection against the burning sun\textsuperscript{206} and premature deaths as a result of skin cancer.\textsuperscript{207} If proper skin protection, such as sunscreen lotion with a protection factor of twenty or higher and opaque clothing are worn, people with albinism can also participate in outdoor activities, even during summer.\textsuperscript{208}

The right to access to health care and health care services is pivotal to albinos who are victims of severe eye and skin problems. In this regard, the nature of the right to access health care services as interpreted by South African courts in recent decisions, will be discussed.

Public health programmes need to take into account the diverse challenges facing people with albinism. At present, there are some programmes ready to deal with the health concerns of albinos in certain parts of Africa.\textsuperscript{209} For example, the Regional Dermatological Training Centre (RDTC) in Moshi, Tanzania, runs a mobile skin care clinic where a doctor and nurse frequently visit villages to ensure that the skin of people living with albinism is protected against radiation and to educate them on the

\textsuperscript{201} Hong et al\textsuperscript{4}.
\textsuperscript{202} Bradley J et al Cape Town, Winelands and the Garden Route (2011, Cape Town: Modern Overland) at 50.
\textsuperscript{203} Hong et al\textsuperscript{4}.
\textsuperscript{205} Norman 39
\textsuperscript{206} Norman 39
\textsuperscript{207} Norman 39
\textsuperscript{208} Cassidy SB & Allanson JE Management of Genetic Syndromes (2005, Somersert: John Wiley & Sons) at 46. Also see Norman 39.
\textsuperscript{209} Hong et al\textsuperscript{6}.
relevant measures to protect themselves from the sun.\textsuperscript{210} South Africa does not have such a facility specifically catering for people with albinism, but the Cancer Association of South Africa (CANSA) has very few Mobile Health Clinics for the general public, which travel to all provinces in South Africa in a bid to reach those without access to cancer screening.\textsuperscript{211}

A school for the visually impaired, with protected walkways, trees in the courtyard and shutters on the windows in order to decrease sun exposure, has been founded.\textsuperscript{212} Despite these efforts, as will be illustrated in a subsequent chapter, more is urgently required to effectively address the health and social needs of people with albinism.

Section 27 of the Constitution provides for the right of access to health care services, which incorporates reproductive health care as well.\textsuperscript{213} Similarly to other socio-economic rights, the right to access to health care is subject to “budgetary implications” and limitations, as the positive duties imposed on the state are visibly restricted.\textsuperscript{214} This section, and its relevance to persons living with albinism, will also be discussed in more detail later in the study.

\textbf{1.10.3.1 The effect of climate change}

Human health is capable of being affected by a broad range of ecological interruptions, such as climate change.\textsuperscript{215} This thesis would be remiss if it did not briefly refer to the issue of climate change, ultraviolet (UV) radiation and fair skinned populations. Several studies indicate that UV radiation is harmful to living organisms and damaging to human health.\textsuperscript{216} Concern about the increased levels of UV-B
radiation reaching the earth’s surface has resulted in the development of ground- and space-based dimension programmes. Scientists believe that the joint result of current stratospheric ozone depletion and its existence in the decades to come will increase the rate of skin cancer in fair-skinned populations.

Chapter 2 of this study, which explores the medical aspects relating to albinism in more detail, will briefly discuss the current and predicted levels of UV radiation and its associated impact on human health, specifically its impact on persons living with albinism. The legal relevance of this development, which is unique to albinos whose susceptibility to skin cancer is very high, above all relates to the need for additional resources to which these persons should have access in terms of any entitlement to health care and health care services.

1.10.4 The right to human dignity

It is necessary to point out at the outset that the right to human dignity of persons living with albinism cannot be severed from a discussion relating to the right to life and the right to equality. Albinos are a very vulnerable group whose appearance is often ridiculed or feared. The protection of their right to human dignity will be addressed in more detail in a subsequent chapter.

1.10.5 The right to freedom and security of the person

The murder of albinos has caused uneasiness among the albino community, who have started to feel very insecure when staying, walking or travelling alone. The Bill of Rights affords everyone the right to freedom and security of the person, including the right:

a. not to be deprived of freedom arbitrarily or without just cause;
b. not to be detained without trial;
c. to be free from all forms of violence from either public or private sources;
d. not to be tortured in any way; and
e. not to be treated or punished in a cruel, inhuman or degrading way.

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217 Ghetti et al 85-95.
218 McMichael 65-68.
219 Section 12 of the Constitution of 1996.
This study will look more closely at whether the violence to which albinos are generally exposed on a continuous basis constitutes an infringement of the right to freedom and security of the person as listed in section 12 of the Constitution.

1.10.6 The right to social security

Social security law and its implementation in South Africa are premised on a rights-based framework.\textsuperscript{220} The right to social security is a fundamental right in many contemporary states and an essential foundation of society.\textsuperscript{221}

For several people with disabilities, their limited prospects in respect of education, training and employment compound their exposure to poverty and poor living conditions.\textsuperscript{222} For this reason, several adults and children with disabilities need access to a regular form of income to compensate for the loss of income, as well as the extra costs resulting from their medical condition.

Whilst every effort has been made in South Africa to incorporate disabled people under the Social Security Act,\textsuperscript{223} a question arises as to whether people with albinism qualify for social security grants on the basis of their condition or because of the disability associated with their condition. In this regard, the study will take a close look at whether albinos are appropriately considered by the social security system in South Africa.

1.10.7 Special education for people living with albinism

As mentioned already, visual impairments are a common feature of albinos.\textsuperscript{224} Children with albinism experience problems that are not only of a legal, physiological and socio-physiological nature, but also educational. A special school is an ideal setting for people affected by albinism, with the entire school focused on and being aware of the harmful effects of the sun and the importance of skin protection. The school authorities could support its implementation by scheduling the time of outdoor

\textsuperscript{220} Olivier P et al The Role of Standards in Labour and Social Security Law, International Regional and National Perspectives (2013, Cape Town: Juta) at 122-123.
\textsuperscript{221} Olivier P et al 122.
\textsuperscript{224} Lund & Gaigher 371.
activities, such as gardening and sport, to the early hours of the day or during the late afternoons to avoid high heat exposure. In essence, the special school provides an ideal environment for young children with albinism.

The limited capacity of special schools, particularly in rural areas, has resulted in the majority of learners from these areas being excluded from educational opportunities altogether, as the environment in regular schools does not facilitate integration.

The South African Department of Basic Education recently indicated that it is estimated that 489 036 children with disabilities of school-going age are presently not attending school. This naturally results in illiteracy and low skills amongst adults with disabilities, contributing significantly to high levels of unemployment. The right of children with albinism to education, with special focus on special needs education, requires a more detailed discussion in a subsequent chapter.

1.10.8 The right to privacy

The right to privacy is protected in section 14 of the Constitution which reads as follows:

Everyone has the right to privacy, which includes the right not to have -
(a) their person or home searched;
(b) their property searched;
(c) their possessions seized; or
(d) the privacy of their communications infringed.

This right will be discussed in detail in a subsequent chapter. The right to privacy in the context of albinism has several implications for people living with the condition which include privacy and confidentiality in the realm of their health, genetic tests and counselling, medical information as well as genetic and genomic research.

1.11 Definitions

- The term strabismus refers to the muscle imbalance of the eyes, “crossed eyes” (esotropia), “lazy eye” or an eye that deviates out (exotropia). Crossed eyes can

225 Lund & Gaigher 371.
be treated during infancy using eye patches and surgery or medicine injections.\textsuperscript{227} Treatment may improve the appearance of the eye.\textsuperscript{228}

- The term “gene” refers to the basic unit of genetic material located at a particular place on a chromosome.\textsuperscript{229} Genes are passed on from parents to children when the sperm and egg unite during conception.\textsuperscript{230}

- “DNA” is the acronym for “deoxyribonucleic acid,” the primary carrier of genetic information found in the chromosomes of almost all organisms.\textsuperscript{231} The entwined double structure allows the chromosomes to be copied exactly during cell division.\textsuperscript{232}

- “Melanin” is the pigment made in the hair, skin and eyes.\textsuperscript{233}

\textbf{1.12 Conclusion}

An investigation of the medical and legal issues that arise in relation to albinism is long overdue. These issues are complex and relate to a broad range of constitutional, social, socio-legal and clinical issues. This study makes specific suggestions and recommendations which will assist in a better understanding of the legal challenges facing persons living with albinism, as well promoting their protection in terms of South African law.

\textsuperscript{227} Sacharowitz 41. Also see Dominguez 14.
\textsuperscript{232} Schaechter 285. Also see Meyers 236,365, 836-840 and 915; Kakeshita 275; and Newton 90.
\textsuperscript{233} Riede UN & Werner N \textit{Color Atlas Pathological Principles} (2011, New York: Thieme Verlag) at 112.
CHAPTER 2: CLINICAL OVERVIEW OF ALBINISM

“If lawyers are to be competent members of the public health team and understand the public health implications of the laws, rules, and regulations they draft, enforce, litigate, and adjudicate, they should be more firmly grounded in the theory, practice, and problems of public health.” 1

2.1 Contextual background and significance of the chapter

Although most legal researchers do not characteristically have training in medicine, the need to research health care, diagnoses, injuries, and of course medical terminology arises from time to time. 2 The scope of the relationship between medicine and law is immense. It ranges from issues relating to health care, the impact of law on medical practice, for instance, informed consent, neglectful diagnosis and treatment, confidentiality, human reproduction and euthanasia, to issues relating to the impact of medicine on law, such as post-mortem investigations, intoxication, degrees of incapacity, and evaluation of personal injury, 3 to mention but a few.

Legal research involving a strong medical component requires one to be aware of the fine points, and to have a fundamental understanding of the most relevant medical details. The following pages will discuss all the pertinent clinical aspects of albinism in order to gain greater insight into this condition, with the aim of contextualising the legal discussion in the rest of the thesis and addressing some of the misconceptions regarding albinism. The continued study and understanding of the genetics behind albinism is as important as any other awareness campaign of any stigmatised condition or disease.

2.2 Clinical definition of albinism

Albinism, a condition caused by a lack of skin pigmentation in humans,\textsuperscript{4} results from a mutation of one of numerous genes.\textsuperscript{5} Differently stated, it is a heterogeneous genetic disorder, characterised by a lack of or huge reduction in pigment in the skin, hair and eyes.\textsuperscript{6}

Genetic heterogeneity, referred to above, denotes a phenomenon where a single genetic disorder may possibly be caused by one of several numbers of alleles or non-allele mutations\textsuperscript{7} where a single genetic disorder may be caused by mutations in the same gene (allelic heterogeneity) or mutations in different genes (locus heterogeneity). An allele is an alternative form of a gene at a specific locus.\textsuperscript{8} Allele is an abbreviation of allelomorph.\textsuperscript{9}

Some writers in medicine refer to albinism as a disease,\textsuperscript{10} while others submit that albinism should not be classified as a disease.\textsuperscript{11} Referring to oculocutaneous albinism, one type of albinism, the Oxford handbook of ophthalmology states that

\begin{itemize}
\item Hunter 148; Kings & Summers at Chapter 5; Riede & Werner 96; Falco et al 1027; and Richard et al 112.
\item Scott SA “New Category of Color: Analyzing Albinism under the Title VII and the Americans with Disabilities Act” (1999) 2 The Journal of Gender, Race and Justice 493-522 at 494; and Jack J et al Clinical Ophthalmology: A systematic approach (2011, Blackpool: Elsevier Limited) at 648. Also see Hunter at 148; Kings & Summers at Chapter 5; Riede & Werner 96; Falco et al 1027; and Richard et al 112.
\item O’Toole MT Mosby’s Medical Dictionary (2013, St Louis: Elsevier) at 64.
\item O’Toole 64.
\end{itemize}
this type of albinism is a disease which is recessive. Some writers are of the view that there should be a differentiation between a genetic trait and a genetic disease, submitting that the term genetic disease may be used if the trait results in medical problems. If the effects of albinism are merely cosmetic, these may perhaps be called generic traits instead. For this reason, colouration in albinism appears to be a cosmetic trait rather than a disease.

Vision problems are generally associated with albinism. A factual lack of pigmentation results in skin damage and skin cancers due to exposure to ultra violet radiation. In such instances, the term genetic disease may be more appropriate, since the trait results in medical problems. Albinism is severe enough to be regarded as a generic disease. In cases where a person has albinism but is able to manage his or her vision and other medical problems, such as skin cancer, albinism may be considered as a trait, since such a person can manage to live a normal healthy life.

The question whether albinism is classified as a disability or not is relevant to this chapter. The debatable legal nature of this question merits that it be answered in a separate chapter.

2.3 Gene mutation and albinism

The genetic information is stored within the deoxyribonucleic acid (DNA) molecule. Specific genes within the DNA molecules encodes for proteins involved in the

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13 Richards & Hawley 35.
14 Richards & Hawley 35.
15 Richards & Hawley 35.
17 Richards & Hawley 35. Also see Horobin 29.
18 Richards & Hawley 35.
19 Richards & Hawley 35.
production of melanin in the melanocytes.\textsuperscript{21} A mutation in one or several genes may lead to the deficiency of melanin production or a complete stoppage of production of melanin.\textsuperscript{22}

To have albinism, a person has to inherit two copies of a mutated gene, one from each parent.\textsuperscript{23} Clinically, this is known as recessive inheritance.\textsuperscript{24} A person who has merely one copy of the mutated gene will have normal hair, skin or eyes and is considered a carrier of the disorder.\textsuperscript{25} A gene which comprises of several diverse properties is considered pleiotropic.\textsuperscript{26} Albinism is believed to be pleiotropic since it has an effect on skin colour or eyes and is considered a carrier of the disorder.\textsuperscript{27}

In spite of the type of mutated gene which is present in any human being, vision impairment is a common feature in all types of albinism.\textsuperscript{28} Such eye impairments are the result of a deranged development of the nerve trail from the eye to the brain, as well as an irregular growth of the retina.\textsuperscript{29} The symptoms of albinism in early childhood comprise poor vision, sensitivity to bright light, nystagmus and strabismus.\textsuperscript{30} Vision may vary from normal for persons living with albinism who are moderately affected, to legal blindness or complete blindness for people with the more severe types of albinism.\textsuperscript{31} Normally, persons with albinism who have the least

\textsuperscript{21} Also see Hunter 148; and Robert CK A Dictionary of Genetics (2006, New York: Oxford University Press) at 265.
\textsuperscript{23} Scott 497. Also see Cummings 58-64.
\textsuperscript{25} Ash P & Robinson DJ The Emergence of Humans: An Exploration of the Evolutionary Timeline (2010, Somersert: John Wiley & Sons) at 38. Also see Richards & Hawley 29.
\textsuperscript{26} Richards & Hawley 31. Also see Macdonald RB Biology of Ageing (2014, New York: Tylor and Francis) at 74.
\textsuperscript{27} Richards & Hawley 13. Also see Lerner RM & Benson JB Embodiment and Epigenesi: Theoretical and Methodological Issues in Understanding the Role of Biology within the Relational Development System (2013, London: Elsevier) at 292.
\textsuperscript{29} Pine J et al Paediatric Retina (2005, Philadelphia: Lippincott Williams & Wilkins) at 198.
pigmentation have the poorest vision.\textsuperscript{32}

Where albinism affects the hair and the skin, it leaves a stark white to whitish-yellow colour.\textsuperscript{33} Such skin is extremely fair and people with this form of albinism suffer from photo-ageing cancer and an amplified prevalence of all types of skin cancer.\textsuperscript{34}

2.4 Classification of albinism

Different types of Oculocutaneous albinism (OCA) are classified depending on the gene involved.\textsuperscript{35} Currently 7 types of OCA have been identified, OCA1 to OCA7.\textsuperscript{36} The 4 most common types are discussed in more detail in this thesis.

2.4.1 Oculocutaneous albinism

Oculocutaneous albinism is the result of mutation in at least one of four genes.\textsuperscript{37} Such mutations have results and symptoms allied to vision (ocular) as well as symptoms allied to skin (cutaneous), hair and iris colour.\textsuperscript{38}

2.4.1.1 Type 1

Type 1 oculocutaneous albinism (OCA1) results from a mutation in a gene on chromosome 11.\textsuperscript{39} It results from a mutation in the tyrosinase gene (TYR), the “rate-
limiting enzyme” in the production of melanin.\(^{40}\) A good number of people who have this type of albinism have milky white skin, white hair and blue eyes at birth.\(^{41}\) Some of the albinos with this type of disorder do not experience adjustments in pigmentation, while others start to produce melanin at some stage in childhood and adolescence.\(^{42}\) The hair of people living with this type of albinism can develop into a golden blond or brown.\(^{43}\) Their skin generally does not change colour, but it may tan to some extent.\(^{44}\) The irises may also change colour and lose some of their translucency.\(^{45}\)

### 2.4.1.2 Type 2

Oculocutaneous albinism Type 2 (OCA2) results from a mutation in the P gene on chromosome 15.\(^{46}\) Its occurrence is highly prevalent among Sub-Saharan Africans\(^{47}\), African-Americans and Native Americans, compared to people in other population groups.\(^{48}\) With Type 2, the hair is likely to be yellow in colour, auburn, ginger or red, while the eyes are likely to be blue-gray or tan.\(^{49}\) At birth, a child with Type 2 oculocutaneous albinism has white skin.\(^{50}\) Amongst people of African origin, the skin may be light brown, whereas in the case of persons of Asian or Northern European

\(^{40}\) Rudshagen U et al “Mutations in the MTAP Gene in Five German Patients Affected by Oculocutaneous Albinism Type 4” (2004) 23 Human Mutation 106-110 at 106. Also see Oetting 320.


\(^{46}\) Oetting WS et al P Gene Mutations Associated with Oculocutaneous Albinism Type II (OCA2) (2005, Beijing: Wiley-Liss) at 1. Also see Wynbrandt & Lundman 17; Rudshagen U et al 106 and Ramsay M et al “The Tyrosinase-positive Oculocutaneous Albinism Locus Maps to Chromosome ISq I1.2-q 12” (1992) 51 American Journal of Human Genetics 879-884 at 879-884.


\(^{48}\) Ramsay et al 879. Also see Oetting 2; and Hartnett ME Paediatric Retina: Medical and Surgical Approaches (2005, London: Lipincott Williams and Wilkins) at 75.


origin, the skin is more often white.\textsuperscript{51} The colour of the skin of a person living with Type 2 OCA is often similar to the skin tone of the rest of the person’s family, but lighter.\textsuperscript{52} As a result of susceptibility to solar radiation, the skin may possibly ultimately develop skin cancers as well as actinic keratoses.\textsuperscript{53}

\textbf{2.4.1.3 Type 3}

Oculocutaneous albinism Type 3 (OCA3), also known as Rufous/Red albinism,\textsuperscript{54} is the rarer type of oculocutaneous albinism resulting from a mutation in the Tyrosinase-related protein 1 (TYRP) gene.\textsuperscript{55} Type 3 among South Africans usually has the following characteristics:\textsuperscript{56}

- red or reddish-brown skin,
- ginger or reddish hair, and
- hazel or brown irises.

\textbf{2.4.1.4 Type 4}

Oculocutaneous albinism Type 4 (OCA4) is caused by a mutation in the solute carrier family 45 member 2 (SLC45A2) gene also known as the membrane associated transporter protein (MATP) gene.\textsuperscript{57} This mutation causes a lack of melanin production and can be recognised by the following features:\textsuperscript{58}

\begin{thebibliography}{99}
\bibitem{Lund} Lund & Taylor 2.
\bibitem{Rudshagen} Rudshagen U \textit{et al} 106. Also see King RA \textit{et al} “MC1R Mutations Modify the Classic Phenotype of Oculocutaneous Albinism Type 2 (OCA2)” (2003) 73 \textit{American Journal of Human Genetics} 638-645 at 639.
\bibitem{Rudshagen3} Rudshagen \textit{et al} 106. Also see Inagaki \textit{et al} 451-453.
\end{thebibliography}
• hypopigmentation (i.e. loss of colour) of the skin, hair, and eyes; and also
• the fact that this type is the most frequently found type among people of East Asian descent.\(^{59}\)

### 2.4.2 X-linked ocular albinism

X-linked ocular albinism is caused by mutations in the G protein coupled receptor 143 (GPR143) gene and occurs almost exclusively in males.\(^{60}\) This kind of albinism is associated with the developmental and functional vision problems of albinism. With X-linked ocular iris transillumination deficiency, hypopigmentation of the retinal pigment epithelium (RPE), as well as “foveal hypoplasia”\(^{61}\) characterise this type of albinism.\(^{62}\) In X-linked ocular albinism the skin and hair are normal.\(^{63}\)

### 2.4.3 Hermansky-Pudlak syndrome

Hermansky-Pudlak syndrome is an uncommon type of albinism which results from mutations in one of at least eight genes related to this syndrome.\(^{64}\) Pathogenic variations in adaptor-related protein complex 3 beta 1 subunit (AP3B1), Hermansky-Pudlak syndrome 1 (HPS1), Hermansky-Pudlak syndrome 2 (HPS2), Hermansky-Pudlak syndrome 3 (HPS3), Hermansky-Pudlak syndrome 4 (HPS4), Hermansky-Pudlak syndrome 5 (HPS5), Hermansky-Pudlak syndrome 6 (HPS6), Hermansky-Pudlak syndrome 7 (HPS7), Hermansky-Pudlak syndrome 8 (HPS8) and biogenesis...

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\(^{60}\) Eagle RC Eye Pathology: An Atlas and Text (2011, Philadelphia: Lippincott Williams & Wilkins) at 137. Also see Traboulsi at 754; and Mayo Clinic Staff at http://www.mayoclinic.com/health/albinism/DS00941/DSECTION=causes (visited 16 June 2015).

\(^{61}\) This disorder is associated with mutations in the PAX6 gene (11p13) and is inherited as an autosomal dominant. The protein product of the PAX6 gene is a transcription factor that attaches to DNA and regulates the expression of other genes. PAX6 plays a major role primarily in the development of the eye and central nervous system but evidence suggests it is also active postnatally, Poulter JA et al “Foveal hypoplasia”, at http://disorders.eyes.arizona.edu/disorders/foveal-hypoplasia (visited 16 June 2015). Also see Traboulsi 754.


\(^{63}\) Nusinowitz & Sarraf 789. Also see Eagle 137.

of lysosomal organelles complex 1 subunit 3 (BLOC1S3) are identified as causes of Hermansky-Pudlak syndrome.\(^{65}\)

These signs and symptoms are similar to those of oculocutaneous albinism, except that sufferers also develop lung and bowel diseases and a bleeding disorder.\(^{66}\) This syndrome is characterised by the following:

- autosomal recessive disorder,\(^{67}\)
- oculocutaneous albinism\(^{68}\)
- platelet storage pool deficiency; and lysosomal accumulation of ceroid lipofuscin.\(^{69}\)

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\(^{67}\) Autosomal recessive is one of several ways that a trait, disorder or disease can be passed down through families, Fogel BL et al “Autosomal Recessive” at http://www.nlm.nih.gov/medlineplus/ency/article/002052.htm (visited 14 March 2013). Also see Baum & O’Flaherty 172; and Bagheri A & Abadollahi A “Hermansky-Pudlak syndrome; A Case Report” (2010) 5(4) Journal of Ophthalmic & Vision Research 269-272 at 269.

\(^{68}\) See the discussion above on oculocutaneous albinism.

\(^{69}\) Storage pool deficiencies “are a group of disorders caused by problems with platelet granules. Granules are little sacs inside the platelet in which proteins and other chemicals important to its function are stored. There are two types of granules: alpha granules and dense granules. Some storage pool deficiencies are caused by a lack of granules, but the most common ones are caused by a failure of the platelets to empty the contents of the granules into the bloodstream (this is called the secretory or release mechanism). Release defects are a diverse group of disorders caused by a problem with the secretory mechanism. Even though the granules are present within the platelets, their contents are not emptied into the bloodstream properly. Delta storage pool deficiency is a platelet function disorder caused by a lack of dense granules and the chemicals normally stored inside them. Without these chemicals, platelets are not activated properly and the injured blood vessel does not constrict to help stop bleeding. This type of bleeding problem can be a feature of other inherited conditions (such as Hermansky-Pudlak syndrome and Chediak-Higashi syndrome). Grey platelet syndrome is a very rare platelet function disorder caused by a lack of alpha granules and the chemicals normally stored inside them. Without these proteins, platelets cannot stick to the blood vessel wall, clump together the way they should, or repair the injured blood vessel. Symptoms of storage pool deficiencies vary from one individual to the next, but they are usually mild to moderate. People with storage pool deficiencies may experience:

- Easy bruising.
- Nose bleeds.
- Bleeding from gums.
- Heavy or prolonged menstrual bleeding (menorrhagia) or bleeding after childbirth.
- Abnormal bleeding after surgery, circumcision, or dental work.
Hermansky-Pudlak syndrome results in iris transillumination,\textsuperscript{70} different degrees of skin as well as hair hypopigmentation and also congenital nystagmus.\textsuperscript{71}

2.4.4 Chediak-Higashi syndrome

Chediak-Higashi syndrome is an autosomal, recessively inherited, uncommon type of condition, caused by a mutation in the lysosomal trafficking regulator (LYST) gene, with features including the following:\textsuperscript{72}

- oculocutaneous albinism,
- photophobia (light sensitivity),
- nystagmus (rapid eye movements), and
- an irregular vulnerability to cutaneous and respiratory diseases.

Haematological as well as severe neurological defects may in addition emerge.

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\textsuperscript{70} Iris transillumination is a common physical sign that means that the iris of the eye is very pale, with gaps in it. See Olistky SE & Nelson LB \textit{Paediatric Clinical Ophthalmolog: A Colour Handbook} (2012, London: Manson) at 270.

\textsuperscript{71} Bagheri & Abadollahi 269. “Congenital nystagmus is a feature of numerous ocular and systemic disorders. 'Isolated idiopathic congenital nystagmus' (CN), however, refers to a diverse group of abnormal eye movements which are identified at birth or shortly after when no other ocular abnormalities are present. Horizontal eye movements are typical, but vertical and rotary eye movements have also been reported.” If the nystagmus is horizontal, the eye movement is usually “to-and-fro”. In general, as the patient gets older, the amplitude of the nystagmus decreases and the frequency of the nystagmus increases, particularly when the patient tries to fixate or look directly at an object. This nystagmus can increase in size and frequency when the patient is tired, sick, or fatigued. Some very young patients are noted to have head nodding or head shaking, but these usually disappear over time. Vision is reduced and varies through the day. Balance may also be affected. Many patients have a ‘null point’ where the eye movement is reduced and vision is improved. They will often alter their head position in an effort to maximize their vision. Nystagmus cannot be cured. However, several treatments can be beneficial. Glasses and contact lenses, and, occasionally, extraocular muscle surgery may be helpful. The latter should be considered especially when patients adopt a consistent head position for best vision. This avoids long-term secondary changes in neck muscles and many individuals experience an improvement of two or more lines in visual acuity. Low vision aids should be offered.” University of Arizona “Nystagmus 1, Congenital, X linked” at http://disorders.eyes.arizona.edu/disorders/congenital-nystagmus-0 (visited 3 April 2013). Also see Olistky & Nelson 210.

2.5 Symptoms of albinism

Albinism is usually apparent at birth with one of the following symptoms:

- Absence of colour in the hair, skin, or iris of the eye.\(^73\)
- Lighter than normal skin and hair.\(^74\)
- Patchy, missing skin colour.\(^75\)

In early childhood, the symptoms associated with the albinism are often the following:

- Crossed eyes (Strabismus).\(^76\)
- Light sensitivity (photophobia).\(^77\)
- Rapid eye movements (nystagmus).\(^78\)
- Vision problems or functional blindness.\(^79\)

2.6 Diagnosis of albinism

Genetic testing through DNA analysis is the most accurate way to diagnose albinism.\(^80\) Where there is a family history of albinism, testing is imperative.\(^81\) Doctors may also diagnose albinism merely on the basis of the appearance of a person’s skin, hair, and eyes.\(^82\) An ophthalmologist can perform an electroretinagram test to test vision problems associated with albinism.\(^83\) Where such a decision is uncertain,
a ‘visual evoked potentials test’ may be useful.\textsuperscript{84}

2.7 Treatment of albinism

The purpose of treating albinism is to relieve symptoms\textsuperscript{85} and treatment is allied to the degree of the condition.\textsuperscript{86} Treatment involves protecting the skin and eyes from the sun as follows:

- Reducing sunburn risk by avoiding the sun, using sunscreen with a high sun protection factor (SPF),\textsuperscript{87} and protecting the body with protective clothing;\textsuperscript{88}
- Sunglasses with a high ultraviolet (UV) protection screen may relieve light sensitivity;\textsuperscript{89}
- Glasses are prescribed for treatment of infertile nystagmus and to correct eye sight problems as well as eye position;\textsuperscript{90}
- Muscle surgery of the eyes is at times advisable to correct abnormal eye movements.\textsuperscript{91}

2.7.1 Albinism and skin cancer

Due to the error in the synthesis of tyrosinase, people living with oculocutaneous albinism have little protection against ultraviolet radiation (UVR) damage.\textsuperscript{92} As a

\textsuperscript{84} Morton DA Nolo’s Guide to Social Security Disability; Getting and Keeping your Benefits (2010, California: Delta Printing Solution) at 21. A visual evoked potential test evaluates the visual pathways in the brain. During the test, the patient watches a video monitor with a moving pattern. Watching the moving pattern produces electrical activity in the patient’s brain that is measured by several electrodes attached to his or her head. The test evaluates the visual pathways in the brain.


\textsuperscript{86} Horobin 29. Also see Chhabra & Chhabra 123.

\textsuperscript{87} Horobin 29. Also see Chhabra & Chhabra 123.

\textsuperscript{88} Mcgarry KA & Tong IL The 5-Minute Consult Clinical Companion to Women’s Health (2013, Philadelphia: Lippincott Williams & Wilkins) at 224. Also see the United States National Library of Medicine at http://www.nlm.nih.gov/medlineplus/ency/article/001479.htm (visited 16 June 2015); and Chhabra & Chhabra 123.

\textsuperscript{89} Horobin 29. Also see Chhabra & Chhabra 123.

\textsuperscript{90} Brodsky MC Pediatric Ophthalmology (2010, New York: Springer) at 405.

\textsuperscript{91} Enderle JD Horizontal Eye Movements, Early Models of Saccades and Smooth Pursuits (2010, San Raelal: Morgan and Claypool) at 164. Also see Traboulsi 748.

\textsuperscript{92} Reisler T "Interesting Case Series: Albinism and Skin Cancer" at http://www.eplasty.com/images/PDF/eplasty-d-09-00135.pdf (visited 8 December 2011). Also see Rudshagen \textit{et al} 106; and Oetting 320.
result, exposure to high levels of contact to (UVR) enhances the risk of contracting all three main types of skin cancer.\(^93\)

### 2.7.1.1 The skin

The skin is in fact an additional body organ\(^94\) which fulfils a number of vital functions within the body, such as protecting all the organs.\(^95\) The skin is composed of two major layers\(^96\), the epidermis on the outside and the dermis beneath.\(^97\) New cells are formed in the bottom layers of the epidermis and are pressed towards the surface.\(^98\) Few blood vessels exist in the epidermis, which means that these cells die as a result of lack of both food and oxygen.\(^99\) The surface layers of the skin are made up of dead cells and are filled with a material known as keratin,\(^100\) a hard, waxy substance that assists the skin in protecting the outer part of the body.\(^101\)

### 2.7.1.2 Skin cancer and albinism

Long term exposure to sunburn promotes skin cancers among people living with albinism.\(^102\) The Cancer Association of South Africa (Cansa) believes that persons living with albinism in South Africa face the highest risk of developing skin cancer.\(^103\) While this information regarding their susceptibility to cancer is very important, Cansa acknowledged in 2009 that such information was communicated at a very

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94 Sanders MJ et al Mosby’s Paramedic Textbook (2010, Barlington: Jones and Bartlett learning) at 155.

95 Sanders et al 155.

96 Hess CT Clinical Guide: Wound Care (2005, Philadelphia: Lippincott Williams & Wilkins) at 5. Also see Sanders 155.

97 Hess 5. Also see Sanders 155.

98 Hess 5. Also see Sanders 155.


100 Beckett 88.

101 Beckett 88.

102 Lund & Taylor 2. Also see Ostler 40; and Kromberg & Jenkins 383.

late stage to persons living with albinism, especially those living in rural areas of South Africa.\textsuperscript{104}

There are two main types of non-melanoma skin cancer called basal cell carcinoma (BCC) and squamous cell skin cancer (SCC).\textsuperscript{105} A history of sunburn enhances the risk of (BCC) skin cancer.\textsuperscript{106} Such risk is particularly high when a person has experienced prolonged exposure to the sun during childhood.\textsuperscript{107}

The risk of (SCC) is associated with continuous sun exposure throughout a person’s life. This means that open-air workers such as farm workers, gardeners and building site workers have an increased risk of getting (SCC).\textsuperscript{108} A history of sunburn during childhood increases the risk of (SCC).\textsuperscript{109} Fair-skinned people, with light-coloured hair and eyes, or those more likely to burn than tan, are further at a high risk of sun damage compared to dark-skinned people.\textsuperscript{110}

A person has a higher risk of skin cancer if they are elderly or have previously had skin cancer.\textsuperscript{111} A family history of skin cancer also increases their risk of contracting skin cancer.\textsuperscript{112} A previous skin condition, radiotherapy, exposure to chemicals and having a weakened immune system also increases the risk of getting skin cancer.\textsuperscript{113}

2.8 Lifespan of a person living with albinism

Although albinism does not usually shorten a person’s lifespan,\textsuperscript{114} rare types of albinism, such as the Hermansky-Pudlak syndrome, cause medical complications such as bruising, bleeding, and susceptibility to diseases that affect the bowels and

\textsuperscript{106} Lund & Taylor 2; Ostler 40; Kromberg & Jenkins 383; and Bradley J et al Cape Town, Winelands and the Garden Route (2011, Cape Town: Modern Overland) at 51.
\textsuperscript{107} Ostler 40; and Kromberg & Jenkins 383.
\textsuperscript{108} Bradley et al 51.
\textsuperscript{111} Diepgen & Mahler 1-6.
\textsuperscript{112} Diepgen & Mahler 1-6.
\textsuperscript{113} Diepgen & Mahler 1-6.
\textsuperscript{114} Kinsey B Encyclopedia of Health (2010, New York: Marshal Cavendish) at 42. Also see Chhabra & Chhabra at 123.
lungs which have the effect of shortening the lifespan of the sufferer due to lung disease or bleeding problems as well as skin cancer.\textsuperscript{115} Each of these may impact on the life-span of individuals affected by the disorder.

2.9 Conclusion

It would be impractical and impossible to discuss all the clinical aspects relating to albinism in this chapter. The vulnerability of persons living with albinism, as discussed in this chapter, makes them a category in need of specific health protection, ranging from visual aids, eye surgery and regular check-ups for skin cancer, to sunglasses offering high (UV) protection. To compound their vulnerability, they are also at increased risk of becoming victims of muti killings, stigmatisation and discrimination based on their appearance. Elsewhere in this thesis, the question of whether they are adequately protected in the present South African legal framework will be explored in detail.

\textsuperscript{115} Kinsey 42. Also see King E et al Interstitial Lung Disease, an Issue of Clinics in Chest Medicine (2012, Philadelphia: Elsevier) at 96.
CHAPTER 3: THE CONSTITUTIONAL FRAMEWORK RELEVANT TO PERSONS LIVING WITH ALBINISM

“The worst expression of discrimination against persons with albinism is their dehumanization, which lays the foundation for horrifying physical attacks against them.”

3.1 Introduction

This chapter explores human rights law as an instrument for the protection of persons living with albinism. Human rights are a system consisting of both national and international human rights law. They are universal legal guarantees which protect persons and, to some degree, groups of people against “actions and omissions” which obstruct elemental freedoms and entitlements. Such protection is afforded at various levels.

The national level, also known as the domestic or municipal level, is the initial level of protection against an impediment of a protected right. It is at the national level that the government and other duty bearers have a duty to protect persons and groups of people. At this level human rights law is included in the form of a bill of rights in a constitution, a human rights act or human rights provisions included in a constitution and, in addition, a domesticated international human rights law. The South African Constitution is the supreme law of the country and any obligations imposed by it should be fulfilled. The State has a duty to respect, protect, promote and fulfil the rights of all people in the Bill of Rights. The Constitution applies to

3 Nienaber AG “Ethics and Human Rights in HIV-Related Clinical Trials in Africa with Specific Reference to Informed Consent in Preventative HIV Vaccine Efficacy Trials in South Africa” 2007 Thesis submitted in fulfilment of the requirements for the Degree Doctor Legum in the Faculty of Law at the University of Pretoria, 1-587 at 177.
4 Nienaber 177.
5 McInerney-Lankford 4.
6 Nienaber 177.
8 Hansen 184.
natural and juristic persons, as well as all law.\textsuperscript{9} It binds together the legislature, the executive, the judiciary and all organs of state.\textsuperscript{10}

The regional level is the next level of human rights protection. The regional human rights protection on our continent was set up to address the need to “Africanise human rights”.\textsuperscript{11} Such a regional system has a significant function as the expression of the “official African view” in relation to human rights.\textsuperscript{12} Within this system, countries within a region or continent use the same system of human rights protection.\textsuperscript{13}

The ultimate recourse for protection against abuse of human rights is at the international or United Nations (UN) level.\textsuperscript{14} International human rights law attaches great importance to safeguarding human rights globally. The UN remains active in protecting human rights globally, generally through the functions of its major organs which are the General Assembly, the Security Council, the Economic and Social Council and the Human Rights Council.\textsuperscript{15} Countries all over the world conform to human rights principles which are incorporated in international human rights documents as well as treaties.\textsuperscript{16} Nevertheless, international law does not in any way substitute national law,\textsuperscript{17} although it instructs self-governing states on globally acknowledged human rights, and essentially these sovereign states are expected to apply these norms domestically.\textsuperscript{18}

International human rights law comes into force when state sovereignty is abused.\textsuperscript{19} Membership of international human rights treaties allows states to willingly surrender their sovereignty and consent to supervision of their conformity to the provisions of a

\textsuperscript{9} Currie I & De Waal J \textit{The Bill of Rights Handbook} (2013, Cape Town: Juta) at 36.
\textsuperscript{10} Currie & De Waal 42.
\textsuperscript{11} Brems E \textit{Human Rights Universality and Diversity} (2001, Netherlands: Martinis Nijhoff) at 91.
\textsuperscript{12} Brems 91.
\textsuperscript{13} Nienaber 177.
\textsuperscript{14} Nienaber.
\textsuperscript{16} Nienaber 177.
\textsuperscript{17} Nienaber 177.
\textsuperscript{18} Trebilcock MJ & Howse R \textit{The Regulation of International Trade} (2005, New York: Taylor & Francis) at 579.
\textsuperscript{19} Nienaber 178.
particular treaty.20 Such supervision also incorporates appropriate steps for intervention where necessary by a self-regulating regional or global body.21

The complainant whose human rights have been infringed has to first seek a remedy at the national level.22 Should there be no remedy, such a person may turn to the international level which could be either the regional or the global level.23 In this regard, Nienaber asserts that the role of the international level of protection of human rights is consequently to operate as a “safety net, to catch victims of human rights violations who fall through the crack of the national level.”24

For more than forty years, from 1948 to 1990, South Africa was at odds with the international society and international law.25 Apartheid was founded on principles such as racial discrimination and the infringement of human rights, and was in opposition to the law of the UN Charter as well human rights rules, non-discrimination and self-determination, which were part of the post-World War II order.26

In South Africa, reference to the use of comparative law was first authorised by the Interim Constitution under section 35(1),27 which concluded discussions on the status of international law in South African domestic law.28 This phase represented a split from the apartheid legal system, a system closely related to the abuse of international law.29 The incorporation of international law into South Africa’s legal

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20 Nienaber 178.
22 Nienaber 178.
23 Nienaber 178.
24 Nienaber 178.
26 Dugard “International Law and the South African Constitution” 77.
27 Section 35(1) of the Constitution of the Republic of South Africa Act 200 of 1993 (hereinafter referred to as the Interim Constitution of 1993) reads as follows: “In interpreting the provisions of this Chapter a court of law shall promote the values which underlie an open and democratic society based on freedom and equality and shall, where applicable, have regard to public international law applicable to the protection of the rights entrenched in this Chapter, and may have regard to comparable foreign case law.”
29 Olivier 26. Also see Dugard “International Law and the South African Constitution” 84.
system illustrated to the rest of the world that South Africa was prepared to observe international law.\(^{30}\)

Section 35(1) of the Interim Constitution of 1993 is substantially captured in the final Constitution which provides that:

When interpreting the Bill of Rights, a court, tribunal or forum
(a) must promote the values that underlie an open and democratic society based on human dignity, equality and freedom; 
(b) must consider international law; and
(c) may consider foreign law.\(^{31}\)

Considering international and foreign law in interpreting the Bill of Rights is therefore permissible. Courts, however, are obliged to take account of international law when interpreting the Bill of Rights. Needless to say, consideration of international or foreign law by a South African court does not make a specific law binding in South Africa\(^{32}\) except in cases where South Africa has ratified said laws.\(^{33}\) International agreements which South Africa has signed and ratified ought to form part of South African laws to the extent that they are not in conflict with the Constitution of 1996.\(^{34}\)

Subsequent to the founding of the Interim Constitution of 1993, our courts have expressed readiness to be guided by international human rights law.\(^{35}\)

\(^{30}\) Olivier 1.


\(^{33}\) Viljoen 23.

\(^{34}\) Olivier 1.

\(^{35}\) For example in the *S v Makwanyane and Another* case, *S v Makwanyane* 1995 (3) SA 391 (CC) (hereinafter referred to as the *Makwanyane* case), the Constitutional Court was faced with the constitutionality of the death penalty. The 1993 Constitution did not expressly discuss the issue of capital punishment. During the negotiating process of the 1993 Constitution it was decided that the death penalty would neither be excluded from nor endorsed by the Interim Constitution but the matter would be left to the Constitutional Court to make a decision whether the death penalty is in line with the bill of rights. This matter was decided in *S v Makwanyane and Another* where the accused were sentenced to death for murder. It was argued on behalf of the accused that the death penalty was a cruel, inhuman and degrading punishment which should be declared unconstitutional. Judge Chaskalson relied heavily on international law in coming to his judgement. He turned to international law in interpreting the Constitution. He particularly referred to the European Court of Human Rights as well as the United Nations Committee on Human Rights whose concerns are informed by travaux préparatoires as pronounced by article 32 of the Vienna Convention on the Law of Treaties. He also referred to countries such as Germany, Canada, the United States of America and
of the European Commission and Court of Human Rights have delivered the
greatest assistance, but our courts have at times taken similar account of the views
of the United Nations Human Rights Committee and United Nations reports on
human rights matters.\textsuperscript{36} This will also be done in the current chapter and subsequent
chapters of this thesis. The texts of the primary international human rights
conventions and the principal international human rights treatises have by now
turned out to be documented in constitutional source materials.\textsuperscript{37}

It is clear from the preceding chapters that certain rights of persons living with
albinism are under threat. This chapter will provide a detailed overview of the specific
human rights applicable to albinos. The chapter examines the rights to equality, life,
dignity, freedom and security of the person, the right to special education and the
right to privacy against the backdrop of glaring examples of the threat to these rights
among persons living with albinism.

3.2 The right to equality within the constitutional framework

3.2.1 Theoretical observations

Disability and disease discrimination is not a new phenomenon. In earliest
documented history, people with disabilities, diseases and various other conditions
have faced ostracisation, rejection and discrimination within the societies in which
they live.

As seen in the previous chapters, persons living with albinism continue to suffer
stigma and discrimination in all sectors of society. Albinism, as a condition which
cannot be concealed, means that albinos stand out as different among groups of
dark-skinned people.\textsuperscript{38} Albinos are a visible minority and are subjected to open and
blatant discrimination in most African countries, including South Africa.

Myths, stereotypes and false notions, such as those discussed in chapter one of this
thesis, lead to discrimination and associated maltreatment as well as violations of the

\textsuperscript{36} Dugard "International Law and the South African Constitution" 85.
\textsuperscript{37} Dugard “International Law and the South African Constitution” 85.
\textsuperscript{38} Lund PM "Health and Education of Children with Albinism in Zimbabwe" (2001) 16 (1) \textit{Health
Education Research} 1-7 at 1.
rights to equality and human dignity and other basic freedoms of persons living with albinism. The realisation of equality as a principle and a right is very important, as equality is understood to be at the heart of and fundamental to the Constitution. In light of the history of discrimination in South Africa, the importance of the principle of equality is echoed in the very first chapter of the Constitution.

When interpreting the Constitution, equality is the central standard together with the concepts of dignity and freedom. Equality is entrenched as a value in sections 7, 36 and 39 of the Bill of Rights. Equality, dignity and freedom influence the

40 Chapter 1 of the Constitution of 1996 hereinafter referred to as the Constitution of 1996) states that the achievement of equality is one of the founding values of the Republic of South Africa.
41 Mswela M “The Role of HIV/AIDS and Gender Violence in South African Law” 2007 Dissertation submitted in fulfilment of the requirements for the Degree Master of Law in the College of Law at the University of South Africa 1-187 at 78.
43 Section 7 of the Constitution of 1996 reads as follows:
“(1) This Bill of Rights is a cornerstone of democracy in South Africa. It enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom.
(2) The state must respect, protect, promote and fulfil the rights in the Bill of Rights.
(3) The rights in the Bill of Rights are subject to the limitations contained or referred to in section 36 or elsewhere in the Bill.”
44 Section 36 of the Constitution of 1996 reads as follows:
“(1) The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including -
(a) the nature of the right;
(b) the importance of the purpose of the limitation;
(c) the nature and extent of the limitation;
(d) the relation between the limitation and its purpose; and
(e) less restrictive means to achieve the purpose.
(2) Except as provided in subsection (1) or in any other provision of the Constitution, no law may limit any right entrenched in the Bill of Rights.”
45 Section 39 of the Constitution of 1996 reads as follows:
“(1) When interpreting the Bill of Rights, a court, tribunal or forum –
(a) must promote the values that underlie an open and democratic society based on human dignity, equality and freedom;
(b) must consider international law; and
(c) may consider foreign law.
(2) When interpreting any legislation, and when developing the common law or customary law, every court, tribunal or forum must promote the spirit, purport and objects of the Bill of Rights.
interpretation as well as the application of all other rights as stipulated in chapter 2 of the Constitution. Equality, together with the values of human dignity and freedom, is integral to the open and democratic society that South Africa desires to be. Throughout the Constitution, the notion of an “open and democratic society based on human dignity, equality and freedom” is consistently clear.

Every natural person or individual is a bearer of the right to equality while juristic persons are also in principle bearers of the right to equality. Section 8(2) of the Constitution states that the Bill of Rights binds both natural and juristic persons in as far as that is applicable taking into account the attributes of the right itself and of any duty imposed by such a right. An interpretation of the phrasing of section 8(2) suggests that certain rights, specifically the right to dignity, privacy and equality before the law and equal benefit and protection before the law, may well relate to private persons, while other rights such as the right to citizenship and rights relating to arrest and detention, are not only applicable between private persons, but also to the State and natural persons as referred to in section 8(1).

The right to equality as described in section 9 of the Constitution is open to a variety of interpretations. Most importantly, it ought to be determined whether section 9 as a whole should be interpreted as embedding equality in a formal or a substantive

(3) The Bill of Rights does not deny the existence of any other rights or freedoms that are recognised or conferred by common law, customary law or legislation, to the extent that they are consistent with the Bill.
sense.\textsuperscript{54} Formal equality entails that each person is an equal holder of both rights and obligations in a fair and lawful order,\textsuperscript{55} for instance in understanding a particular statute with the purpose of establishing whether a relevant justification exists for same or different treatment.\textsuperscript{56} For this reason, equality is seen as a “state of affairs” realised by giving equal rights to every person in accordance with the “same, general, non-preferential” standard.\textsuperscript{57}

As a result, the formal meaning of equality has hardly anything to do with “institutionalized, structural distinctions” in equality.\textsuperscript{58} Such a formal interpretation does not focus on real social and economic differences between people or classes of people in society.\textsuperscript{59} Accordingly, it has a propensity to sustain and determine rather than to do away with disparities.\textsuperscript{60}

Conversely, substantive equality involves an assessment of the factual material circumstances of people and groups of people, simultaneously investigating the way in which government action is capable of reforming and advancing adverse social and economic conditions.\textsuperscript{61} Substantive equality is therefore responsive to and deals with the real social and economic situations which may be an outcome of unequal treatment of and discrimination against individuals as well as categories of people.\textsuperscript{62}

In the Constitution, equality is introduced into the framework by the preamble which lists the objectives of the Constitution.\textsuperscript{63} The preamble positions the Constitution as a basis for a democratic and open society in which government is based on the will of the people and every citizen is equally protected by law.\textsuperscript{64}

Directed by this purpose, the first section of the Constitution lists “the achievement of equality” along with “non-racialism as well as non-sexism” among the founding

\textsuperscript{54}Van Reenen 154.
\textsuperscript{56}Macklem 212.
\textsuperscript{57}Van Reenen 153.
\textsuperscript{58}Macklem 212. Also see Van Reenen 153.
\textsuperscript{59}Mswela 79.
\textsuperscript{60}Van Reenen 153.
\textsuperscript{61}Macklem 212.
\textsuperscript{62}Van Reenen 153.
\textsuperscript{63}Kruger 101.
\textsuperscript{64}Kruger 101.
values of our constitutional democracy. The preamble of the Constitution also states that “South Africa belongs to all who live in it” and calls for the realisation of “a unity in our diversity”. This call for the growth of a single nation is conceivably the Constitution’s prevailing objective. Redress, as a constitutional means of social justice, ought to be designed and embarked upon in a way which is attuned to the objective of establishing a single nation.

The Constitution’s Bill of Rights regulates vertical as well as horizontal relations between persons. Sections 9(3) and 9(4) of the equality clause (section 9) are applicable to government as well as private persons jointly with regard to public as well as private law transactions. The Certification case corroborated such an intended vertical and horizontal application of section 9.

The horizontal application of rights has an effect on all individuals as well as juristic persons and every institution of civil society. Notably, section 9 prohibits both the State and any human being from unfairly discriminating against anyone on diverse grounds. The central intention of a Bill of Rights is to restrict the authority of the

Section 9 of the Constitution of 1996 reads as follows:

“9(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.”

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65 Kruger 101.
66 See the preamble of the Constitution of 1996.
67 See the preamble of the Constitution of 1996.
69 Currie & De Waal 45. Also see Freedman W Understanding the Constitution of the Republic of South Africa (2013, Cape Town: Juta) at 309.
70 Van Reenen 156.
71 Ex Parte Chairperson of the Constitutional Assembly: In Re Certification of the Constitution of the Republic of South Africa 1996 (4) SA 744 (CC), paragraph [54].
72 Freedman 309. Also see Currie & De Waal 45.
73 Section 9 of the Constitution of 1996 reads as follows:

“9(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.”
State as well as to protect persons from the exploitation of power by the State. Creating a horizontally pertinent equality section will set in motion excessive government involvement, with significant consequences. Compared with the Interim Constitution, the Constitution of 1996 takes a more lucid position regarding the horizontal application of the Bill of Rights. In light of South Africa’s historical background as well as the need for the transformation of South African society, the horizontal application of the Bill of Rights is indispensable, since a vertical application is generally not adequate for dealing with existing inconsistencies.

According to section 9, “everyone has a right to be equal before the law as well as a right to equal protection and benefit before the law”. Section 9(4) also explicitly states that “[n]o person may unfairly discriminate against anyone […].” This formulation is very different from the widely used “everyone has the right to…” which is essential to the general application of the Bill of Rights. It is apparent from this that the prohibition of unfair discrimination binds private persons in their dealings with each other. With the aforementioned in mind, private dealings regulated by legislation, customary law or religious systems of law are not exempt from the application of the Bill of Rights. The first specific right listed in the Bill of Rights is the right to equality. The fact that this right is listed first emphasises its

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75 Langford M et al Socio-economic rights in South Africa: Symbols or Substance (2014, New York: Cambridge University Press) at 68. Also see Freedman 309.
77 Rabe J Equality, Affirmative Action and Justice (2001, Norderstedt: Books on Demand GmbH) at 329. Rabe furthers this discussion by pointing out the negative aspects relating to the horizontal application of the Constitution. He argues as follows: “There are, however, both positive and negative aspects involved with regard to the horizontal application of the constitutional provisions. The negative side of the horizontal application is the state’s encroachment in the private sphere and the difficulty related to containing the ambit of the application. The complete horizontal application of the Bill of Rights is unacceptable as this would for example mean that it would apply to family relationships and a child may claim a violation of his/her rights if other children in the family received some extra benefits”.
79 Section 9(4) of the Constitution of 1996.
80 Andrew 437.
81 Andrew 437.
82 Bradshaw & Ndegwa 278.
83 Section 9 of the Constitution of 1996 reads as follows: “9(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.”
The importance of the right to equality is further highlighted by the insertion of section 9 in the list of non-derogable rights in section 37 which provides for states of emergency. Despite the fact that section 37 allows for permissible limitation of basic rights during a state of emergency through an Act of Parliament, it exclusively stipulates that such an Act may not permit unfair discrimination on grounds of race, colour, ethnic or social origin, sex, religion or language.

The interpretation of the Constitution began when the Constitutional Court started its work under the Interim Constitution. Just like the Constitution of 1996, the Interim Constitution protected equality as a value as well as a right. Equality “between men and women and people of all races” underpinned the constitutional project embarked upon in 1994. Seen as a value, equality informed the interpretation and limitation of rights entrenched in the Interim Constitution, and as a right, it ensured equal protection and equality before the law and prohibited unfair discrimination. The constitutional principles which guided the drafting of the final Constitution included

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair."

Section 37 of the Constitution of 1996 reads as follows:

“(1) A state of emergency may be declared only in terms of an Act of Parliament, and only when the life of the nation is threatened by war, invasion, general insurrection, disorder, natural disaster or other public emergency; and the declaration is necessary to restore peace and order.

[...]

(5) No Act of Parliament that authorises a declaration of a state of emergency, and no legislation enacted or other action taken in consequence of a declaration, may permit or authorise

(a) indemnifying the state, or any person, in respect of any unlawful act;

(b) any derogation from this section; or

(c) any derogation from a section mentioned in column 1 of the Table of Non-Derogable Rights, to the extent indicated opposite that section in column 3 of the Table.” See Annexure E for the Table of Non-Derogable Rights.

Van Reenen 152; and Dupper O et al Essential Employment Discrimination Law (2007, Cape Town: Juta) at 16.

Kruger 103.

several references to equality and non-discrimination, particularly pertaining to racial discrimination. In this way constitutional commitment to the eradication of racial inequality and unfairness was guaranteed.

Irrespective of race, gender, sex, state of pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth, all South Africans are equal before the law. Equal worth among holders of rights is protected by the right to equality.\(^88\) People are bearers of equal worth in the sense that everyone has human dignity in addition to all other rights.

Section 9 of the Constitution stipulates that equality consists of the “full and equal enjoyment of all rights and freedoms.”\(^90\)

Section 9(1) prohibits unequal treatment generally.\(^91\) While section 9(3)\(^92\) deals with a definite type of differentiation, namely unfair discrimination, section 9(1) prohibits all forms of differentiation which do not amount to unfair discrimination in terms of section 9(3).\(^93\) Section 9(3) stipulates that the State may not unfairly discriminate either directly or indirectly on the basis of the sixteen specific grounds which are recognised.\(^94\) Of these, discrimination on the basis of disability and colour is relevant to this study.

Section 9(3) of the Constitution prohibits direct or indirect unfair discrimination by the State on any listed grounds.\(^95\) Such discrimination may well be based on more than one ground, for instance, discrimination on the basis of race and gender or on the

\(^{88}\) Rautenbach & Malherbe 358.


\(^{90}\) Rautenbach & Malherbe 358.

\(^{91}\) Section 9(1) of the Constitution of 1996 states that: “everyone is equal before the law and has the right to equal protection and benefit of the law.” Also see Rautenbach & Malherbe at 360.

\(^{92}\) Section 9(3) of the Constitution of 1996 reads as follows: “(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.”

\(^{93}\) Rautenbach & Malherbe 360.

\(^{94}\) Section 9(3) of the Constitution of 1996.

\(^{95}\) Section 9(3) of the Constitution of 1996. Also see Rautenbach & Malherbe 359.
basis of colour and disability. In instances where discrimination is based on more than one ground, the impact of such discrimination may be more serious.  

Differentiation on grounds expressly stated in the differentiating measure is referred to as direct discrimination, while indirect discrimination is differentiation resulting

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96 Rautenbach & Malherbe 359. Multi discrimination was confirmed in the National Coalition for Gay and Lesbian Equality and Another v Minister of Justice and Others 1999 (1) SA 6 (CC) case (hereinafter referred to as the National Coalition for Gay and Lesbian Equality case), where Judge Sachs noted that “[o]ne consequence of an approach based on context and impact would be the acknowledgement that grounds of unfair discrimination can intersect, so that the evaluation of discriminatory impact is done not according to one ground of discrimination or another, but on a combination of both, that is globally and contextually, not separately and abstractly.” See National Coalition for Gay and Lesbian Equality case, paragraph [113]. “Critical race feminists are at the forefront of the movement towards a contextual treatment and understanding of the lives of those who face multiple discrimination. A major thrust of the critical race genre is to focus on the multileveled identities and multiple consciousness of women of colour, in particular, who are often discriminated against on the basis of race, gender and economic class. In doing so, critical race feminism draws attention to the need for conscious consideration of fundamental rights within the context of persons whose identities may involve the intersection of race, gender, class, sexual orientation, physical disadvantage or other characteristics which often serve as the basis for unfair discrimination.” See National Coalition for Gay and Lesbian Equality case, footnote [7]. Also see Hughes A Human Dignity and Fundamental Rights in South Africa and Ireland (2014, Pretoria: Pretoria University Press) at 321; and Ucellari P “Multiple Discrimination: How Law can Reflect Reality” (2008) 1 The Equal Rights Review 25-49.

97 Cotter AM et al Discrimination law: Professional Practice Guide (2005, London: Routledge Cavendish) at 1. The Hoffman v South African Airways 2001 (1) SA 1 (CC) case (hereinafter referred to as the Hoffman case) is a very good example of an occurrence of direct discrimination. In this case, the appellant, Hoffman, was denied employment solely because of his HIV status. The appellant was HIV positive. In September 1996 he applied for employment as a cabin attendant with South African Airways (SAA). He successfully completed a four-stage selection process. The appellant was found to be a suitable candidate for employment subject to a pre-employment medical examination that included a blood test for HIV/AIDS. Whilst the medical examination found the appellant to be clinically fit, and therefore suitable for employment, he was deemed 'unsuitable' due to testing HIV positive. He challenged the constitutionality of the refusal to employ him on the basis that it was unfair dismissal and violated his constitutional right to equality, human dignity, and fair labour practices. The court set out that those living with HIV, including the appellant, were a vulnerable minority treated with intense prejudice by society and subjected to disadvantage, stigmatisation and marginalisation. As such any discrimination could be interpreted as a fresh instance of stigmatisation and assault on their dignity. The impact in the field of employment can be especially devastating since it denies them a right to a living, condemning them to ‘economic death’. Subsequently, the legitimate commercial interests of the respondent, important though they may be, could not be allowed to justify unwarranted prejudice and stereotyping. The court concluded that the refusal to employ the appellant violated his right to equality as guaranteed by section 9 of the Constitution of 1996. The court held that the appellant, having been denied employment solely because of his HIV status, should be entitled to the fullest redress available, namely re-instatement from the date of the court order. See the Hoffman case, paragraphs [5], [7], [28] and [41]. Canada is one of the countries which follow the approach that differentiation based on a listed ground is direct discrimination. In the Canadian case of Central Alberta Dairy Pool v Alberta (Human Rights Commission) (1990) 2 S.C.R. 48, direct discrimination was defined as follows in paragraph [490]: ‘The essence of direct discrimination in employment is the making of a rule that generalizes about a person’s ability to perform a job based on membership in a group sharing a common personal attribute like sex, age, religion, etc. The ideal human rights legislation is that each
from a measure that has a discriminatory result without differentiating specifically in its formulation, or on grounds not explicitly stated in the formulation.\textsuperscript{98} Indirect discrimination transpires, for instance, when fair policies are implemented in a way that adversely influences an imbalance in terms of a particular group.\textsuperscript{99} Direct and indirect discrimination may be intentional or unintentional.\textsuperscript{100} An impartial measure might be put in place with the intention of singling out members of a certain group, or it may be put in place \textit{bona fide} but all the same have a detrimental outcome on an unequal number of people within a particular group.\textsuperscript{101} The peculiarity of direct and indirect discrimination is as a result of, not simply the difference between, purposeful and unintentional discrimination.\textsuperscript{102}

Unfair discrimination comprises of unequal treatment which harms human dignity or affects people in a comparably serious manner, for example through an infringement of any right.\textsuperscript{103} An assumption concerning the unfairness of the discrimination arises when there is a \textit{prima facie} case of infringement on one of the listed grounds.\textsuperscript{104} A
person who alleges a differentiation on any of the grounds expressly stated, has to provide factual evidence that the discrimination is not fair.\textsuperscript{105} Race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth are the grounds specifically listed in section 9(3) of the Constitution.\textsuperscript{106}

Throughout the ages, discrimination on the aforementioned grounds has resulted in grave human rights infringements and it can be rationally supposed that human dignity is infringed upon in such situations, unless the contrary is established.\textsuperscript{107} Unfairness based on discrimination on any other grounds must be proved by the complainant.\textsuperscript{108}

An understanding of the connection between the right to equality before the law and protection against unfair discrimination is fundamental to any appreciation of the right to equality.\textsuperscript{109} The right to equality as regulated by the Bill of Rights has to be understood as well as protected within the context of the Bill of Rights and the Constitution in its entirety.\textsuperscript{110} The Constitution has its own broader context within which a case must be construed.\textsuperscript{111} Such an interpretation is influenced by the political history of South Africa as well the history of the drafting of the Constitution which provides the context in which the Constitution should be interpreted.\textsuperscript{112} In addition, giving meaning to the rights in the Constitution has to be done against the background of the agenda of transformation and social justice envisioned by the Constitution.\textsuperscript{113}

For the reason that the right to equality protects the equal worth of people, this right is not strictly speaking a right to equal treatment; it is a right that protects a person’s

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\textsuperscript{105} Rautenbach & Malherbe 359.
\textsuperscript{106} Section 9(3) of the Constitution of 1996.
\textsuperscript{107} Rautenbach & Malherbe 359.
\textsuperscript{108} Rautenbach & Malherbe 359.
\textsuperscript{110} Government of the Republic of South Africa and Others v Grootboom and Others 2001 (1) SA 46 (CC) (hereinafter referred to as the Grootboom case), paragraphs [22] and [24]. Also see Kruger 101.
\textsuperscript{111} Kruger 101.
\textsuperscript{112} Kruger 101. Also see Campbell T Sceptical Essays on Human Rights (2001, Oxford: Oxford University Press) at 304. Also see Van Reenen 155.
\textsuperscript{113} Kruger 101.
\end{flushleft}
equal worth in relation to others, and such protection extends to the reverence for and promotion and fulfilment of such equal worth.\textsuperscript{114} It is for this reason that the right to equality from time to time entails that specific people should be treated differently.\textsuperscript{115}

Inequality as a consequence of formal equal treatment is frequently known as “substantive inequality”.\textsuperscript{116} When specific categories of people, for instance children, the aged or people living with disabilities, are always treated in the same way as others, their human dignity and equal worth as humans may be impaired by this equal treatment.\textsuperscript{117} In President of the Republic of South Africa and Another v Hugo,\textsuperscript{118} Goldstone J highlighted the need to develop a notion of unfair discrimination which acknowledges that even if society affords every person equal treatment on the basis of equal worth and freedom, this objective cannot be met by insisting on equal treatment in all circumstances.

In terms of the South African Bill of Rights, it is stipulated that measures may be put in place to protect and advance persons or categories of persons who were previously disadvantaged by unfair discrimination.\textsuperscript{119} Section 9(2) of the Constitution ensures that legislative and other measures that are intended to protect or advance persons or categories of persons disadvantaged by unfair discrimination may be taken.\textsuperscript{120} In the National Coalition for Gay and Lesbian Equality v Minister of Home Affairs,\textsuperscript{121} the Constitutional Court held that the phrasing of section 9, the equality clause, is indicative that the Constitution supports an understanding of substantive equality.

\begin{itemize}
\item \textsuperscript{114} Rautenbach & Malherbe 359.
\item \textsuperscript{115} President of the Republic of South Africa and Another v Hugo 1997 (4) SA 1 (CC) (hereinafter referred to as the Hugo case), paragraph [41]. Also see Nikolaidis C The Right to Equality in European Human Rights Law: The Quest for Substance in the Jurisprudence of the European Courts (2015, New York: Routledge) at 30; and Rautenbach & Malherbe 359.
\item \textsuperscript{116} Rautenbach & Malherbe 359. Also see Currie & De Waal 98 for a discussion on the nature of inequality.
\item \textsuperscript{117} Rautenbach & Malherbe 359. Hugo case, paragraph [41].
\item \textsuperscript{118} Rautenbach & Malherbe 359. For a concise explanation of the nature of affirmative action against the backdrop of South Africa’s history, see Leonard A “Communicating Affirmative Action during Transformational Change: A South African Case Study Perspective” 2004 Dissertation submitted in fulfilment of the requirements for the Degree Master of Philosophy Communication Management in the Faculty of Economic and Management Sciences at the University of Pretoria 1-263 at 62.
\item \textsuperscript{119} Rautenbach & Malherbe 360. Also see Currie & De Waal 242-243.
\item \textsuperscript{120} National Coalition for Gay and Lesbian Equality case, paragraph [15].
\end{itemize}
This redress directive was constitutionally protected for the reason that it was acknowledged that particular social groups in our society were discriminated against in the past.\textsuperscript{122} The provision allows for affirmative action.\textsuperscript{123}

The coming into effect of the Employment Equity Act\textsuperscript{124} is one of the major legislative advancements in South Africa. The purpose of the Employment Equity Act is to implement the comprehensive equality goals of the Constitution in the employment sector by prohibiting all forms of unfair discrimination in the workplace.\textsuperscript{125} The Act also requires that employers introduce affirmative action measures that cater for Black people,\textsuperscript{126} women and people with disabilities. The provisions of the Employment Equity Act, in as far as they relate to disability and albinism will be discussed in a subsequent chapter.

Measures taken in terms of section 9(2) must be aimed at persons or categories of persons who have been the target of unfair discrimination, must be reasonably capable of advancing or protecting those persons, and must promote the achievement of equality.\textsuperscript{127} The priority of the Constitution is therefore to establish an “equal playing field” and to deal proactively with the consequences of past injustices.\textsuperscript{128}

The limitation of rights frequently stems from the categorisation of people.\textsuperscript{129} Time and again, unequal treatment includes an element of the limitation of other rights.\textsuperscript{130}

\begin{footnotes}
\textsuperscript{122} National Coalition for Gay and Lesbian Equality case, paragraph [15].
\textsuperscript{123} Rautenbach & Malherbe 360.
\textsuperscript{124} Employment Equity Act 55 of 1998.
\textsuperscript{125} The preamble of the Employment Equity Act reads as follows:
"Recognising-that as a result of apartheid and other discriminatory laws and practices, there are disparities in employment, occupation and income within the national labour market, and that those disparities create such pronounced disadvantages for certain categories of people that they cannot be redressed simply by repealing discriminatory laws, Therefore, in order to-
promote the constitutional right of equality and the exercise of true democracy;
eliminate unfair discrimination in employment;
ensure the implementation of employment equity to redress the effects of discrimination;
achieve a diverse workforce broadly representative of our people; promote economic development and efficiency in the workforce; and give effect to the obligations of the Republic
as a member of the International Labour Organisation…"
\textsuperscript{126} Chapter 1 of the Employment Equity Act defines “Black people” as a generic term which means Africans, Coloureds and Indians”.
\textsuperscript{127} Rautenbach & Malherbe 360.
\textsuperscript{128} For a concise explanation of the nature of affirmative action against the backdrop of South Africa’s history, see Leonard 1-263.
\textsuperscript{129} Rautenbach & Malherbe 358.
\end{footnotes}
In other words, the encroachment on the right to equality repeatedly overlaps with the violation of other rights, and in nearly every instance the limitation clause is applied in the same way. The general limitation clause applies to nonconformity with the obligations in terms of both section 9(1) and section 9(3). In addition, the distinction between the prohibition of unequal treatment in section 9(1) and the prohibition of unfair discrimination in section 9(3) largely has an effect on the manner in which the general limitation clause is applied in the two instances.

The limitation clause is applied very strictly for the reason that the nature and extent of the consequences of unfair discrimination are very serious as they involve an impairment of human dignity which is usually viewed as equally grave. Despite the requirement that there be a rational relationship between the limitation and its purpose, much emphasis is placed on the importance of the purpose of the limitation. A limitation can be justified purely on the basis of an exceptionally pressing purpose whose promotion necessitates the limitation. As a result, extremely limited (if any) discretion is allowed with regard to alternative ways of achieving the purpose.

The effect of unequal treatment which does not amount to unfair discrimination is less serious and in such cases the general limitation clause is applied less strictly. The existence of a rational relationship between the limitation and its purpose is

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130 Rautenbach & Malherbe 358.
131 Rautenbach & Malherbe 358. Also see Ackermann 267-286.
133 Rautenbach & Malherbe 360.
134 Rautenbach & Malherbe 360. A person who alleges unfair discrimination has to prove that such differentiation is likely to impair their dignity. The burden to prove that dignity is likely to be impaired is not easy. The following cases illustrate this: Jordan & Others v S 2002 (6) SA 642 (CC); and Volks NO v Robinson & Others 2005 (5) BCLR 446 (CC). McConnachie C provides a brilliant discussion of the courts’ approach to human dignity in his article “Human dignity, ‘Unfair Discrimination’ and Guidance” (2014) 34 (3) Oxford Journal of Legal Studies 609–629. McConnachie criticises Justice Ackermann’s view that a profound reflection on and understanding of human dignity can afford South African courts clear guidance in ascertaining what constitutes unfair discrimination. Also see Ackermann 267-286.
135 Rautenbach & Malherbe 360.
136 Rautenbach & Malherbe 360-361.
138 Rautenbach & Malherbe 361.
emphasised.\textsuperscript{139} The importance of the purpose does not play a determining role and, moreover, those limiting the right are given wide discretion in terms of alternative ways to achieve the purpose.\textsuperscript{140}

An affirmative action scheme characteristically entails that an affiliate of a disadvantaged group must enjoy preference in the allocation of some benefit over a person who is not a member of that group.\textsuperscript{141} The test for unequal treatment as a result of affirmative action is practically the same as the test for unequal treatment which does not amount to unfair discrimination.\textsuperscript{142} The purpose of the limitation (protection and development of persons and categories of persons disadvantaged by unfair discrimination) is constitutionally regarded as more important than the nature and extent of the limitation.\textsuperscript{143} Affirmative action should not be viewed as derogation but rather as a substantive and additional part of advancing the right to equality.\textsuperscript{144} The test consists primarily of the rational relationship test and wide discretion is afforded in respect of alternative ways in which to achieve the purpose.\textsuperscript{145} It is however a stricter test than the rational relationship test in its basic form.\textsuperscript{146} A specific purpose is precise and the differential treatment must be rationally capable of promoting the purpose.\textsuperscript{147} The rationality standard has been implemented in a number of South African arbitration cases around affirmative action. In \textit{Durban City Council (Electricity Department) v SAMWU},\textsuperscript{148} the arbitrator found that the goal of affirmative action does not support the appointment of Coloured or Asiatic persons in an environment where these categories are already employed in numbers.

In the context of employment, the onus is on employers to justify any affirmative action programme. In \textit{Antoinete McInnes v Technicon Natal},\textsuperscript{149} the South African

\textsuperscript{139} Rautenbach & Malherbe 361.
\textsuperscript{140} Rautenbach & Malherbe 361.
\textsuperscript{141} Currie & De Waal 241.
\textsuperscript{143} Rautenbach & Malherbe 361.
\textsuperscript{144} Currie & De Waal 241-242.
\textsuperscript{145} Rautenbach & Malherbe 361.
\textsuperscript{146} Rautenbach & Malherbe 361.
\textsuperscript{147} Rautenbach & Malherbe 361.
\textsuperscript{148} \textit{Durban City Council (Electricity Department) v SAMWU} (1995) ARB 6.9.23 (unreported).
\textsuperscript{149} \textit{Antoinete McInnes v Technicon Natal} (2000) 9 LC 6.15.1, paragraph [33].
Labour Court stated that the onus rests on the respondent employer to prove that by selecting a designated group affiliate on the basis of race, the employer was adopting or implementing employment policies and practices intended to accomplish the acceptable protection and improvement of persons or categories of persons previously subjected to unfair discrimination.

3.2.2 The right to equality in the context of albinism

3.2.2.1 Colour as a ground for discrimination against persons living with albinism

A combination of diverse sociological and psychological factors gives skin colour the connotation it has today. In the history of Africa, discrimination on the basis of skin colour is not a new phenomenon. “Colourism”, “shadism”, “skin tone bias”, “pigmentocracy” and “colour complex” are all terms used to describe the system of privilege and prejudice which is based on the extent of lightness present in the colour of a person’s skin. Such identification of people suggests discrimination, stereotyping and perceptions about beauty amongst people of the same race whereby light-skinned members of the group are more highly valued than dark-skinned members.

However, no matter what label is attached to a person’s skin colour, it is harmful to do so. As previously seen in chapter one, the skin colour of persons living with albinism has led to a number of negative social constructions around this group of people, such as the association of fair tanned skin colour with harmful myths, false notions and curses.

The stigma and discrimination attached to persons living with albinism are matters of grave concern. It will be argued in the next section that albinos are often discriminated against on the basis of colour, specifically the fair tanned colour of their skin which lacks pigmentation. In South Africa in particular, the interpretation of

152 Gabriel 11.
153 Gabriel 11.
colour discrimination has been applied to Black, White, Indian and Coloured persons. The extension of colour to incorporate "fair tanned", the colour distinctively associated with albinos, will perhaps broaden the existing understanding of the right to equality in as far as it relates to colour as a basis for unfair discrimination. This may hopefully lead to a greater awareness of the subtle manner in which persons with albinism are differentiated and discriminated against in Africa and particularly South Africa.

In 2006, a conference was hosted by the Africa Genome Education Institute in South Africa with the purpose of reflecting on the genetics and social-ethical aspects of human variation in colour and disease. One of the topics considered at the conference was the biology of pigmentation. Despite South Africa’s history of apartheid and racial segregation, colour variation and its impact on citizens has not been explored in much detail. It is hoped that the discussion that follows will highlight the role played by skin colour in categorising people and specifically persons with albinism.

A discussion of colour as a ground for discrimination would be remiss if it failed to refer to South Africa’s history of racial and colour discrimination. This history demonstrates how South African society has used skin colour as well as race itself to distinguish superficially between races, and clearly illustrates how colour as a racial trait was an instant means of identifying racial affiliation.

Skin colour and race are regularly and erroneously used synonymously, with skin colour being seen as a way of determining race. This is specifically apparent in the use of the term Black to denote African Americans and the term White to denote Caucasians, despite the fact that these are common words that can include a plethora of ethnic groups.

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155 Howard A “An Exploration of Colorism and its effects on African American and White American Communities” 2011 Project submitted in partial satisfaction of the requirements for the Degree Master of Social Work at the University of California 1-80 at 14.
156 Howard 14-15.
During apartheid, people were firmly categorised as Black, White, Coloured or Indian and there was a strong identification with these groups. The Nationalist Party differentiated between these four groups of people and still today people refer to each other by race and colour, albeit to a lesser extent.

Any socially acknowledged type of racial detection is problematic, especially when the notion of whiteness is strongly associated with "purity and fairness" and blackness with "dirt, evil and death". Such derogatory and belittling terms linked to the colour black have been harmful to persons with darker skin tones. The same applies to persons living with albinism, as their distinctive fair tanned skin tone has many social implications in the communities in which they live.

The term "colourism" is not a new invention but until now colour discrimination has been subsumed by racism. It is always instructive to investigate whether claims relating to colour discrimination are racial or non-racial in nature. It is often difficult to determine whether colourism practices constitute race-based discrimination or race-related discrimination. Jones argues that colourism is a type of discrimination not affiliated to race, since colourism calls to mind diverse stereotypes and stigmas based on skin tone and not race. The Africa Genome Education Institute argues that attributing labels or "racial" features to skin pigmentation makes little sense. Race and skin colour are two distinctive phenomena which

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159 Howard 15.
160 Howard 15.
161 Jones 1489.
162 Jones 1489.
occasionally overlap.\textsuperscript{167} Race and skin colour are both “social constructions” for the reason that they are continually developing products of the way in which society understands group differences and assigns meaning to such differences.\textsuperscript{168} The significance of race and colour comes from the specific meaning that we attribute to them.\textsuperscript{169}

Gross morphological differences such as “broadness of the nose”, “fullness of the lips” and “curl of the hair” continue to be used to describe racial groups and to associate persons with specific racial groups.\textsuperscript{170} Among these characteristics used to denote race, skin colour plays a major role.\textsuperscript{171} The whiter the skin colour of a person, the more it is expected that such a person is of Caucasian origin or White.\textsuperscript{172} Likewise, the darker or browner a person’s pigmentation, the more such a person is identified as Negroid or Black.\textsuperscript{173} These classifications are loaded with societal meaning.\textsuperscript{174} For example, in the United States, being White immediately signals access to the “psychological and economic privileges of whiteness”,\textsuperscript{175} while being

\begin{footnotesize}
\begin{enumerate}
\item Jones 1493; Figueroa 5-6; and Schaefer RT \textit{Encyclopaedia of Race, Ethnicity, and Society} (2008, London: SAGE) at 1091.
\item Jones 1493; and Figueroa 5-6.
\item Jones 1494; and Figueroa 5.
\item Jones 1494; and Figueroa 5.
\item Jones 1494.
\item Jones 1494.
\item Jones 1494; and Schaefer 1091.
\end{enumerate}
\end{footnotesize}
Black means that one is labelled as inferior within the social hierarchy. Closer to home, the apartheid system ensured that the privileges granted to White people were far beyond the reach of Black people, which is the reason for the present economic disparities between Blacks and Whites in South Africa.

Racial classification is not determined by skin colour alone. Traditionally, other features have also been used to allocate people to racial groups. Such factors include ethnicity and bloodlines. For instance, although a person is light enough to appear White, if their immediate ancestors were classified as Black, they are considered Negroid. In such cases, skin colour does not establish race. Rather, the classification of race is based on ancestry.

Racial classification is therefore not based exclusively on skin colour, as several factors are used to designate race. Skin colour is only one of the attributes used to assign people to a racial class. Race turns out to be the social meaning attributed to that category. It is a set of values or assumptions about persons categorised within a certain racial group. Such beliefs can be very broad ranging and include

“According to a University of Cape Town study, about 30% of black South African women are regular skin bleachers. In Nigeria, an estimated 77% of the female population use skin lighteners notwithstanding the fact that medical research has found that skin bleaching damages the skin, causing thinning, skin sensitivity and red blotches”. See Maune B “Gallery Skin Lightening Celebrities” at http://www.timeslive.co.za/lifestyle/2014/09/10/gallery-skin-lightening-celebrities (visited 12 July 2015).

Jones 1497. People often have the wrong impression about the positive association between the value associated with being a member of the white race and the value attached to a lighter skin tone. In other words, despite “pride-saving” and race-affirming statements like “Black is Beautiful” and “the blacker the berry, the sweeter the juice,” phrases like “White is right” more precisely capture modern understanding of both the racial and the colour ladders. Consequently, with race and skin colour discrimination, the lighter one’s skin tone, the higher one’s economic and social status is deemed to be. Such a parallel time and again suggests that racism and colourism are the same.


Schaefer 1091.

Richard 456.

Jones 1497.

Jones 1497.

Jones 1497.

Schaefer 1091.

Figueroa 5.

Jones 1497.
assumptions about a group’s “intellect, physical attractiveness, work ethic, class and morality”, to name but a few.\textsuperscript{186}

In instances where two persons are categorised as belonging to the same race but one is “milk chocolate brown” and the other “dark chocolate brown”, regardless of the fact that they belong to the same race, the first person may receive better treatment due to their skin colour being perceived as lighter.\textsuperscript{187} When viewing these two people, an observer may not use skin colour to associate them with a specific racial category.\textsuperscript{188} Rather, any differential treatment may be the result of the value attached to skin colour itself and not of racial classification \textit{per se}.\textsuperscript{189}

At the time of the writing of this thesis, South Africa has no local precedents to resolve jurisprudential issues on colourism in the context of albinism, whereas in the United States of America, one finds legal judgments dealing with the issue of colourism. Examples of American case law illustrate the complexities associated with establishing colour as a new basis for action autonomous of race. This thesis therefore discusses case law from the United States with the purpose of finding a basis for an appropriate investigative framework relevant to colourism issues.

In the United States case of \textit{Rodriguez v Gattuso},\textsuperscript{190} the court found that discrimination based on colour was actionable under the Fair Housing Act of 1968, although the plaintiff and the defendant were persons of the same race. The plaintiff, a dark-skinned Latino, was denied rental of an apartment which was later rented to his light-skinned Latino wife.\textsuperscript{191} The court stated that a colour discrimination claim was appropriate for the reason that the defendant treated the plaintiff and his wife differently based on their shade of skin colour.\textsuperscript{192}

\textsuperscript{186} Jones 1497. For instance, if one were to see Oprah Winfrey and Rosie O’Donnell on the street, Oprah’s brown skin tone would probably cause the observer to come to the conclusion that she is Black. However, it is not her brown skin tone which determines her racial status, but her classification as Black, as well as the associated societal observations linked to her racial classification. With colourism, skin colour hardly serves as an indicator of race. Rather, it is the social meaning attached to the skin colour itself which results in differential treatment.

\textsuperscript{187} Jones 1497
\textsuperscript{188} Jones 1497.
\textsuperscript{189} Jones 1497.
\textsuperscript{190} Rodriguez v Gattuso 795 F. Supp. 860, 865 (N.D. Ill. 1992) (hereinafter referred to as the \textit{Rodriguez case}), paragraph [863].
\textsuperscript{191} Rodriguez case, paragraph [863].
\textsuperscript{192} Rodriguez case, paragraph [866].
In such an instance, where views on colour are the basis for differential treatment, such discrimination is specifically called colourism. With colourism, therefore, it is the social meaning attached to one’s colour which establishes one’s status. In the case of racism, on the other hand, it is the social meaning associated with one’s race that establishes one’s status.

The literature on colour discrimination tends to treat skin tone bias as an internal phenomenon within non-White communities, but skin tone discrimination can in fact be both interracial and intraracial. It is vital to take cognisance of the fact that colour discrimination functions both intraracially and interracially. Intraracial colour discrimination occurs when an affiliate of a particular racial group makes a distinction on the basis of skin colour between members of their own race, while interracial colourism occurs when an affiliate of a particular racial group makes a distinction on the basis of skin colour between affiliates of another racial group.

Discrimination and classification difficulties become evident when people use colour to group as well as label people. Discrimination on the basis of albinism has generally been overlooked by the courts. This is particularly the case in South Africa. A consideration of how to effectively protect persons with albinism against colour discrimination in South Africa is therefore indispensable.

The grounds of discrimination termed “race”, “colour” and “ethnic origin” suggest that in the equality clause, colour is an indication of race. The International Covenant on the Elimination of All Forms of Discrimination defines racial discrimination as

193 Jones 1497.
194 Jones 1497. Also see Gabriel 11. Colourism, shadism, skin tone bias, pigmentocracy and colour complex, are some of the words that are used to describe the system of privilege and prejudice which is founded on the degree of lightness of a person’s colour of skin.
195 Jones 1497. Time and again people confuse skin colour and race for the reason that skin colour is used to assign people to their particular racial categories. Without doubt, colour is frequently used to explain racial categories; for example Black is used to describe African-Americans while White is used to describe Caucasians.
197 Jones 1498.
198 Jones 1498.
200 Scott 495.
201 Currie & De Waal 227.
unfair discrimination based on “race, colour, descent, or national or ethnic group”\textsuperscript{202}. Currie and De Waal regard race, colour, descent, or national or ethnic group discrimination as biological and social clusters based on which controlling and damaging principles of “superiority and inferiority” have been interpreted.\textsuperscript{203} In their explanation of “race, colour and ethnic origin”, Currie and De Waal emphasise the obduracy of the apartheid system and the need to redress this past.\textsuperscript{204} The authors refer to various statutes that were repealed which impacted on the Black community.\textsuperscript{205} Particular reference is made to the Black Administration Act 38 of 1927, which systemised and imposed a colonial type of affiliation on a leading White minority, which had citizenship rights, and an inferior Black majority, which was oppressed.\textsuperscript{206} It is possible that the historical division of Black and White entrenched in various statutes as well as the physical segregation of Blacks, Whites, Coloureds and Asians may have influenced the drafters of the Constitution to include colour in their analysis of racial discrimination. In light of this, colour will have to be interpreted against the backdrop of South Africa’s historical context.

The inclusion of race and colour separately as prohibited grounds for unfair discrimination highlights the fact that they are distinct terms and should be interpreted independently of each other. Persons living with albinism must be protected against unfair discrimination on the basis of their colour. In this regard, Scott argues that categorising these persons as White or African-American will not

\textsuperscript{202} Article 1 of the International Covenant on the Elimination of All Forms of Racial Discrimination (6660 UNTSS 195, entered into force 4 January 1969) reads as follows:

“In this Convention, the term ‘racial discrimination’ shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.”

\textsuperscript{203} Currie & De Waal 227.
\textsuperscript{204} Currie & De Waal 227.
\textsuperscript{205} Currie & De Waal 227.
\textsuperscript{206} Currie & De Waal 227. In the Chinese Association of South Africa and Another v Minister of Labour and Others case No (59251/2007), paragraph [1], the Chinese Association of South Africa took the South African government to court, on grounds that its members had been discriminated against. The South African High Court ruled that Chinese people of South African descent are to be reclassified as Black. The court issued this order so that the ethnic Chinese could benefit from government policies aimed at the elimination of White dominance within the private sector. The association argued that the Chinese often failed to qualify for business contracts and job promotions because they were regarded as Whites. The association representing the Chinese further argued that the Chinese had faced widespread discrimination during the years of apartheid when they had been classified as people of mixed race.
afford adequate protection; hence his insistence on colour as a new category relevant to persons with albinism. He further argues that albinos are discriminated against because they defy the construct of racial classification. This view cannot be accepted, as what distinguishes these persons is that they lack pigmentation which consequently makes them look pale compared to normal skinned African-Americans or white Americans. An understanding of the underlying clinical aspects relating to albinism makes it clear that the melanin balance is the component that differentiates a person with albinism from other persons with normal skin pigmentation. It would be incorrect to say that they defy racial classification because their skin colour is unique and different.

Seeking redress on the grounds of colour will make it possible for a person with albinism to challenge discrimination by employers or potential employers. The employment context offers persons with albinism a distinctive opportunity for integration within a larger community for the reason that in an integrated working environment, employees are obliged to face the stereotypes, misconceptions and all other false notions about albinism.

No statistics are available in South Africa on the number of persons with albinism who have experienced unfair discrimination. People such as Nomasonto Mazibuko, the Chairperson of the Albinism Society of South Africa, advocate against the discrimination which albinos face. Because of their vulnerability, persons with albinism do not always have a unified voice for asserting their rights and their very existence. They are seldom heard as they are a marginalised group.

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207 Scott 508.
208 Scott 508.
209 Scott 508.
210 Scott 508. In the United Nations General Assembly, Report on Persons with Albinism, A/HRC/24/57, 12 September 2013 at 16, it was noted that the Committee on the Elimination of Racial Discrimination has not yet examined the issue of discrimination on the basis of colour with respect to persons with albinism.
211 Scott 508. The discussion of the right to equality is evidence that the final Constitution of 1996 includes equality as a value and equality as a substantive human right. Section 9 sanctions a formal approach to equality by illegalising unfair discrimination and providing for affirmative action which is a form of substantive equality.
212 Scott 509.
213 Scott 509.
The South African Constitution lists colour as an independent prohibited ground of unfair discrimination. The inclusion of colour separately from race suggests that this may have been done to provide for extraordinary instances. Since the equality clause applies to everyone, a claim based on discrimination on the ground of colour also applies to persons living with albinism. In circumstances where people with albinism find themselves unfairly discriminated against based on their pale colour, it is submitted that the courts should be sensitive to the issue and extend the interpretation of colour as a ground of discrimination in order to protect these persons.

In the United States case of *Walker v Secretary of the Treasury*, the court held that a light-skinned African-American employee had an actionable Title VII claim of colour discrimination against a dark-skinned African-American employer. The *Walker* case highlights differences in both colour and physical features between people of African descent. The court acknowledged the problems innate to claims based on colour but questioned whether the plaintiff's termination was a result of colour discrimination. On remand, the court found that the plaintiff had failed to prove that her termination was because of colour discrimination. The court in the *Rodriguez v Gattuso* discussed earlier adopted the reasoning in the *Walker* case and found that discrimination based on colour was actionable under the Fair Housing Act of 1968, although the plaintiff and the defendant were persons of the same race.

It is the responsibility of the courts in South Africa to fully develop the rights entrenched in the Constitution, and “common values of human rights protection the world over and foreign precedents” may be instructive in this regard. The United States cases referred to above are instructive in their emphasis on the unique and nuanced context in which race and colour, separately and jointly, play a role in the discrimination of persons living with albinism.

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215 *Walker* case, paragraph [406-410].
216 *Walker* case, paragraph [407].
217 *Rodriguez* case, paragraph [863].
218 *Makwanyane* case, paragraph [302].
In the United States, the recognition of a new basis of action independent of race raised questions regarding the legal bases for the action as well as the proper investigative framework relevant to colourism issues. Jones’s approach to colourism, discussed above, does not take into account the possible development of new forms of racism and presumes the readiness of courts to address the often novel and nuanced forms that discrimination may take. As Banks observes on the situation in the United States, claims relating to unfair discrimination based on race are well “grounded in constitutional as well as state laws.” Furthermore, while judges and legislatures understand the core motives behind race-based laws, the subtle shades of discrimination relative to colourism often go unnoticed.

This study asserts that persons living with albinism, especially those in South Africa, have suffered discrimination on the basis of both colour and race. Although colourism is a phenomenon which affects many South Africans, it is a subject that has received scant attention. A discussion of colourism requires an integrated and multidisciplinary approach, as an understanding from medical, legal and social points of view is needed.

3.3 The right to life in the constitutional framework

3.3.1 Theoretical observations

While both national and international law regulates a diversity of fundamental human rights, significant value is assigned to the right to life. Human rights depend on the

219 Banks 219.
220 See above discussion on racism and colourism.
221 Banks 220.
222 Banks 219.
223 Banks 219.
225 Currie & De Waal 258. “The right to life is, in one sense, the antecedent to all the other rights in the Constitution. Without life in the sense of existence, it would not be possible to exercise rights or to be the bearer of them. But the right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes, but the right to human life: the right to live as a human being, to be part of a broader community, to share in the experience of humanity. This concept of human life is at the centre of our constitutional values. The Constitution seeks to establish a society where the individual value of each member of the society is recognised and treasured. The right to life is central to such a society.” Makwanyane case, paragraph [326]. Also see Carmichele v Minister of Safety and Security 2001 (4) SA 938 (CC) (hereinafter referred to as the Carmichele case).
continued survival of the biological process that is life. Human rights relate to humanity as non-figurative, as well as to real persons in terms of the continuation of the life process. The right to life is thus intended to protect the continued “physical–biological” existence of human beings which is a prerequisite for the existence of the human being as a holder of such rights and freedoms. With this in mind, the right to life ought to be seen as the principal right of all human beings.

The right to life is protected under section 11 of the Constitution. However, the right to life as protected under this section only relates to natural persons. The nature of and duties associated with this right are phrased in such a way that only private persons are bound by this right.

Traditionally, the right to life protects a person’s life against possible attack. In recent times, the right to life has come to include circumstances pertaining to scientific and medical involvement in the conception, growth or interruption of the life process. For instance, the status of a human embryo is closely linked to the question of when human life begins. Human life is hence no longer only a certainty which the law has to protect, it is also an “artefact” calling for rules to govern the way in which persons deal with human life. This is often left in the hands of research ethics committees to decide. It is a terrain in which constitutional and international courts routinely tread very lightly.

Unlike other jurisdictions, the right to life under the South Africa Constitution is unqualified. Countries such as the United States and Canada, as well as

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227 Mathieu 9.
228 Rautenbach & Malherbe 366.
229 Mathieu 9. Also see Rautenbach & Malherbe 366.
230 Mathieu 9.
231 Section 11 of the Constitution of 1996 states: “Everyone has the right to life.”
232 Mathieu 9.
233 Mathieu 9.
235 Mathieu 9.
236 Mathieu 9-10.
237 Currie & De Waal 259. See Makwanyane case, paragraph [354]: “Our Constitution in this sense is different from those that expressly authorise deprivation of life if due process of law is followed, or those that prohibit the arbitrary taking of life. The unqualified statement that ‘every person has the right to life’, in effect outlaws capital punishment”.

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international instruments such as the International Convention on Civil and Political rights, have qualified the right to life.\textsuperscript{238} This is normally done by stating that the right to life “may not be deprived arbitrarily or other than in accordance with a sentence of a court of law”.\textsuperscript{239} Under the South African Constitution, a limitation of the right to life can only be achieved in terms of the general limitation clause.\textsuperscript{240} It is important to note that the absence of a qualification clause in the Interim Constitution meant that the Constitutional Court (and not Parliament) had the power to make a decision on the complicated question of the death penalty.\textsuperscript{241} In a political sense, it afforded the court the power to make a decision on this issue and to revoke punishment by death despite strong communal support for the retention of the death penalty.\textsuperscript{242}

The right to life is not absolute and may only be limited in terms of section 36, the general limitation clause.\textsuperscript{243} Bearing in mind the importance of the right, as well as the fact that it is impossible to reverse a violation of this right, justification of the limitation has to be extremely convincing.\textsuperscript{244} Examples in this regard are the killing of a person in order to save one’s own life or someone else’s life or the application of lethal force by the State for the purpose of killing “a hostage taker” to save the life of a guiltless hostage whose life is in actual peril.\textsuperscript{245} The State may also kill for the

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\textsuperscript{238} Currie & De Waal 259.\textsuperscript{239} Currie & De Waal 259.\textsuperscript{240} Venter B “A Selection of Constitutional Perspectives on Human Kidney Sales” (2013) 16 (1) Potchefstroom Electronic Law Journal 352-403 at 361. Also see Currie & De Waal 259.\textsuperscript{241} Currie & De Waal 259.\textsuperscript{242} Currie & De Waal 259.\textsuperscript{243} Venter 361. Also see Mubangizi JC The Protection of Human Rights in South Africa: A legal and Practical Guide (2005, Lansdowne: Juta) at 83.\textsuperscript{244} Makwanyane case, paragraph [9].\textsuperscript{245} Makwanyane case, paragraph [138]. In the very same paragraph the court noted: “Self-defence is recognised by all legal systems. Where a choice has to be made between the lives of two or more people, the life of the innocent is given preference over the life of the aggressor. This is consistent with section 33(1). To deny the innocent person the right to act in self-defence would deny to that individual his or her right to life. The same is true where lethal force is used against a hostage taker who threatens the life of the hostage. It is permissible to kill the hostage taker to save the life of the innocent hostage. But only if the hostage is in real danger. The law solves problems such as these through the doctrine of proportionality, balancing the rights of the aggressor against the rights of the victim, and favouring the life or lives of innocents over the life or lives of the guilty. But there are strict limits to the taking of life, even in the circumstances that have been described, and the law insists upon these limits being adhered to. In any event, there are material respects in which killing in self-defence or necessity differ from the execution of a criminal by the State. Self-defence takes place at the time of the threat to the victim’s life, at the moment of the emergency which gave rise to the necessity and, traditionally, under circumstances in which no less-severe alternative is readily available to the potential victim. Killing by the State takes
purpose of suppressing a rebellion or in circumstances of defending itself from exterior aggression.\textsuperscript{246} These situations are undoubtedly different from the execution of a criminal by the State.\textsuperscript{247} Where a person is killed in self-defence or to protect the life of a hostage, the right to life of the offender needs to be objectively weighed up against the right of the victim.\textsuperscript{248} In critical situations like these, there seems to be no other choice but to destroy life, and a law authorising such killing comprises a lawful limitation of the right to life.\textsuperscript{249} In situations of rebellion or war, by essential inference from the fact that any constitutional state may well lawfully act to protect itself from rebellion or external aggression, the killing ought to be constitutionally acceptable.\textsuperscript{250}

In the *Makwanyane* case, the Constitutional Court held that the death penalty constitutes a cruel, inhuman and degrading punishment, as such punishment infringed on the right to life and the right to human dignity.\textsuperscript{251} With determination, the court associated the right to life with the right to dignity and further established that the relation between these two rights, viewed in line with the risk of arbitrariness and error, and over and above the possibility of imprisonment for life as an alternative, overrode the unverified deterrent effect of execution and society’s understandable call for retribution.\textsuperscript{252} The Constitutional Court emphasised that “retribution cannot be accorded the same weight under our Constitution as the rights to life and dignity.”\textsuperscript{253}

In addition, the State has a positive duty to protect its citizens from “life-threatening attacks”.\textsuperscript{254} In the *Carmichele* case,\textsuperscript{255} this duty was emphasised in the context of the

\textsuperscript{246} *Makwanyane* case, paragraph [139]: “The examples of war and rebellion are also not true analogies. War and rebellion are special cases which must be dealt with in terms of the legal principles governing such situations. It is implicit in any constitutional order that the State can act to put down rebellion and to protect itself against external aggression. Where it is necessary in the pursuit of such ends to kill in the heat of battle the taking of life is sanctioned under the Constitution by necessary implication, and as such, is permissible in terms of section 4(1). But here also there are limits. Thus prisoners of war who have been captured and who are no longer a threat to the State cannot be put to death; nor can lethal force be used against rebels when it is not necessary to do so for the purposes of putting down the rebellion.”

\textsuperscript{247} Currie & De Waal 261.

\textsuperscript{248} *Makwanyane* case, paragraph [139].

\textsuperscript{249} Currie & De Waal 261.

\textsuperscript{250} Currie & De Waal 261. Also see *Makwanyane* case, paragraph [139].

\textsuperscript{251} *Makwanyane* case, paragraph [166].

\textsuperscript{252} *Makwanyane* case, paragraphs [94] and [273].

\textsuperscript{253} *Makwanyane* case, paragraph [146].

\textsuperscript{254} Currie & De Waal 263.
protection of the public by police officials and prosecutors from life-threatening attacks.

Muller and Milne pose a very relevant question for this thesis, namely that of the interpretation of the right to life. Their question involves the issue of whether South African courts have interpreted the right to life as an effective constitutional model that advances the quality of life, and in particular a “safe” life, which exists concurrently with the constitutional rights and values of human dignity, equal worth and freedom.256

Such a “safe” life allows everyone to enjoy a quality of life that goes beyond mere survival.257 It is contested that our judiciary system is hesitant to construe the right to life as including the right to a certain “quality of life”.258 This is because the State’s obligations in terms of rendering such quality of life are already listed in the Constitution, primarily in the form of socio-economic rights.259 In view of the fact that the unqualified nature of the right to life contributes to the unwillingness of the judiciary to associate the right to life with a certain quality of life, Muller and Milne propose that the right to life ought to be rethought and reinterpreted in order to be more meaningful.260 The right to life should be construed more broadly to incorporate the right to a “safe” life which should be extended to the protection of persons

255 Carmichele case, paragraphs [26], [28] and [30]. Also see Burchell J Principles of Criminal Law (2013, Cape Town: Juta) at 79-86.
256 Muller NB & Milne J “Rethinking the State’s Duty to Uphold the Right to Life in a Criminal Justice Context” (2009) 30 (2) Obiter 307-327 at 307. Also see Burchell 79-86.
257 Muller & Milne 308.
258 Muller & Milne 308.
259 Muller & Milne 308. Rautenbach and Malherbe argue that within the scope of the interpretation of the right to life, it is not essential to include social rights, as incorporated in a bill of rights, for the purpose of protecting a “minimum level” for a human being’s continued survival. The right to life as intended to protect the “physical–biological” continued existence of human beings should be differentiated from instances where the biological process of life is violated or is at risk due to socio-economic and environmental degradation, war, internal disorder or military and security action. Socio-economic and environmental degradation amount to infringements or threats to the right to life but they do not have an effect on the protective scope of the right to life. Currie and De Waal argue that the courts are customarily cautious about imposing obligations on the state that facilitate a certain standard of living, since they see this as the legislature’s and executive’s powers. See Currie & De Waal 268.
260 Muller & Milne 312.
against fear, threats and the consequences of violent crime. In this case, socio-economic rights will not be included in an analysis of the right to life.

In the *Makwanyane* case it was held that:

> [i]t is the responsibility of the Courts, and ultimately this Court, to develop fully the rights entrenched in the Constitution. But that will take time. Consequently, any minimum content which is attributed to a right may in subsequent cases be expanded and developed.

The court acknowledged its duty to develop the right to life. However, until now, the right has been interpreted in the context of the right not to be deprived of one’s life and of the social policy surrounding the death penalty. To this end, our courts have in fact failed to deal efficiently with such entitlement to a certain quality of life and its accompanying obligations. In view of the discussion above, Snyman argues that, amongst others, a principal threat to the legality of the South African Constitution is that victims, as well as possible victims, of brutal crime see the Bill of Rights as being interpreted in a way which protects criminals rather than their victims.

However according to Burchell, victims’ rights are attaining the appropriate significance they did not have in the early development of criminal justice. Victims of crime can make use of the provision for “victim impact statements” after the verdict but before the sentence. This type of statement can reflect the impact of the crime on the victim, the circumstances surrounding the crime, the perpetration of the crime and the views of the victim or the victim’s family in terms of a suitable sentence. Section 274(1) of the Criminal Procedure Act states that before passing any sentence a court may receive evidence as it deems fit in order to inform itself on the appropriate sentence, and victim impact statements may perhaps form part of

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261 Muller & Milne 309.
262 Muller & Milne 312.
263 *Makwanyane* case, paragraph [325]. Also see Muller & Milne 308.
264 Muller & Milne 309.
265 Muller & Milne 309. Also see Snyman CR *Criminal Law* 6th ed (2014, Durban: LexisNexis) at 19. Also see Muller & Milne 309.
266 Snyman 27-29.
268 Burchell 4.
269 Burchell 4.
270 Criminal Procedure Act 51 of 1977 (hereinafter referred to as the Criminal Procedure Act).
such evidence.\textsuperscript{271} In the case of \textit{S v Matyityi},\textsuperscript{272} the court strongly emphasised that information pertaining to the gravity of the offence, the effect of the crime on the victim and victim empowerment be used for the purpose of restorative justice, the process of restoring the victim to the position that was disturbed by the crime.\textsuperscript{273} Even if punishment is the main purpose of criminal prosecution, the compensation of victims of crime is recognised by the Criminal Procedure Act\textsuperscript{274} in cases where the criminal offence results in damage to property or loss of property. Section 29 of the Protection and Combating of Trafficking in Persons Act\textsuperscript{275} extends the compensation of victims of human trafficking crimes to include not only property damage or economic loss but also physical, psychological and other losses.

The leading criticism of deducing the right to a “safe” life from the right to life is the contestation that the right to freedom from violence is already protected in the Constitution under section 12(1)(c) of the Bill of Rights. Section 12(1) (c) provides that:

\textit{[e]}everyone has the right to freedom and security of the person, which includes the right to be free from all forms of violence from either public or private sources.

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{271} Burchell 5.
\item \textsuperscript{272} \textit{S v Matyityi} 2011 (1) SACR 40 (SCA), paragraph [17]. In addition, section 153(3) of the Criminal Procedure Act may possibly be seen as over-broad as it seems to be focused on protecting the privacy of victims; see the South African Law Commission Report “The Application of the Bill of Rights to Criminal Procedure, Criminal Law, the Law of Evidence and Sentencing” Project Report 1-116 at 65. Section 153 (3) of the Criminal Procedure Act, provides circumstances in which criminal proceedings shall not take place in open court. Section 153 (3) reads as follows:
\item \textsuperscript{273} \textit{“153 (3) In criminal proceedings relating to a charge that the accused committed or attempted to commit-}
\item \textsuperscript{274} (a) any sexual offence as contemplated in section 1 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act, 2007, towards or in connection with any other person; 
\item \textsuperscript{275} (b) any act for the purpose of furthering the commission of a sexual offence as contemplated in section 1 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act, 2007, towards or in connection with any other person; or
\item \textsuperscript{276} (c) extortion or any statutory offence of demanding from any other person some advantage which was not due and, by inspiring fear in the mind of such other person, compelling him to render such advantage, the court before which such proceedings are pending may, at the request of such other person or, if he is a minor, at the request of his parent or guardian, direct that any person whose presence is not necessary at the proceedings or any person or class of persons mentioned in the request, shall not be present at the proceedings: Provided that judgment shall be delivered and sentence shall be passed in open court if the court is of the opinion that the identity of the other person concerned would not be revealed thereby”.
\end{itemize}
\end{footnotesize}
With this in mind, it is instructive to assess the ambit of section 12(1)(c) of the Constitution. In attempting to interpret this section, Muller and Milne pose the question of whether the freedom and security of the person, for example freedom from all forms of violence, are violated when violence or fear and threat of violence is inflicted.\textsuperscript{276} It seems that the protection derived from this section is limited to specific cases that have resulted in the progression of duties stemming from the law of delict.\textsuperscript{277}

\begin{quote}
[The] net of unlawfulness [is cast] wider because constitutional duties are now placed on the State to respect, protect, promote and fulfill the rights in the Bill of Rights and, in particular the right of women to have their safety and security protected.\textsuperscript{278}
\end{quote}

This reference to the safety and security of women applies equally to persons with albinism. Following the above case, these constitutional duties result in the expansion of state accountability to incorporate circumstances where:

the authorities knew or ought to have known at the time of the existence of a real and immediate risk to the life or physical integrity of an identified individual or individuals from the criminal acts of a third party and that they failed to take measures within the scope of their powers which, judged reasonably, might have been expected to avoid that risk.\textsuperscript{279}

Nevertheless, such protection is available \textit{post facto} and restricted to individual protection in specific “well-defined” situations.\textsuperscript{280} The focus is on the protection of the right to life not only in situations in which the threat of a violent crime is existent or instant, but also where the fear caused by the general incidence of violent crime is of such a nature that it violates the right to a “safe” life.\textsuperscript{281} In the \textit{Grootboom} case, Judge Yacoob noted that the people of South Africa are committed to the realisation of social justice and the advancement of the quality of life for every person.\textsuperscript{282} This commitment is also stated in the preamble to our Constitution.

It is thus contended that the net should be cast even wider in order to ensure protection for all holders of this right over and above the direct violation of their physical integrity. In this regard, it is argued that the courts should relinquish judicial

\textsuperscript{276} Muller & Milne 309.
\textsuperscript{277} Currie & De Waal 282.
\textsuperscript{278} \textit{Carmichele} case, paragraph [57].
\textsuperscript{279} Muller & Milne 309.
\textsuperscript{280} Muller & Milne 309.
\textsuperscript{281} Muller & Milne 309.
\textsuperscript{282} \textit{Grootboom} case, paragraph [1].
restraint and fulfill their constitutional mandate by further developing the right to life to encompass the right to a “safe” life in situations where other specific entitlements fail to do so.

Given the argument that the unqualified composition of the right to life contributes to a judicial “reluctance” to construe and apply the right to life to incorporate a particular “quality of life”, Muller and Milne propose that the right to life ought to be rethought and re-interpreted with the purpose of making it more effective. They contend that the urgency of the crime situation in South Africa calls for making the development of the right to life a priority within the criminal justice framework.283

As seen in chapter one, infanticide of children with albinism is rife. Infanticide refers to the practice of parents deliberately killing an infant themselves or consenting to their being murdered for various reasons.284 Burchell defines infanticide as the killing of newborn children.285 *Crimen expositionis infantis* is a crime which existed under Roman-Dutch law.286 This crime took two forms, namely abandoning a child with the expectation that the child would eventually die, and abandoning a child in a place where the child would possibly be fostered.287 Abandoning a child with the expectation that it would eventually die was punished by death while the sentence for abandoning a child in a place where it might be fostered was more lenient.288

*R v Adams*289 is the landmark case in which the accused was charged with *crimen expositionis infantis*. In this case, Christina Adams abandoned her son on the day he was born290 and was found guilty of *crimen expositionis infantis*.291 Subsequent to the *Adams* case, there do not appear to have been any cases in which the charge

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283 Muller & Milne 309.
285 Burchell 567.
286 Burchell 567; and Snyman 444.
287 Burchell 567; and Snyman 444.
288 Burchell 567.
289 *R v Adams* 1903 (20) SC 556 (hereinafter referred to as the *Adams* case).
290 *Adams* case, pages [556] and [557].
291 *Adams* case, pages [556] and [557].
was *crimen expositionis infantis*. Subsequent offenders were in fact charged with “concealment of birth” under Cape Ordinance 10 of 1845.

To date, infanticide is not considered a separate crime under South African law. It is recognised as the common-law crime of murder since every intentional killing of an infant is murder. The same is applicable to a parent who deserts his or her baby deliberately with the purpose of killing the child. Should the baby subsequently die, the parent may be charged with murder. In circumstances where the baby does not die, the parent can be charged with attempted murder. Culpable homicide applies where the parent negligently abandons a baby child.

South Africa does not have specific legislation dealing with infanticide. Infants’ lives are protected by general legislation only. Section 113 of the General Law Amendment Act stipulates that any person who disposes of the body of a newly born child with intent to conceal the fact of its birth, whether the child died before, during or after birth, shall be guilty of an offence and liable on conviction to a fine or to imprisonment for a period not exceeding three years. Under the Criminal Procedure Act, a child is deemed to be born alive if the child has breathed or has experienced independent circulation of blood. It is not necessary to prove that

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292 Van der Westhuizen 188; and Snyman 444.
293 Cape Ordinance 10 of 1845. Also see *R v Arends* 1913 CPD 194 and *R v Verrooi* 1913 CPD 864.
294 Van der Westhuizen 190; and Burchell 567.
295 Van der Westhuizen 190; and Snyman 444.
296 Van der Westhuizen 190; and Snyman 444.
297 Van der Westhuizen 190; Burchell 569-570; and Snyman 444.
298 General Law Amendment Act 46 of 1935 (hereinafter referred to as the General Law Amendment Act); and Criminal Procedure Act.
299 Section 113 of the General Law Amendment Act.
300 Section 239 of the Criminal Procedure Act reads as follows: “Evidence on charge of infanticide or concealment of birth.
(1) At criminal proceedings at which an accused is charged with the killing of a newly-born child, such child shall be deemed to have been born alive if the child is proved to have breathed, whether or not the child had an independent circulation, and it shall not be necessary to prove that such child was, at the time of its death, entirely separated from the body of its mother.
(2) At criminal proceedings at which an accused is charged with the concealment of the birth of a child, it shall not be necessary to prove whether the child died before or at or after birth.”

In a fairly recent case, *S v Molefe* (A240/12) [2012] ZAGPPHC 52; 2012 (2) SACR 574 (GNP) (3 April 2012) the accused, an adult female, was convicted in the Magistrates’ Court of Bloemhof for contravening section 113 of the General Law Amendment Act. The accused unlawfully and intentionally concealed the fact of the birth of a child and attempted to dispose of the body of the said child. It was submitted that the crux of the crime is the “disposal” or “attempted disposal” of the body of a child. In the case at hand the accused did not admit
such child was entirely separated from the body of its mother at the time of its death.\footnote{301} The right to life, as discussed, naturally extends to infants.

Despite the constitutional protection of life in South Africa, infanticide still persists.\footnote{302} It is also relevant to mention that foetal interests can arise in the context of albinism. A conflict may arise about the continued existence of an albino foetus where the foetus is not regarded as a legal subject and the woman as a legal subject, exercising her right to autonomy by terminating her pregnancy. The Choice on Termination of Pregnancy Act\footnote{303} is the law which governs abortion in South Africa. The Choice on Termination of Pregnancy Act permits a female of any age to consent to a termination of pregnancy.\footnote{304} This Act gives effect to a woman’s right to privacy and equality and her right to the freedom and security of her person.\footnote{305} The Termination of Pregnancy Act specifies the circumstances under which the

that she either disposed or attempted to dispose of the body. The Magistrate was not satisfied that the accused acknowledged all the crucial elements of the offence. In this regard it was submitted that the act of “disposing” is determined by permanence and not merely placement for all to see. The court consequently, came to the conclusion that “in order to sustain a conviction, there has to be evidence before the court that the fetus had arrived at that stage of maturity at the time of birth that it might have been born a living child. In casu there was no evidence regarding the duration of the pregnancy nor of the viability of the fetus/child. All that is known is that the ‘child’ was in fact born prematurely and was dead at birth. For this reason alone it could not be found that the accused disposed of the body of a child and consequently the conviction and sentence should be set aside.”

\footnote{301}{See section 239 of the Criminal Procedure Act.}
\footnote{302}{Naidoo Y “Abandoned babies on the Increase in South Africa” at http://westcapenews.com/?p=2049 (visited 24 April 2012). Also see Van der Westhuizen at 190.}
\footnote{303}{Choice on Termination of Pregnancy Act 92 of 1996 (hereinafter referred to as the Choice on Termination of Pregnancy Act).}
\footnote{304}{Section 1 of the Choice on Termination of Pregnancy Act defines a woman as any female person of any age.}
\footnote{305}{The preamble of the Choice on Termination of Pregnancy Act reads as follows: “Recognising the values of human dignity, the achievement of equality, security of the person, non-racialism and non-sexism, and the advancement of human rights and freedoms which underlie a democratic South Africa; Recognising that the Constitution protects the right of persons to make decisions concerning reproduction and to security in and control over their bodies; Recognising that both women and men have the right to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice, and that women have the right of access to appropriate health care services to ensure safe pregnancy and childbirth; Recognising that the decision to have children is fundamental to women’s physical, psychological and social health and that universal access to reproductive health care services includes family planning and contraception, termination of pregnancy, as well as sexuality education and counselling programmes and services; Recognising that the State has the responsibility to provide reproductive health to all, and also to provide safe conditions under which the right of choice can be exercised without fear or harm; Believing that termination of pregnancy is not a form of contraception or population control.”}
termination of a pregnancy may occur. In the case of Christian Lawyers Association v Minister of Health, the High Court of South Africa ruled on the constitutionality of this Act. The Christian Lawyers Association brought an application that abortion encroaches upon section 11 of the Constitution. The government argued that constitutional rights do not apply to foetuses. The court concurred with the government's argument and the case was dismissed.

The purpose of the above discussion was to contextualise the following section on the threat to the lives of persons with albinism on the African continent and elsewhere.

3.3.2 The right to life in the context of albinism

The most disturbing construct with respect to the right to life of albinos is the myth that certain body parts of persons with albinism can bring wealth. The increased number of unnatural deaths among albinos in Africa, particularly as a result of brutal murder, clearly points to a violation of their right to life. The continued killings in Tanzania and other African countries are indicative of a failure to protect the most valued human right.

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306 Circumstances and conditions under which pregnancy may be terminated under the Choice on Termination of Pregnancy Act:

“2 (1) A pregnancy may be terminated - (a) upon request of a woman during the first 12 weeks of the gestation period of her pregnancy; (b) from the 13th up to and including the 20th week of the gestation period if a medical practitioner, after consultation with the pregnant woman, is of the opinion that- (i) the continued pregnancy would pose a risk of injury to the woman's physical or mental health; or (ii) there exists a substantial risk that the fetus would suffer from a severe physical or mental abnormality; or (iii) the pregnancy resulted from rape or incest; or (iv) the continued pregnancy would significantly affect the social or economic circumstances of the woman; or (c) after the 20th week of the gestation period if a medical practitioner, after consultation with another medical practitioner or a registered midwife, is of the opinion that the continued pregnancy- (i) would endanger the woman's life; (ii) would result in a severe malformation of the fetus; or (iii) would pose a risk of injury to the fetus.

2 (2) The termination of a pregnancy may only be carried out by a medical practitioner, except for a pregnancy referred to in subsection (1) (a), which may also be carried out by a registered midwife who has completed the prescribed training course.

3 (1) The surgical termination of a pregnancy may take place only at a facility designated by the Minister by notice in the Gazette for that purpose under subsection (2).

3 (2) The Minister may designate any facility for the purpose contemplated in subsection (1), subject to such conditions and requirements as he or she may consider necessary or expedient for achieving the objects of this Act.

3 (3) The Minister may withdraw any designation under this section after giving 14 days' prior notice of such withdrawal in the Gazette.*

307 Christian Lawyers Association v Minister of Health 2005 (1) SA 509 (T) (hereinafter referred to as the Christian Lawyers Association case).

308 Christian Lawyers Association case, paragraph [59].

309 Christian Lawyers Association case, paragraph [59].
In a previous chapter, reference was made to alleged *muti* murders of persons with albinism in South Africa. Reports of incidents of the killing of children with albinism in Mbabane, Swaziland within a few days of each other suggest that such murders are migrating southwards. Malawi has recorded six attacks in the most recent spate of murders within a 10 week period, which clearly challenges the country’s humanist movement. The Inspector General of Police, Lexen Kachema, has since issued a strong directive to shoot criminals who attack albinos.

In chapter one, examples were given of how persons living with albinism become targeted victims of violence. In South Africa, witchcraft murder is rife but not necessarily linked to persons with albinism. Vicious murders, amputations and trafficking in human body parts of South Africans are testament to the grave infringement of the constitutional rights to life and human dignity which in all probability involve persons living with albinism.

As recently as 8 July 2015, a report compiled by Under the Same Sun Canada and Tanzania indicated that in a total of 25 countries, 148 killings of people with albinism and 232 attacks had been reported. These numbers include survivors of mutilation, violence against persons with albinism, desecration of graves and albinos seeking asylum. Of the 25 countries listed in this report, Tanzania is responsible

313 See S v Netshiuvhu 1990 (1) SACR 331 (A); R v Fundakabi 1948 (3) SA 810 (A); S v Ndlovu 1971 (1) SA 27 (RA); S v Mokonto 1971 (2) SA 319 (A); S v Ngubane 1980 741 (A) 745D; S v Motsepa 1991 (2) SACR 462 (A); and S v Phama 1997 (1) SA 539 (E).
315 Under the Same Sun “Reported Attacks on Persons with Albinism—Most Recent Attacks Included” at http://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version_1.pdf (visited 23 August 2015), see annexture F.
for the majority of killings and attacks.\textsuperscript{317} Zihada Msembo, the Secretary General of the Albinism Society of Tanzania, noted the following:

Our biggest fear right now is the fear of living. If you leave work at night as an albino, you are unsure of reaching home safely. When you sleep you are unsure of waking up in one piece.\textsuperscript{318}

As seen from the theoretical observation of the right to life, every person in South Africa, including a person living with albinism, has an inherent right to life. This right should be recognised and respected and the State needs to protect everyone against any form of infringement of this right. Persons living with albinism have the right to be protected against any form of violation of their bodies.

It may be argued that the murder of persons with albinism is to be expected in a country where people believe in witchcraft, particularly if there is already concern that children may be sacrificed for witchcraft purposes, and especially where there is no strong legal framework for the protection of persons living with albinism.\textsuperscript{319} This appears to explain the deaths of albinos in Uganda. South Africa has also seen a number of witchcraft related deaths.\textsuperscript{320}

One South African example of infanticide of an albino child is the case of Tom, whose mother was arrested when he was a baby.\textsuperscript{321} This infant was left in the yard where his mum was arrested.\textsuperscript{322} It appeared that he lived in the yard with a dog.\textsuperscript{323} He was rescued from near death as a result of sunburn and starvation, and was

\footnotesize{\textsuperscript{317} Under the Same Sun at http://www.underthesamesun.com/sites/default/files/Attacks\%20of\%20PWA\%20extended\%20version_1.pdf (visited 23 August 2015).}
\footnotesize{\textsuperscript{318} Obulutsa G “Albinos Live in Fear after Body Parts Murders” at http://www.guardian.co.uk/world/2008/nov/04/tanzania-albinos-murder-witchcraft (visited 13 July 2015).}
\footnotesize{\textsuperscript{320} Petrus T “Defining Witchcraft-Related Crime in the Eastern Cape Province of South Africa” (2011) (3) International Journal of Sociology and Anthropology 1-8 at 1.}
\footnotesize{\textsuperscript{321} Begegnungen S “A Place of Safety and Care for Abandoned Babies” at http://archiv.schoenstatt.de/news2001/07juli/1t0702en_tlc_ministry.htm (visited 13 July 2015).}
\footnotesize{\textsuperscript{322} Begegnungen at http://archiv.schoenstatt.de/news2001/07juli/1t0702en_tlc_ministry.htm (visited 13 July 2015).}
\footnotesize{\textsuperscript{323} Begegnungen at http://archiv.schoenstatt.de/news2001/07juli/1t0702en_tlc_ministry.htm (visited 13 July 2015).}
unable to speak. Many children born with albinism are immediately exposed to discrimination within their families. Persistent exposure to cruel treatment from an early age has enduring consequences. Some mothers of these infants kill or abandon their children out of fear and because of the stigma attached to albinism. Fathers tend to abandon children born with this condition due to the belief that it was caused by unfaithfulness on the part of the mothers or because of the general stigma of having an albino in the family. This trend was remarked upon by the explorer, David Livingstone. The Salif Keita Global Foundation has found that infanticide of infants with albinism appears to be a fairly common practice in some African countries. In the Great Lakes Region in Tanzania, infanticide is the foremost threat to persons with albinism, often occurring through an agreement between the father of the child and the midwife.

Gradual social acceptance of albinos will result in the disappearance of the deadly myths surrounding albinism and by implication improve the situation of persons living with albinism.

328 Baker 172-173.
332 Selepe DM “Teenagers with Oculocutaneous Albinism in Polokwane: Their Self-Esteem and Perceptions of Societal Attitudes” 2007 Mini-dissertation submitted in fulfilment of the requirements for the Degree Master of Education in the Faculty of Humanities at the University of Limpopo 1-84 at 60. Also see Naidoo at http://westcapenews.com/?p=2049 (visited 15 July 2015) for a discussion of child abandonment in South Africa. According to an article in the West Cape News, abandoned babies have become a common phenomenon in South Africa. In 2010, Child Welfare South Africa (CWSA) reported an increase of approximately 10% on the more than 2,000 babies abandoned in 2009. These statistics do not include CWSA’s Cape Town and Johannesburg branches. Babies are abandoned in hospitals, others in safe houses and several have been dumped at rubbish sites in the hope that they will starve or suffocate. For a detailed and recent discussion of child abandonment in
The current trend of albino murders in East African countries has aroused fears that have gained the attention of domestic and regional bodies as well as the international community. Much of the support and attention of global organisations appears to be focused on those nations with documented killings. The absence of documented cases in certain African countries may to some extent explain the lack of concern of human rights organisations about protecting this vulnerable group. In Tanzania and Burundi several international interventions have been reported.

It is therefore submitted that in countries where these murders have not yet occurred, community advocacy should be a priority. This will encourage the various communities in Africa to be aware of what is happening in their neighboring countries and to be cautious and vigilant about these practices.

South Africa, see Blackie DE “Sad, Bad and Mad: Exploring Child Abandonment in South Africa” 2014 Dissertation submitted in fulfilment of the requirements for the Degree of Master of Anthropology in the Department of Anthropology in the Faculty of Humanities at the University of the Witwatersrand 1-100.

Salewi DH “The Killing of Persons with Albinism in Tanzania: A Social-Legal Inquiry” 2011 Dissertation submitted in partial fulfilment of the requirements of the Degree LLM (Human Rights and Democratisation in Africa) at the Faculty of Law, Centre for Human Rights, University of Pretoria 1-47 at 4. Among others, the domestic bodies which have intervened in Tanzania include the Tanzanian Commission for Human Rights and Good Governance, the Tanzania Albinism Society, the Ministry of Regional Administration, the Legal and Human Rights Centre, and local government and traditional healers. Regional and international bodies include the Red Cross Society, the United Nations, United Nations Child Emergency Fund, Plan International and Under the Same Sun. Also see Burke et al “Media Analysis of Albino Killings in Tanzania: A Social Work and Human Rights Perspective” (2014) 8 (2) Ethics and Social Welfare 117-134.


3.4 The right to health care services

3.4.1 Introduction

The right to the highest attainable standard of health, frequently referred to as “the right to health”, was initially laid down in the Constitution of the World Health Organisation of 1946\(^{336}\) and was restated in the 1978 Declaration of Alma Ata\(^{337}\) as well as in the World Health Declaration adopted by the World Health Assembly in 1998.\(^{338}\) This right has been firmly endorsed in a wide range of international\(^{339}\) and regional human rights instruments,\(^{340}\) as well as in national instruments.\(^{341}\)

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\(^{336}\) The Constitution was adopted by the International Health Conference held in New York from 19 June to 22 July 1946. It was signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organisation No. 2, p. 100) and entered into force on 7 April 1948. Amendments adopted by the Twenty-sixth, Twenty-ninth, Thirty-ninth and Fifty-first World Health Assemblies (Resolutions WHA26.37, WHA29.38, WHA39.6 and WHA51.23) came into force on 3 February 1977, 20 January 1984, 11 July 1994 and 15 September 2005 respectively. Article 2 of the Constitution of the World Health Organisation of 1946 reads as follows:

“The objective of the World Health Organization (hereinafter called the Organization) shall be the attainment by all peoples of the highest possible level of health.”

\(^{337}\) In September 1978, the International Conference on Primary Health Care was held in Alma-Ata, USSR (now Almaty, Kazakhstan). The Declaration of Alma-Ata, co-sponsored by the World Health Organization (WHO), is a brief document that expresses the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world. Article 1 of the Declaration of Alma-Ata reads as follows:

“We, the Member States of the World Health Organization (WHO), reaffirm our commitment to the principle enunciated in its Constitution that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being; in doing so, we affirm the dignity and worth of every person, and the equal rights, equal duties and shared responsibilities of all for health.”

\(^{338}\) Examples of international instruments that have firmly endorsed the right to the highest attainable standard of health include the Convention on the Rights of Persons with Disabilities (2515 UNTS 3, entered into force 3 May 2008); and the Convention on the Rights of the Child (1577 UNTS 3, entered into force 2 September 1990). Article 25 of the Convention on the Rights of Persons with Disabilities of 2008 reads as follows:

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c. Provide these health services as close as possible to people’s own communities, including in rural areas;

d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 24 of the Convention on the Rights of the Child of 1990 reads as follows:

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) To combat disease and malnutrition, including within the framework of primary health care, through, *inter alia*, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.


Article 14 of the Charter on the Rights and Welfare of the Child of 1990 reads as follows:

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

2. States Parties to the present Charter shall undertake to pursue the full implementation of this right and in particular shall take measures:

(a) to reduce infant and child mortality rate;

(b) to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) to ensure the provision of adequate nutrition and safe drinking water;

(d) to combat disease and malnutrition within the framework of primary health care through the application of appropriate technology;
The right to health as such is not explicitly mentioned in the South African Constitution. The Bill of Rights, however, guarantees the right of access to health care services, adequate housing, sufficient food and social security, for the reason that insufficient access to such rights violates the protected interests of various other rights, such as the right to human dignity, equality and life, as well as the right to bodily and physical integrity.

The right to health is basic to the physical and mental wellbeing of all human beings and is essential for the exercise of other human rights. Section 27(1)(a) of the Constitution states that:

> everyone has the right to have access to health care services, including reproductive health care.

Section 27(2) states that the government must take reasonable legislative and other measures within its available resources to achieve the progressive realisation of the right to health. This in fact means that the government has to ensure that this right

(e) to ensure appropriate health care for expectant and nursing mothers;
(f) to develop preventive health care and family life education and provision of service;
(g) to integrate basic health service programmes in national development plans;
(h) to ensure that all sectors of the society, in particular, parents, children, community leaders and community workers are informed and supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of domestic and other accidents;
(i) to ensure the meaningful participation of non-governmental organizations, local communities and the beneficiary population in the planning and management of a basic service programme for children;
(j) to support through technical and financial means, the mobilization of local community resources in the development of primary health care for children.

Article 16 of the African Charter on Human and People’s Rights of 1986 reads as follows:

“(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.
(2) State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”

Examples of national instruments that have firmly endorsed the right to the highest attainable standard include section 27(1) of the Constitution of 1996; which provides as follows:

“everyone has the right to have access to – (a) health care services, including reproductive health care; (b) sufficient food and water; and (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.”

Article 43 of the Constitution of the Republic of Kenya of 2010 states that:

“Every person has the right— (a) to the highest attainable standard of health, which includes the right to health care services, including reproductive health care...”

See section 27(1) of the Constitution of 1996. Also see Rautenbach & Malherbe at 386. Rautenbach & Malherbe at 386.

Section 27(2) of the Constitution of 1996 reads as follows:

“The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights”.

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is protected, promoted and fulfilled, and that eventually universal access to quality and all-inclusive health care is realised. This incorporates the passing of laws by Parliament\(^{345}\) and the provincial legislatures, but is not limited to such. Section 27 is a powerful provision aimed at ensuring health policy and practice.

The right to health imposes a negative duty on the state and members of society not to impair access to the amenities and services associated with this right.\(^{346}\)

Limitations with respect to the right to health must meet the terms of the limitation

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\(^{345}\) The National Health Act was passed by Parliament in 2003 to give effect to the right to access to health care services. The objectives of the National Health Act are to regulate the national health system, to accord equality in respect of health services by harmonising the inequalities of health services of the past and to institute a national health system which protects, respects, promotes and fulfils the rights of everyone in South Africa in particular the progressive realisation of the constitutional right of access to health care services. Section 3 of the National Health Act 61 of 2003 reads as follows:

“The Minister must, within the limits of available resources- (a) endeavour to protect, promote, improve and maintain the health of the population; (b) promote the inclusion of health services in the socio-economic development plan of the Republic; (c) determine the policies and measures necessary to protect, promote, improve and maintain the health and well-being of the population; (d) ensure the provision of such essential health services, which must at least include primary health care services, to the population of the Republic as may be prescribed after consultation with the National Health Council; and (e) equitably prioritise the health services that the State can provide. (2) The national department, every provincial department and every municipality must establish such health services as are required in terms of this Act, and all health establishments and health care providers in the public sector must equitably provide health services within the limits of available resources”.

Not every person accessing the health system is able to exercise their health rights easily. Vulnerabilities such as having a disability or being an illegal migrant are further barriers to access to health care services. As a result, one of the objectives of the National Health Act is to protect, respect, promote and fulfill the rights of vulnerable groups such as women, children, older people and people with disabilities. The National Health Act prescribes eligibility for free health services in public health institutions.

Section 4 of the National Health Act reads as follows:

“(1) The Minister, after consultation with the Minister of Finance, may prescribe conditions subject to which categories of persons are eligible for such free health services at public health establishments as may be prescribed. (2) In prescribing any condition contemplated in subsection (1), the Minister must have regard to- (a) the range of free health services currently available; (b) the categories of persons already receiving free health services; (c) the impact of any such condition on access to health services; and (d) the needs of vulnerable groups such as women, children, older persons and persons with disabilities. (3) Subject to any condition prescribed by the Minister, the State and clinics and community health centres funded by the State must provide- (a) pregnant and lactating women and children below the age of six years, who are not members or beneficiaries of medical aid schemes, with free health services; (b) all persons, except members of medical aid schemes and their dependants and persons receiving compensation for compensable occupational diseases, with free primary health care services; and (c) women, subject to the Choice on Termination of Pregnancy Act, 1996 (Act 92 of 1996), free termination of pregnancy services.”


Rautenbach & Malherbe 386.
The State has a further positive duty to fulfil the right to health.\textsuperscript{347} Thus far, the Constitutional Court has addressed the impact and effect of the State’s failure to act in terms of the conduct and interests protected by the rights to human dignity, equality, life, and personal freedom and security.\textsuperscript{349} This implies that in the very first stage of inquiry into an infringement of the right to health, it must be established whether or not the State’s failure to provide health care indeed impairs the right to human dignity and life, and the physical and psychological integrity of the claimants.\textsuperscript{350}

In terms of the second stage of inquiry, section 27(2) of the Constitution stipulates that the State must take “reasonable legislative and other steps within its available resources to attain the progressive realisation of” health care services”.\textsuperscript{351} This implies that the State may justify its failure to act or its failure to meet a positive obligation, provided that reasonable legislative and other measures were taken within its available resources to accomplish the progressive realisation of the right.\textsuperscript{352}

3.4.2 Guidelines formulated by the Constitutional Court to determine whether the State has realised its positive duties

3.4.2.1 Reasonable legislative and other measures

The qualification “reasonable legislative and other measures” suggests that the State ought to institute rational programmes which assign responsibility to the various levels of government to guarantee that appropriate resources are available.\textsuperscript{353} Bearing in mind that both legislative and other measures may be taken,
reasonableness can be evaluated at the level of a legislative programme as well as the level of its implementation.\textsuperscript{354} Courts may require that the State demonstrate which measures were taken to realise socio-economic rights.\textsuperscript{355}

Taking into account that socio-economic rights are a constitutional imperative and that the State ought to try to attain certain developmental objectives, the State has a duty to justify the choices it makes in achieving these objectives to the public.\textsuperscript{356} Put

\textsuperscript{354} \textit{Grootboom} case, paragraphs [21], [28] and [35]. Legislative measures by themselves are not likely to ensure constitutional compliance. Legislation alone is not enough. The state is obliged to act to achieve the intended result, and legislative measures will invariably have to be supported by appropriate, well-directed policies and programmes implemented by the executive. These policies and programmes must be reasonable both in their conception and their implementation. The formulation of a programme is only the first stage in meeting the state’s obligations. The programme must also be reasonably implemented. An otherwise reasonable programme that is not implemented reasonably will not constitute compliance with the state’s obligations.

\textsuperscript{355} \textit{Grootboom} case, paragraph [32]; and \textit{Treatment Action Campaign (1)} case, paragraph [34]. Currie & De Waal 581-584. In the Constitution of 1996, socio-economic rights incorporate “internal modifiers” whose purpose is to limit the degree to which the rights can be imposed. With this in mind, the rights seem to be subject to two limitation clauses for the reason that the general limitations clause as stipulated in section 36 applies to all rights in the Bill of Rights. Court cases that have been heard regarding socio-economic rights are evidence of the fact that the Constitutional Court has in the past not applied section 36 in the majority of socio-economic rights cases. The Constitutional Court has instead relied exclusively on the “internal modifiers”. In the case of the \textit{Treatment Action Campaign (1)} case as well as in the case of Mazibuko \textit{v} City of Johannesburg 2010 (4) SA 1 (CC), the court evidently followed the principles recognised in the \textit{Grootboom} case in an enquiry to determine whether the relevant governmental measures taken in these cases were reasonable under section 27(2). The court in the \textit{Treatment Action Campaign} case did not fit in a section 36 investigation even though there was a finding that there was an encroachment of the applicants’ right to access to housing. In the Mazibuko case, the court’s decision that the city’s actions were rational and reasonable showed that there was no encroachment of any right, hence a section 36 analysis was not needed. The case of Jaftha \textit{v} Schoeman 2005 (2) SA 140 (CC) (hereinafter referred to as the \textit{Jaftha} case), which also involved the issue of the right to access to housing, differed from the cases discussed above, as the court did in this case engage a section 36 investigation. The applicants’ houses in the \textit{Jaftha} case had been sold in execution with the intention of paying their debts. The applicants invoked the right to housing, maintaining that the state and private persons had a negative obligation under section 26 to refrain from obstructing their existing access to housing. Such an allegation had its basis in the argument that section 67 of the Magistrates Court Act was unlawful, as it made it possible for creditors to deprive debtors of their housing through selling in execution under unjustifiable circumstances. In such situations, the limitation of the right of access to adequate housing was alleged to be unreasonable and unjustifiable under section 36. Since the \textit{Jaftha} case did not entail a case of positive duties placed on the State by the pertinent socio-economic right, the court did not use the reasonableness measurement used in the \textit{Grootboom} case. Instead it carried out a conventional “two-stage” investigation by initially determining whether the challenged law violated the duty to comply with section 26 of the Constitution of 1996, followed by considering whether such an encroachment was reasonable and justifiable under section 36. The court’s finding was that the legislative provision was overbroad as it allowed sales in execution under circumstances where they would not be reasonable. A study of the \textit{Treatment Action Campaign, Mazibuko, Grootboom} and \textit{Jaftha} cases illustrates that, in cases where socio-economic rights issues are encountered, the Constitutional Court tends to focus on the reasonableness of the measures in question and does not entirely engage in trying to
differently, the reasonableness standard firstly calls for reasons to be given.\textsuperscript{357} It is then the duty of the court to evaluate the reasonableness of these reasons\textsuperscript{358} and a reasonable person should be convinced of the coherence of the reasons.\textsuperscript{359}

The duty of justification involves the provision of explanations that would satisfy most people regarding the rationality of a policy, even if they are not convinced of the good judgment of choosing such a policy in the first place.\textsuperscript{360}

Notwithstanding the centrality of the reasonableness standard, the Constitutional Court does not refer to any definition of such a standard. Instead the court stipulates that each case should be determined on its own facts.\textsuperscript{361} According to the court in the \textit{Bel Porto} case,\textsuperscript{362} the test of reasonableness when dealing with socio-economic rights is considered to be on a higher level than the rationality test in section 9(1).

A feature of the legal standard is that substantial “interpretive discretion” is given to the person in charge of adjudicating the application of the reasonableness standard, and that such application does not specify a result in advance.\textsuperscript{363} Standards are applied \textit{ad hoc} and their application varies considerably from one case to another.\textsuperscript{364} However, standards gradually become “more rule-bound” as courts build up guidelines and sets of factors with future applications in mind.\textsuperscript{365}

In the \textit{Grootboom} case, the court held that reasonableness entails the “design, adoption and implementation” of certain measures to achieve the realisation of socio-economic rights that are inclusive in that they include those who need protection the most.\textsuperscript{366} At the initial application of the \textit{Grootboom} case, the court

\begin{flushleft}
\textsuperscript{357} Currie & De Waal 574.
\textsuperscript{358} Currie & De Waal 574.
\textsuperscript{359} Currie & De Waal 574.
\textsuperscript{360} Currie & De Waal 574.
\textsuperscript{361} \textit{Grootboom} case, paragraph [92].
\textsuperscript{362} Bel Porto School Governing Body and Others v Premier of the Western Cape Province and Another 2002 (3) SA 265 (CC), paragraph [46].
\textsuperscript{363} Currie & De Waal 574.
\textsuperscript{364} Currie & De Waal 574.
\textsuperscript{365} Currie & De Waal 574.
\textsuperscript{366} Currie & De Waal 574.
\end{flushleft}
found that reasonableness was absent, hence the State was held to have failed in its duties in terms of section 26(2).  

In the *Minister of Health v Treatment Action Campaign* case, the court’s finding in the *Grootboom* case that reasonableness is inclusive was the foundation for the court’s decision that the government’s policy on the prevention of mother-to-child transmission (MTCT) of HIV was unreasonable. Government policy only made Nevirapine available to a small number of “pilot sites”, namely two state hospitals in each province. The reasoning behind this decision was to use the results of the use of the medication at the selected sites to assess the safety of Nevirapine before making it available to more people. For this reason Nevirapine would not be available to the public but only at the specific pilot sites.

### 3.4.2.2 Progressive realisation

Progressive realisation means that it is accepted that socio-economic rights, including the right to health care services, cannot be attained instantly. The State is nevertheless required to work towards its goal promptly and efficiently. The meaning of the qualification of progressive realisation was interpreted in the *Sooobramoney* case as follows:

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367 *Grootboom* case, paragraph [99].  
368 *Treatment Action Campaign (1)* case, paragraph [1-2] and [23].  
369 *Treatment Action Campaign (1)* case, paragraph [41].  
370 *Treatment Action Campaign (1)* case, paragraph [92].  
371 These guidelines are listed in the *Grootboom* case, paragraphs [36-46]. Also see Rautenbach & Malherbe 386.  
371 *Treatment Action Campaign (1)* case, paragraphs [35] and [71-73]. Also see Rautenbach & Malherbe 386.  
371 *Grootboom* case, paragraphs [36-46]. Also see Rautenbach & Malherbe 386.  
372 *Treatment Action Campaign (1)* case, paragraphs [71-73]. Also see Rautenbach & Malherbe 386.  
373 *Sooobramoney* case, paragraph [11]. The *Sooobramoney* case is one that brought the issue of socio-economic rights to the Constitutional Court. The case involved the issue of access to renal dialysis in a government hospital, which when provided, is supplied at the cost of the state. Only those who meet the stringent medical criteria, qualify for renal dialysis. However, not all of those who require the dialysis, qualify. One requirement for admission to the dialysis programme is medical eligibility for a kidney transplant. Mr Sooobramoney did not satisfy the medical criteria and was therefore denied access. After an unsuccessful application to the Durban High Court, he appealed directly to the Constitutional Court, challenging the denial of access on the basis of two constitutional rights, namely the right to life in section 11 and the guarantee in section 27(3) that no person may be refused emergency medical treatment. The Constitutional Court, however, decided that his claim had to be considered under section 27(2) which sets out the state’s positive duties in terms of the provision of health care services. In the court’s view, the state had indeed complied with its section 27(2)
What is apparent from these provisions is that the obligations imposed on the State by sections 26 and 27 in regard to access to housing, health care, food, water and social security are dependent upon the resources available for such purposes, and that the corresponding rights themselves are limited by reason of the lack of resources. Given this lack of resources and the significant demands on them that have already been referred to, an unqualified obligation to meet these needs would not presently be capable of being fulfilled. This is the context within which section 27(3) must be construed.  

The above denotes that the positive dimension of socio-economic rights is realised over a period of time. However, the fact that the realisation of socio-economic rights occurs progressively does not prevent the State from taking those steps that are within its powers at any point in time. The burden of proof lies with the State to prove its progress towards the realisation of the right in question.

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constitutional duties, because the guidelines according to which access to renal dialysis is limited, are reasonable, and in the case at hand, had been applied “fairly and rationally”. Mr Soobramoney’s claim was therefore dismissed. A week later he died from renal complications. The decision elucidates why the claim had to be considered under section 27(2) and not under section 27(1)(3), the right to life or emergency medical treatment. Access to health care services is specifically dealt with in section 27, so it is not essential to see the right to health as part and parcel of the right to life as some courts, for example the Indian Supreme Court, have done. The focus should remain on section 27. The question arises as to why the courts opt to apply section 27(2) and not section 27(3). The court concluded that emergency medical treatment hardly consists of chronic treatment for "an on-going state of affairs resulting from a deterioration of the applicant's renal function, which is incurable". Despite the fact that renal dialysis may be urgently needed, it is not seen as an emergency treatment. Such an analysis by the court is useful in construing why such reasoning is in fact sound. If section 27(3) had been construed in line with Mr Soobramoney’s claim, the state’s duty to guarantee access to health care services for everyone would have been severely compromised. Instead of the state taking realistic measures to guarantee the progressive realisation of the right to health, as described in section 27(2), the state would continually be required to supply instant access to health care services wherever and whenever such was required.

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375 Currie & De Waal 572.
376 Currie & De Waal 572.
377 Currie & De Waal 572. Also see Grootboom case, paragraph [45] and [88]: “Nevertheless, the fact that realization over time, or in other words progressively, is foreseen under the Covenant should not be misinterpreted as depriving the obligation of all meaningful content. It is on the one hand a necessary flexibility device, reflecting the realities of the real world and the difficulties involved for any country in ensuring full realization of economic, social and cultural rights. On the other hand, the phrase must be read in the light of the overall objective, indeed the raison d'etre, of the Covenant which is to establish clear obligations for State parties in respect of the full realization of the rights in question. It thus imposes an obligation to move as expeditiously and effectively as possible towards that goal. Moreover, any deliberately retrogressive measures in that regard would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the Covenant and in the context of the full use of the maximum available resources.” (The Covenant referred to is the International Covenant on Economic, Social and Cultural Rights.)
3.4.2.3 Within available resources

The qualification “within available resources” suggests that both the pace at which the goal is realised and the reasonableness of the measures employed are administered through and affected by available resources. In the absence of available resources, it is clear that the State’s failure to provide any particular service will not amount to a violation of the right to health. However, where resources are available, it would be difficult for the State to justify its failure to allocate resources to the advancement of the right to health care services. In circumstances where adequate resources are available, the State is expected to do more to realise the right to health care services and any other socio-economic right. This implies that a significant aspect of the “positive dimension” of socio-economic rights is that the State should satisfactorily substantiate its use of public resources to its citizens. The Constitutional court in the Soobramoney case confirmed this through its action in terms of the policy justification advanced by the Department of Health’s provincial health authorities.

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378 Treatment Action Campaign (1) case, paragraphs [71-73]. Also see Rautenbach & Malherbe 386; and Currie & De Waal 390.
380 Gabru 10.
381 Gabru 10.
382 Currie & De Waal 572.
383 Soobramoney case, paragraphs [24-25] and [29]. Paragraph 24 reads: “At present the Department of Health in KwaZulu-Natal does not have sufficient funds to cover the cost of the services which are being provided to the public. In 1996-1997 it overspent its budget by R152 million, and in the current year it is anticipated that the overspending will be R700 million rand unless a serious cutback is made in the services which it provides. The renal unit at the Addington Hospital has to serve the whole of KwaZulu-Natal and also takes patients from parts of the Eastern Cape. There are many more patients suffering from chronic renal failure than there are dialysis machines to treat such patients. This is a nation-wide problem and resources are stretched in all renal clinics throughout the land. Guidelines have therefore been established to assist the persons working in these clinics to make the agonising choices which have to be made in deciding who should receive treatment, and who not. These guidelines were applied in the present case.” Paragraph 25, in addition, reads: “By using the available dialysis machines in accordance with the guidelines more patients are benefited than would be the case if they were used to keep alive persons with chronic renal failure, and the outcome of the treatment is also likely to be more beneficial because it is directed to curing patients, and not simply to maintaining them in a chronically ill condition. It has not been suggested that these guidelines are unreasonable or that they were not applied fairly and rationally when the decision was taken by the Addington Hospital that the appellant did not qualify for dialysis.” Paragraph 29, furthermore, states: “The provincial administration which is responsible for health services in KwaZulu-Natal has to make decisions about the funding that should be made available for health care and how such funds should be spent. These choices involve difficult decisions to be taken at the political level in fixing the health
The “available resources” qualification is also employed in the International Convention on Economic, Social and Cultural Rights, and it refers to the discretion that an instrument of the State has in its selection of means for the realisation of socio-economic rights. In particular, a shortage of resources does not reduce the State’s duty to realise its “core minimum obligations”. Even when resources are scarce, the obligation still resides with the State to ensure fulfilment of the relevant socio-economic rights.

In the *Grootboom* case, the Constitutional Court rejected the call to set a minimum obligation guideline specifically in respect of the right to housing, finding instead that the real question in terms of our Constitution is whether the measures taken by the State to realise the right afforded by section 26 are reasonable.

The court stated that there may be circumstances in which it is possible to consider a core minimum obligation in determining the reasonableness of measures taken by the State. This however cannot be done in the absence of adequate information to determine the minimum core duty in a given situation.

In the case of the *Minister of Health v Treatment Action Campaign*, the court was again advised to establish a core minimum content for the right to health care services. The court rejected the argument that it only had the power to issue a declaratory order and further argued that where an infringement of any right has occurred, including a violation of a socio-economic right, a court is under obligation

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384 Article 2 of the International Covenant on Economic, Social and Cultural Rights (9993 UNTS 3, entered into force 3 January 1976) reads as follows: “1. Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.”


386 Gabru 11.

387 *Grootboom* case, paragraph [14].

388 *Grootboom* case, paragraph [33].

389 *Grootboom* case, paragraph [33].

390 *Treatment Action Campaign (1)* case, paragraph [26].
to make sure that efficient relief is established. In implementing section 27, the State is obliged to take reasonable measures progressively, and it is the court’s duty to ensure that this occurs.

3.4.2.4 How the principle of freedom from discrimination relates to health

Within the public at large, vulnerable and marginalised people are often burdened with a range of health problems. Unfair discrimination not only violates basic human rights in general, but is often found to have a direct impact on a person’s health status. The proscription of discrimination does not mean that differentiation should not be recognised, only that the failure to treat equal cases equally ought to be based on an objective and rational standard aimed at correcting disparities within society.

With respect to health and health care, the foundation for non-discrimination has been developed and can be summarised as prohibiting “any discrimination in access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental stability, health status (including HIV/AIDS), sexual orientation, civil, political, social or other status, which has the purpose of nullifying the equal satisfaction or exercise of the right to health”.

3.4.3 The right to health care services in the context of albinism

Due to the absence of melanin in their skin, persons living with albinism are prone to a number of lifelong physical health problems, in particular skin damage due to sensitivity to the ultraviolet rays of the sun, and visual impairment. As seen in previous chapters, skin cancer is common among persons living with albinism.
Regular visits to a dermatologist for skin check-ups are imperative. It is equally important to have skilled eye assessments and examinations from a very young age.

Several governments have failed to guarantee “access and affordability” of essential items and services. In South Africa, interviews with and campaigns led by the Chairperson of the Albinism Society of South Africa have revealed that the national health system has failed to adequately consider and take into account the health needs of persons living with albinism. The failure of the government to take into account the health concerns of this vulnerable group is perhaps due to the fact that albinism is not viewed as an actual health concern in South Africa because the condition is surrounded by so many myths, stereotypes and false notions. Persons living with HIV/AIDS receive primary health care from the government; specifically anti-retroviral drugs (ARVs) which slow down the damage to their immune systems. When the CD4 count of a person with HIV/AIDS drops to below 200, they are entitled to receive ARVs from the government. One such drug is Nevirapine, which is provided to HIV infected mothers to prevent mother to child transmission of the virus.

The same attention should be afforded to persons living with albinism. The connection between albinism, sunlight and skin cancer, and the extreme importance of a prevention programme in this regard, has been explained in a previous chapter.

397 Thuku M “Myths, Discrimination, and the Call for Special Rights for Persons Living with Albinism in Sub-Saharan Africa” (2011) 1-24 at 11. Thuku writes within the Sub-Saharan context. Despite mentioning that several governments have failed to guarantee “access and affordability” in terms of essential items, the author does not list examples of such countries. The current study presents South Africa as an example. An investigation into other countries cites Zimbabwe as an example, where the implementation of effective health interventions to meet the health needs of people with albinism remains a challenge due to the current economic and political situation. See Taylor JS & Lund P “Experiences of a Feasibility Study of Children with Albinism in Zimbabwe: A Discussion Paper” (2008) 45 (8) International Journal of Nursing Studies 1247-1256. Somalia is yet another example where prolonged conflict and the challenges stemming from the lack of a strong central government affect its population and generate barriers to socio-economic progress. This has major implications for the most vulnerable members of society, including people with albinism. No organisation or government has tried to support people with albinism in Somalia and they do not have access to health care, see Mohamud S “What Do You Know about Persons with Albinism in Somalia” at http://aphad.org/maxaad-kala-soocota-xaalka-dadka-albinoga-ah-ee-soomaaliyeed/ (visited 29 April 2015). In a report on albinism compiled by the United Nations Office of the High Commissioner for Human Rights, it is evident that people with albinism in Burundi require government-sponsored specialised medical care, see United Nations Office of the High Commissioner for Human Rights “Situation of People Living with Albinism in Burundi” at www.ohchr.org/.../albinism/situation_of_people_living_with_albinism_in_burundi-inputs_from_binuca.docx (visited 15 July 2015).

Currently, the government does not provide persons with albinism with protective sunscreen lotion. Very few persons with albinism have access to sunglasses with a high UV protection screen to relieve light sensitivity, or to preventative services such as dermatological skin checks, eye checks and eye corrections. As mentioned in chapter two, the vulnerability of albinos means that they need specific types of health protection, including visual aids, eye surgery, regular skin cancer check-ups and sunglasses offering high UV protection. Government has failed to take into account the health concerns of persons living with albinism, despite the submission of several petitions in this regard.399

The recognition of the right of access to health care services in the South African Constitution affords persons living with albinism the right to challenge the government’s failure to provide skin protection for the prevention of skin cancer, or sunglasses and low vision aids. Under the South African Constitution, the right of access to health care services is a fundamental human right and this right applies equally to all persons, including those living with albinism. Where resources are available, albinos ought to be provided with sunscreen at no cost and in cases where the government does not have the resources to do so, it should subsidise the provision of sunscreen, sunglasses and low vision aids for persons with albinism.

As mentioned in chapter two, if not assisted, persons living with albinism face a shortened life span. It is therefore submitted that the State has a specific duty towards this very unique and vulnerable group in society. Resources should be progressively made available to address the needs of persons living with albinism.

Many persons with albinism are unaware of the health hazards associated with their condition. The Cancer Association of South Africa (Cansa) acknowledges that

399 Mazibuko, the founder of the Albinism Society of South Africa, has been an advocate for the needs of persons living with albinism and has pushed the South African government and medical aid firms to subsidise sunscreen lotions and eye care for people with albinism since the Albinism Society of South Africa was founded in 1991. See IRIN News “Southern Africa: Too White to be Black - The Challenge of Albinism” at http://www.irinnews.org/Report/58169/southern-africa-too-white-to-be-black-the-challenge-of-albinism (visited 1 July 2012), where Mazibuko talks about her concerns regarding the accessibility as well as affordability of sunscreen lotion and the government's failure to provide this to persons living with albinism. Also see Mecaomere V “Public-To-Learn-About-Albinism” at http://www.sowetanlive.co.za/news/2011/09/02/public-to-learn-about-albinism.
persons with albinism face the highest risk of developing skin cancer.⁴⁰⁰ While information concerning their susceptibility to cancer is very important, CANSA observed in 2009 that such information was communicated to persons with albinism at a very late stage, especially those living in rural areas of South Africa. It is therefore imperative that the government also introduce health education programmes aimed at educating albinos about the health risks associated with their condition. An awareness of the causes of albinism and the measures that can be taken to prevent skin cancer, for example, will certainly enhance the health of people living with albinism and reduce the risk of complications associated with the condition. Not only are basic health awareness education programmes for albinos crucial, but programmes to educate people on clinical aspects of albinism will undeniably influence the way in which society perceives persons affected by this condition. These programmes could begin by targeting schools and hospitals.

Depending on the availability of resources, public health programmes such as open days to educate the public on albinism, are another possibility. The Albinism Society of South Africa has been active in this regard.⁴⁰¹ The month of September has been dedicated to albinism awareness.⁴⁰² Such programmes may assist in dispelling myths such as that sex with a young woman with albinism may cure HIV/AIDS. This is a myth that perpetuates gender-based violence towards vulnerable young women. Lack of knowledge about albinism impacts on the position of young women with albinism who live in fear of being raped and of the danger of becoming infected with HIV.

Counselling and trauma centres for this specific segment of society should be established in order to assist albinos who have escaped murder or fallen victim to

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assault, discrimination, rape, amputation of limbs and cancer, to mention but a few of the challenges they face.\textsuperscript{403}

Discrimination against persons living with albinism impedes their right of access to health care services, and the government should adopt a comprehensive approach to ensuring that health care services specifically cater for the unique needs of this group of people. In the \textit{Grootboom} case, the court held that reasonableness entails the “design, adoption and implementation” of certain measures to achieve the realisation of socio-economic rights that are inclusive. These measures should specifically include those in dire need of protection.\textsuperscript{404}

\section*{3.5 The right to special education}

\subsection*{3.5.1 Theoretical observations}

Some countries have developed unique policies to ensure greater inclusivity in the sense of treating persons with disabilities like all other citizens.\textsuperscript{405} These developments in social policy often have the best intentions but may lack real commitment from government or the financial resources needed to effect the necessary transformation and establish new legislative policies.\textsuperscript{406}

Section 9 of the Constitution, the anti-discrimination clause, makes provision for the implementation of disability policies. Policies and legislation have been drafted which regulate education for persons with special needs. The South African Schools Act\textsuperscript{407} requires that education for learners with special education needs be provided, wherever reasonably possible, in standard schools.\textsuperscript{408} In rationally possible circumstances, the Member of the Executive Council (MEC) for Education is obliged to offer education for learners with special education needs at ordinary public schools, and to make available proper educational support services for disabled

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\item \textsuperscript{403} Thuku 17.
\item \textsuperscript{404} \textit{Grootboom} case, paragraph [54].
\item \textsuperscript{405} Kamga SD “Forgotten or Included? Disabled Children’s Access to Primary Education in Cameroon” in Ngwena C \textit{et al} \textit{African Disability Rights Year Book} (2013, Pretoria: Pretoria University Press) at 19, 45, 63-69, 76 and 91.
\item \textsuperscript{406} Kamga 6; 23; 139; 141; and 154.
\item \textsuperscript{407} The South African Schools Act 84 of 1996.
\item \textsuperscript{408} Section 12(3) of the South African Schools Act 84 of 1996 reads as follows:
“A public school may be an ordinary public school or a public school for learners with special education needs.”
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learners.\textsuperscript{409} The South African Schools Act replaces the education statutes of the apartheid system and points to the need for all public schools to afford quality education in spite of learner differences.\textsuperscript{410}

The National Department of Education’s White Paper 6\textsuperscript{411} is an overarching policy for learners with special needs which envisages additional changes to inclusive education. The White Paper recognises that a human rights and development approach to disability has considerable implications for the manner in which education is offered in South Africa.\textsuperscript{412} The policy includes a scheme for integration and inclusion of disability matters into every aspect of governance.\textsuperscript{413} Most significantly, it expresses a paradigm shift from dealing with disability related issues as exclusively health and welfare related, to a rights-based integrative approach.

Subsequent to the White Paper 6, in 2008 the Department of Basic Education implemented a policy called the National Strategy on Screening, Identification, Assessment and Support (SIAS), to drive the implementation of the inclusive education policy.\textsuperscript{414} This strategy describes the procedure for the “identification,

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\item Section 12(4) of the South African Schools Act 84 of 1996 reads as follows:
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assessment, and enrolment” of learners in special schools\textsuperscript{415} in order to avoid the irrational placement of learners in special schools\textsuperscript{416} The National Strategy on Screening, Identification, Assessment and Support offers guidelines for timely identification and support, including determining the type and level of support needed by learners and the best learning locations for support\textsuperscript{417} The strategy also provides guidelines regarding the principal duties of parents and teachers in realising the strategy\textsuperscript{418} The Minister of Basic Education, Angie Motshkga, approved the Policy on Screening, Identification, Assessment and Support on 19 December 2014\textsuperscript{419} The policy was finalised over a period of more than ten years through a difficult process of practical implementation and consultations\textsuperscript{420}

In 2011 the Department of Basic Education adopted the Guidelines for Responding to Learner Diversity in the Classroom through Curriculum and Assessment Policy Statements\textsuperscript{421} These guidelines provide practical guidance to school managers and teachers on planning and teaching in a bid to meet the needs of a diverse array of learners\textsuperscript{422}

The Higher Education Act\textsuperscript{423} deals with discrimination against disabled people in higher education institutions. This Act supports the values of equality and seeks to build a South African academic class that represents the social fabric of our society and contributes to all forms of human advancement\textsuperscript{424}

On an international level, South Africa has ratified a number of international human rights instruments that directly and/or indirectly protect the rights of disabled people,
such as the Convention on the Rights of the Child (United Nations 1989),\textsuperscript{425} the Universal Declaration of Human Rights (United Nations) 1948,\textsuperscript{426} the World Declaration for Education for All: Meeting Basic Learning Needs\textsuperscript{427} and the Convention Against Discrimination in Education (UNESCO 1960).\textsuperscript{428}

3.5.2 The right to education in the context of albinism

Children living with albinism face particular difficulties in ordinary schools because of their poor sight as well as their skin condition. Special arrangements should be made to accommodate these children. Such special consideration may perhaps consist of allowing students with albinism to sit in better places in the classroom, such as closer to the teacher; using suitably legible writing and fonts, and allowing such students additional time to complete tasks and examinations. More individual attention from teachers is also usually required.

South Africa has a policy of inclusive education which incorporates a range of models for the integration of children with special needs into ordinary schools. Not all parents can afford to place their children in special schools. It is therefore submitted that where resources are available, government should take the initiative and promote the principle of inclusive education by building more special schools. Government should also subsidise the school fees of learners living with disabilities, including children with albinism, to enable them to attend special schools with facilities that cater for vulnerable learners. Lack of resources and infrastructure has been cited as the reason why the implementation of the inclusive policy has been so slow, albeit steady.\textsuperscript{429} Special education is not always readily available and disabled children continue to attend mainstream schools where there is no special assistance in terms of facilities and learning.

School-going learners living with albinism also face prejudice and intolerance with the result that they are directly or indirectly denied equal access to education by their fellow students and teachers.\(^{430}\) Both learners and teachers often lack an understanding of albinism, in addition to the dominance of myths and misconceptions that generate fear and discrimination.\(^{431}\) Teachers are normally uninformed about the condition\(^{432}\) and are consequently unable to correct the misconceptions of other learners. Teachers should be sensitised to the special needs of persons living with albinism such as the need to sit close to the front of classes and to be excused from activities that take place in direct sunlight.\(^{433}\) A learning environment that does not make provision for learners with albinism is in total violation of the imperatives of the Higher Education Act\(^{434}\) which prohibits discrimination in schools.

Deep concern exists about abusive language and derogatory name-calling directed at albino learners in schools, and intervention is needed in this regard. Where such name-calling occurs, mechanisms should be instituted to address the problem. Learners with albinism who are subjected to this form of prejudice should be encouraged to report it to the appropriate persons so that steps can be taken against those learners who single them out for abuse.

### 3.6 The right to privacy

#### 3.6.1 Theoretical observations

The Constitution of the Republic of South Africa of 1996 protects the right to privacy in section 14\(^ {435}\) which reads as follows:

\[
\text{Everyone has the right to privacy, which includes the right not to have -}
\\(a\) their person or home searched;
\\(b\) their property searched;
\\(c\) their possessions seized; or
\\(d\) the privacy of their communications infringed.}
\]

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\(^{431}\) Ndomondo 389 and 390.

\(^{432}\) Ndomondo 391.

\(^{433}\) Ndomondo 394.


\(^{435}\) Section 14 of the Constitution of 1996.
According to Currie and De Waal, section 14 is made up of two parts. The first part is the first phrase of the first sentence which reads; “everyone has the right to privacy.” This phrase guarantees a general right to privacy.

The second part protects against specific enumerated violations of privacy including searches and seizures of someone’s person, individual territory, property or possessions, and infringements on the privacy of communications. Although section 14 refers to specific privacy rights, the list is not exhaustive.

The nature of privacy includes isolation from the public and publicity since it involves an individual’s state of life. This involves not having knowledge of a person’s personal dealings, and means that the mere unsanctioned acquaintance by outsiders of an individual’s personal life constitutes an impingement on their privacy. In the Bernstein case, Ackerman J remarked that privacy is actually an individual realm except where an individual channels into joint relations and doings, for instance business and social relations. Under these circumstances, the scope of private freedom shrinks.

The scope of an individual’s constitutional right to privacy covers aspects such as a permissible expectation of privacy, the right to be left alone, the right to development of a person’s individual personality, informational privacy and protection from searches and seizures.

The right to be left alone protects a person’s sanctum which includes body, sexual preference, home and family life. The basis of this right is that outsiders should not interfere with a person’s intimate matters. The right to privacy means that

436 Currie & De Waal 294.
437 Currie & De Waal 294.
438 Currie & De Waal 294.
439 Croome BJ Taxpayers Rights in South Africa (2010, Claremont: Juta) at 122.
440 Neethling et al Law of Delict (2010, Durban; LexisNexis) at 323.
441 Neethling 323.
442 Bernstein v Bester NO 1996 (2) SA 751 (CC) (hereinafter referred to as the Bernstein case), paragraphs [65-67].
443 Currie & De Waal 295-304 and 328.
444 Bernstein case, paragraph [67].
445 Bernstein case, paragraph [67].
everyone is permitted a sphere of personal autonomy to which the community does not have access without approval.\textsuperscript{446}

According to David McQuoid-Mason, personal-autonomy privacy rights can be seen as substantive privacy rights that allow people to make decisions about their lives without any interference from the state, which means that such individuals are empowered to exercise control over procreation, contraception and child-rearing.\textsuperscript{447}

Under South African law, the scope of the right to privacy extends to protection in the law of delict.\textsuperscript{448} This delictual action has been recognised since the classical Roman era. It protects personality rights under the Latin terms \textit{corpus, fama} and \textit{dignitas}, which can be interpreted as meaning an individual’s physical and mental integrity, good name and dignity.\textsuperscript{449} In \textit{Janse van Vuuren and Another NNO v Kruger},\textsuperscript{450} Harms AJA said:

\begin{quote}
To determine whether a prima facie invasion of the right to privacy is justified, it appears that in general the principles formulated in the defences of justification in the law of defamation ought to apply.
\end{quote}

In light of the imprimatur given by the Constitutional Court to the associations between dignity and privacy, one may well concede that the approach of Harms AJA is correct.\textsuperscript{451}

The common law recognition of dignity was by no means abolished by the South African Constitution.\textsuperscript{452} The courts retain the existing common law actions which are consistent with the constitutional values.\textsuperscript{453} In the \textit{NM and Others} case,\textsuperscript{454} the appellants alleged that the High Court failed to protect their rights to privacy, dignity and psychological integrity. The Constitutional Court considered whether the

\begin{flushleft}
\begin{footnotes}
\item[446] Bernstein case, paragraph [67].
\item[449] \textit{NM and Others v Smith and Others} 2007 (5) SA 250 (CC) (hereinafter referred to as the \textit{NM and Others} case), paragraph [151].
\item[450] \textit{Janse van Vuuren and Another NNO v Kruger} 1993 (4) SA 842 (A), paragraph [E].
\item[451] \textit{H v W} 2013 (2) SA 530 (GSJ), paragraph [25].
\item[452] Currie \& De Waal 297.
\item[453] \textit{H v Fetal Assessment Centre} 2015 (2) SA 193 (CC), paragraph [49].
\item[454] \textit{NM and Others} case, paragraph [1].
\end{footnotes}
\end{flushleft}
common law right of privacy had to be developed with the intention of imposing accountability on persons who negligently publish confidential information.\footnote{NM and Others case, paragraph [169].}

Since constitutional rights are not absolute, a breach of such rights may be justifiable when it is in the interest of justice.\footnote{Section 36 of the Constitution of 1996.} The right to privacy is not absolute.\footnote{Venter B “A Selection of Constitutional Perspectives on Human Kidney Sales” (2013) 16 (1) Potchefstroom Electronic Law Journal 352-403 at 356.} As a common law right of personality, it is necessarily limited by the legitimate interests of others and the public in general.\footnote{Section 36 of the Constitution of 1996.}

The right to privacy includes the right not to have one’s person or home searched. According to Carstens and Pearmain, the right not to have one’s person searched denotes that a physical examination of a person directed by a healthcare worker such as a doctor or nurse in a health care context is an infringement of his or her privacy.\footnote{Carstens P & Pearmain D Foundational Principles of South African Medical Law (2007, Durban: LexisNexis) 32. Also see Currie & De Waal 316.} The principle of consent to medical procedures has been restated in cases such as Esterhuizen v Administrator, Transvaal.\footnote{Esterhuizen v Administrator Transvaal 1957 (3) SA 710 (T).} In the Christian Lawyers’ Association v National Minister of Health and Others case,\footnote{Christian Lawyers Association case, paragraph [528].} the Supreme Court of Appeal considered a woman’s right to give informed consent to an abortion, concluding that the right to do so was a fundamental demonstration of the right to individual self-determination. The Court restated that this right to self-determination, reproduced in provisions in South Africa’s Bill of Rights, comprises of the right to bodily and psychological integrity and takes account of the right to make decisions concerning reproduction and the right to security and control over the body as well as the rights to dignity and privacy.\footnote{Christian Lawyers Association case, paragraphs [698-699].}

In the case of Isaacs v Pandie,\footnote{Isaacs v Pandie (12217/07) [2012] ZAWCHC 47 (16 May 2012) (hereinafter referred to as the Isaacs case), paragraph [3].} the plaintiff alleged that the sterilisation procedure performed on her amounted to an assault on her by the defendant since the defendant did not obtain any consent from the plaintiff, written, informed or otherwise, and there was no clinical indication for the defendant to perform the
procedure. As a result the plaintiff alleged that there was a breach of the duty of care that the defendant owed to the plaintiff in that:

the Defendant performed a procedure on the Plaintiff that was not clinically indicated, the Defendant failed to take informed and written consent from the Plaintiff for the sterilisation procedure, the Defendant failed to ascertain whether consent was obtained and recorded by the Plaintiff prior to performing the procedure. Alternatively, the Defendant failed to have regard to, and breached the statutory provisions of the Sterilisation Act and the guidelines of the HPCSA in that the Defendant failed to obtain written and informed consent for performing the sterilisation procedure on the Plaintiff.

The High Court in *Isaacs v Pandie*\(^{464}\) found that an involuntary sterilisation infringed the rights to privacy, dignity, reputation and safety.

In the case of *Castell v de Greef*,\(^{465}\) the court outlined the components of informed consent. Complications occurred after a woman had surgery to remove breast tissue for the purpose of reducing the risk of cancer.\(^{466}\) The patient contended that she had not been advised of the risk of possible complications arising from such a procedure or that an alternative surgical procedure existed.\(^{467}\) In examining the right to informed consent, the Court explained the subjective, patient-centred test for informed consent, and held that a health practitioner has an obligation to disclose all information and risks about a procedure and that a rational person in the patient’s position, if cautioned about the risk, might attach importance to it.\(^{468}\) The Court found that informed consent requires information, understanding and consent. Informed consent requires that a patient:

know the nature and extent of the risk or harm that accompanies a procedure; understand the nature and extent of the risk or harm; agree in detail to the procedure under discussion; and agree in detail to all parts of the risk or possible harm.\(^{469}\)

The outcome of the *Castell v de Greef* case is important for the reason that a subjective, patient-centred test for informed consent is in line with the fundamental rights to self-determination and individual autonomy.

\(^{464}\) *Isaacs case*, paragraph [57].
\(^{465}\) *Castell v de Greef* 1994 (4) SA 408 (C) (hereinafter referred to as the *Castell case*), page [425].
\(^{466}\) *Castell case*, pages [414-415].
\(^{467}\) *Castell case*, page [414].
\(^{468}\) *Castell case*, page [425].
\(^{469}\) *Castell case*, page [426].
Information about a person’s health status, in terms of HIV or cancer for example, is similarly affected by issues of privacy.\textsuperscript{470} According to Slabbert,\textsuperscript{471} an example of an invasion of a patient’s private sphere would be where a doctor, without disclosure to the patient, conducts an HIV/AIDS test or genomic analysis on a blood or tissue sample taken with the knowledge and permission of the patient. An example of the infringement of privacy in terms of disclosure of a patient’s private affairs cited by Slabbert is the disclosure of a patient’s HIV/AIDS status or the outcome of a genomic investigation.\textsuperscript{472} In other words, the right to privacy is generally encroached on when there is disclosure of a person’s personal information, in particular without their consent. The latter involves a violation of the doctor’s duty of confidentiality.\textsuperscript{473} The dual purpose and function of a doctor’s duty of confidentiality includes the “protection of the patient’s right to privacy” as well as the duty “to secure public health”.\textsuperscript{474}

Medical examination is only permissible in cases where the person being examined waives their right to privacy for the purpose of examination.\textsuperscript{475} Conducting a test on a person without their consent therefore amounts to a violation of their privacy.\textsuperscript{476}

The current healthcare legislation in South Africa provides for the protection of personal health information. In comparison to the Constitution which entrenches the right to privacy, the National Health Act merely discusses the right to confidentiality.\textsuperscript{477} In section 14, the National Health Act provides that:

\textsuperscript{470} Carstens & Pearmain 32.
\textsuperscript{471} Slabbert MN \textit{Medical Law in South Africa} (2011, Amsterdam: Kluwer Law International) at 16.
\textsuperscript{472} Slabbert 16.
\textsuperscript{473} Slabbert 16.
\textsuperscript{474} Slabbert 16.
\textsuperscript{475} Carstens & Pearmain 32.
\textsuperscript{476} The same view is upheld by the common law. The \textit{Seetal v Pravitha and Another NO} 1983 (3) SA 827 (D) case is an example of a case which was decided based on common law principles. This case came before the court prior to the enactment of the Constitution of 1996. In this case, there was a disagreement over paternity. The husband was the applicant who brought charges for divorce against his wife claiming that she committed adultery and that blood samples should be taken from his wife, child and himself, and that these samples should be tested for the purpose of establishing if he was the child’s father. The wife refused to let any sample of blood be taken from the child or herself. Didcott J noted that conducting a blood test on a person without their consent is indisputably an invasion of their privacy. The application was dismissed, with costs, with the reasoning that it would in no way benefit the child and therefore was not in the child’s best interests.
(1) All information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment is confidential.
(2) Subject to section 15, no person may disclose any information contemplated in subsection (1) unless - (a) the user consents to that disclosure in writing; (b) a court order or any law requires that disclosure; or (c) non-disclosure of the information represents a serious threat to public health.

The right to confidentiality of health and medical information is thus guaranteed by the National Health Act in South Africa. This right was highlighted in the *Tshabalala-Msimang and Another v Makhanya and Others* case, where the court stated that section 14(1) of the National Health Act imposes a duty of confidence with regard to the information in a person’s health records. Section 14(1) of the National Health Act makes it crucial and obligatory to protect the information in a person’s health records against unauthorised disclosure.

Both the Constitution and the National Health Act indicate that private information contained in the health records of a patient is worth protecting as an aspect of autonomy and dignity to the extent that people who unlawfully reveal such private information could be punished by law.

### 3.6.2 The right to privacy in the context of albinism

In this discussion, the dual aspects of stigma and discrimination are addressed. The thesis has discussed the albinism-based stigma associated with the appearance of the albino skin and albino eyes. In addition to this, failure to respect the privacy of people with albinism in matters of their health could exacerbate the discrimination they face.

Since people with albinism are at high risk of contracting cancer, they are normally advised to test for cancer periodically. Such testing should be done voluntarily to avoid violating their right to voluntary testing and counselling and their right to confidentiality in dealings with healthcare services. The screening of a person with albinism for skin cancer without their consent could violate fundamental rights such as the rights to equality, non-discrimination, freedom and security of the person, and

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478 *Tshabalala-Msimang and Another v Makhanya and Others* (18656/07) [2007] ZAGPHC 161 (WLD) (hereinafter referred to as the *Tshabalala-Msimang case*), paragraph [27].
479 *Tshabalala-Msimang case*, paragraph [27].
privacy. The cultural context of cancer may further amplify the already existing discrimination associated with albinism.

Just like any other medical procedure, cancer tests and eye tests should be conducted with the voluntary and informed consent of the individual with albinism. Unlawful testing generally occurs when informed consent is not obtained. For people with albinism this can occur in a variety of circumstances, such as where the patient is not given comprehensive information about the test, or there is a failure to offer pre- and post-test counselling. Unlawful testing can also take the form of patients not being informed that the test is being conducted or of consent being obtained through coercion, such as where cancer testing is a condition for employment.

A theoretical understanding of the right to privacy clearly indicates that every person, including people with albinism, has a right to confidentiality of their medical information. Unlawful disclosure of medical information can take place in a health care setting, in the workplace, within families and within communities.

A discussion of the genetic characteristics of albinism and the right to privacy is especially timely in light of current genetic and genomic research. Globally, there is a scientific agenda to research genomics and the causes of genetic disorders for the purpose of making earlier diagnoses, interventions and targeted treatments possible. In an effort to find solutions to genetic diseases, genetic and genomic research has become a crucial tool for translational medicine.\footnote{Wolf SM \textit{et al} “Managing Incidental Findings and Research Results in Genomic Research Involving Biobanks & Archived Datasets” (2012) 14 (4) \textit{Genetics in Medicine} 361-364 at 361. Also see Zawati MH & Knoppers BM “International Normative Perspectives on the Return of Individual Research Results and Incidental Findings in Genomic Biobanks” (2012) 14 (4) \textit{Genetics in Medicine} 484-489 at 484. Regarding the position on the handling of incidental findings in biobanks in South Africa, see Mswela MM & Molusi AP “Incidental Findings in Biobanks in South Africa: Ethical and Legal Issues” (2014) 35 (2) \textit{Obiter} 344-366.} The handling of important genetic information during research is very crucial since a breach of confidentiality with regard to a person’s genetic information can result in further human rights violations such as marginalisation, stigmatisation, dismissals and being barred from benefits and services.
In the context of genetic or genomic research involving people with albinism, it is clear from a theoretical understanding of the right to privacy that no one should be able to take another person’s genetic material without their consent.

There are a number of situations in which people with albinism could be subjected to unlawful disclosure of their genetic information to third parties without their informed consent. As genetic testing becomes more accessible, the risk of this information being used without consent increases. People with albinism should be protected against any illegal intrusions in terms of their genetic information.

Genetic biobanks such as Telethon are repository facilities for patients and their families, and these repositories already store genetic information about people with albinism.\textsuperscript{481} Such genetic information must be handled with great caution. With a national biobank in South Africa having been proposed,\textsuperscript{482} it is likely that the DNA of people with albinism will also be stored there, and it is anticipated that researchers and clinicians will have access to this data. Issues around the distribution of DNA samples to the scientific community for specific research projects have severe implications in terms of the right to confidentiality.

### 3.7 Conclusion

According to our Constitution every person is born free and equal. Persons living with albinism are human beings who ought to enjoy all the rights and freedoms enjoyed by others. This unique group of people forms part of and contributes to the diversity of human society. Their genetic condition requires that society care for them as a special minority. Their rights to equality, life, dignity, health care services, special education and privacy should be respected. Government and the health professions as well as organisations, civil society, the media and concerned individuals have a duty to assist them in realising their potential by taking into

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account the challenges they face in terms of health, stigma, discrimination and attacks.
CHAPTER 4: THE LIMITATIONS ANALYSIS

“Within the proportionality test, balancing has to be done according to the law of balancing, that means openly and traceably.”¹

4.1 Introduction

The discussion of the specific fundamental rights affected by and relevant to the mystification of albinism is incomplete without an inquiry into the legitimacy of the limitations of these rights. An inquiry into the legitimacy of the limitation of the rights discussed in chapter three requires a detailed and comprehensive understanding of the basic theoretical principles underlying the limitation clause. Such an understanding is indispensable as a framework for examining the legitimacy and justifiability of alleged violated rights.

In diverse ways, bills of rights generally provide for the legitimate limitation of rights.² Peace and order are non-existent in societies where human rights can be put into effect with no limitations all the time. In specific situations, bills of rights limit rights in a particular way. Such limitation of rights is applied for the protection of the interests of the community, as well as the protection of the rights of others.³ It is imperative to take note that the limitation clause does not only allow for the limitation of rights, it also contains strict requirements in terms of such limitation.⁴ Contemporary bills of rights hardly ever allow organs of state to limit rights without any qualification.⁵ Limitation of rights without any qualification would amount to rendering any bill of rights meaningless.

No right in the bill of rights can be exercised in a way which violates the rights of any citizens or in a way which unreasonably and unjustifiably hinders the State in its

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⁴ Currie I & De Waal J The Bill of Rights Handbook (2013, Cape Town: Juta) at 146-151.
legitimate purpose of government.\textsuperscript{6} If this were allowed, the bill of rights would become a useless instrument; essentially a “charter for the abuse of rights”.\textsuperscript{7} A number of modern bills of rights consequently include a limitation clause which permits human rights to be limited in a lawful way.\textsuperscript{8}

Section 36 of the Constitution, known as the general limitation clause, makes provision for a system that allows for an open review of opposing values and interests.\textsuperscript{9} The general limitation clause calls on the legislature or the executive to attempt to solve socio-legal problems that are found to be constitutionally illegitimate.\textsuperscript{10} Such an assessment also allows for the resolution of tensions around the issues of democracy and rights.\textsuperscript{11} An infringement of human rights is not always essentially unconstitutional. If an encroachment passes the limitation test, it means that the infringement of the right is constitutionally legitimate.\textsuperscript{12}

The weighing of rights disallows an “absolute” or “rigid” set of principles.\textsuperscript{13} The basis for limiting any basic human right has to be extremely strong.\textsuperscript{14} The Constitution allows the limitation of a right to be done by law alone and also requires a justified basis for such limitation.\textsuperscript{15} In other words, the reason for the limitation must be compelling and critical.\textsuperscript{16}

\begin{flushleft}
\textsuperscript{7} Buhlungu 101.
\textsuperscript{8} Buhlungu 101; and Klatt & Meister 1-2.
\textsuperscript{9} Hughes 127.
\textsuperscript{10} Woolman SC \textit{The Selfless Constitution: Experimentalism and Flourishing as Foundations of South Africa’s Basic Law} (2013, Cape Town: Juta) at 262.
\textsuperscript{13} This was affirmed in \textit{S v Manamela} 2000 (3) SA 1 (CC) (hereinafter referred to as the \textit{Manamela} case), paragraph [32]. Also see Axam HS “If the Interest of Justice Permits: Individual Liberty, the Limitation Clause and the Qualified Constitutional Right to Bail” (2001) 17 (3) \textit{South African Journal on Human Rights} 320-340 at 320; and Mswela M “The Role of HIV/AIDS and Gender Violence in South African Law” 2007 \textit{Dissertation submitted in fulfillment of the requirements for the Degree Master of Law} in the College of Law at the University of South Africa 1-187 at 120.
\textsuperscript{14} Axam 320.
\textsuperscript{15} Woolman 262; and Axam 325.
\textsuperscript{16} Axam 325; and Currie & De Waal 163.
\end{flushleft}
The general limitation of rights is explained as follows:\textsuperscript{17}

It is widely accepted in the domestic law of most states, in international law and according to international and other human rights documents, that only a very limited number of rights, if any, are absolute. These include freedom from torture, the abuse and exploitation of children and possibly freedom from servitude, freedom of conscience, belief, thought, and opinion. The overwhelming majority of human rights and liberties are of necessity restricted by the inherent duty, which should be perceived as the inextricable counterpart of a corresponding right, to respect the rights of others. The classical example in this regard is that freedom of speech does not allow one person to defame another nor would it sanction a person shouting ‘fire’ in a full theatre when there is no fire.

The relationship between the State and the individual is not equal in nature, and the intention of a bill of rights is to protect persons against the exploitation of state power.\textsuperscript{18} Section 8\textsuperscript{19} of the Constitution clearly explains that the Bill of Rights applies both vertically and horizontally. Both natural and juristic persons may invoke the rights contained in the Bill of Rights.\textsuperscript{20} Section 8(2) emphasises that the provisions in the Bill of Rights bind both natural and juristic persons if, and to the point that, it is applicable, taking into account the characteristics of the right and the nature of any obligation imposed by the right.\textsuperscript{21} Rights applying between persons denote a

\begin{itemize}
\item[\textsuperscript{17}] Devenish GE \textit{A Commentary on the South African Constitution} (1998; Durban: Butterworths) at 89.
\item[\textsuperscript{18}] Currie & De Waal 41.
\item[\textsuperscript{19}] Section 8 of the Constitution of the Republic of South Africa, 1996 (hereinafter referred to as the Constitution of 1996), reads as follows:
\begin{enumerate}
\item “The Bill of Rights applies to all law, and binds the legislature, the executive, the judiciary and all organs of state.
\item A provision of the Bill of Rights binds a natural or a juristic person if, and to the extent that, it is applicable, taking into account the nature of the right and the nature of any duty imposed by the right.
\item When applying a provision of the Bill of Rights to a natural or juristic person in terms of subsection (2), a court
\begin{enumerate}
\item in order to give effect to a right in the Bill, must apply, or if necessary develop, the common law to the extent that legislation does not give effect to that right; and
\item may develop rules of the common law to limit the right, provided that the limitation is in accordance with section 36(1).
\end{enumerate}
\end{enumerate}
A juristic person is entitled to the rights in the Bill of Rights to the extent required by the nature of the rights and the nature of that juristic person.”
\item[\textsuperscript{20}] Andrew B \textit{The International Survey of Family Law} (1998, The Hague: Martinus Nijhoff Publishers) at 436. Also see section 8(2) of the Constitution of 1996 which reads as follows: “A provision of the Bill of Rights binds a natural or a juristic person if, and to the extent that, it is applicable, taking into account the nature of the right and the nature of any duty imposed by their right.” Also see \textit{Du Plessis and Others v De Klerk and Another} 1996 (5) BCLR 658 (CC), paragraph [8].
\item[\textsuperscript{21}] Section 8(2) of the Constitution of 1996 reads as follows: “A provision of the Bill of Rights binds a natural or a juristic person if, and to the extent that, it is applicable, taking into account the nature of the right and the nature of any duty imposed by their right.”
\end{itemize}
horizontal application of the Bill of Rights, while rights that find application between the State and an individual, denote a vertical application of the Bill of Rights.

### 4.2 The proportionality test

Section 36(1) of the Constitution states that:

> [t]he rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including - (a) the nature of the right; (b) the importance of the purpose of the limitation; (c) the nature and extent of the limitation; (d) the relation between the limitation and its purpose; and (e) less restrictive means to achieve the purpose.

The South African courts have adopted a two-stage approach to rights adjudication. The initial stage determines the scope of the right. If the law of general application limits the protected scope of the right, a second stage justification investigation is conducted. This stage draws on the elements specified in section 36(1) to determine if the intrusion on the right is justifiable in an open and democratic society based on human dignity, equality and freedom.

The State’s interests are addressed in the second justification stage. In the first stage, courts construe rights generously and broadly, reserving any qualification of the right for the second stage of the inquiry. Within the context of the Interim Constitution, Ackermann J in *Ferreira v Levin* noted the following:

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22 Freedman W *Understanding the Constitution of the Republic of South Africa* (2013, Cape Town: Juta) at 309. Also see *Ex Parte Chairperson of the Constitutional Assembly: In Re Certification of the Constitution of the Republic of South Africa 1996* (4) SA 744 (CC), paragraph [54].
24 *President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC); *Dawood v Minister of Home Affairs 2000* (3) SA 936 (CC) (hereinafter referred to as the ‘Dawood case’); *Christian Education South Africa v Minister of Education 2000* (4) SA 757 (CC); and *S v Walters 2002* (4) SA 613 (CC) (hereinafter referred to as the ‘Walters case’). Also see Kevin I “A Fresh Look at Limitations: Unpacking Section 36” (2007) 23 (1) South African Journal on Human Rights 68-92 at 77.
25 Kevin 70.
26 Kevin 70.
27 Currie & De Waal 152-171.
28 See *S v Zuma* 1995 (2) SA 642 (CC) (hereinafter referred to as the ‘Zuma case’), paragraphs [14-15]; and *S v Makwanyane 1995* (3) SA 391 (CC) (hereinafter referred to as the ‘Makwanyane case’), paragraph [9].
29 Zuma case, paragraph [21].
30 *Ferreira v Levin NO* 1996 (1) SA 984 (CC), paragraph [82].
If a limitation is sought to be made at the first stage of the enquiry, it requires, at best, an uncertain, somewhat subjective and generally constitutionally unguided normative judicial judgment to be made. The temptation to, and danger of, judicial subjectivity is great. This Court would, in my view, be discharging its interpretative function best, most securely and most constitutionally, if, as far as is judicially possible, it seeks for any limitation of an entrenched right through section 33(1). It may well be that the Constitution itself, either because of the descriptive ambit of one or more of the many other rights entrenched in chapter 3, or in some other way, expressly or by clear implication, indicates a limitation of an entrenched right at the first stage of the enquiry. Absent such an indication, the Court would be on safer constitutional ground if it were to find any limitation on the basis of the prescribed criteria in section 33(1). This approach will afford a better guarantee against the Court, however unwittingly, reading its own subjective views into the Constitution.

The first stage of the two-stage approach is only interpretative. It entails a descriptive analysis of the scope of the right as well as a delineation of the boundaries of constitutionally protected action. At times, the boundaries of the right in question are specified by means of the wording of the Constitution or by incorporating an internal limitation. However in other cases, the boundaries of

31 Kevin 72.
32 Currie and De Waal 150.
33 A fine example is the wording of section 16 of the Constitution of 1996, the right to freedom of expression. Section 16 of the Constitution of 1996 reads as follows:
   *(1) Everyone has the right to freedom of expression, which includes-
   (a) freedom of the press and other media;
   (b) freedom to receive or impart information or ideas;
   (c) freedom of artistic creativity; and
   (d) academic freedom and freedom of scientific research.
   (2) The right in subsection (1) does not extend to-
   (a) propaganda for war;
   (b) incitement of imminent violence; or
   (c) advocacy of hatred that is based on race, ethnicity, gender or religion, and that constitutes incitement to cause harm.*
   In the case of *Islamic Unity Convention v Independent Broadcasting Authority* 2002 (4) SA 294 (CC), paragraphs [32-33], Langa J held that section 16(2) of the Constitution limits the scope of the right and that this section does not limit the right to freedom of expression itself.
   A further example is that of political rights, under section 19 of the Constitution, which are limited to citizens. Section 19 of the Constitution of 1996 reads as follows:
   *(1) Every citizen is free to make political choices, which includes the right-
   (a) to form a political party;
   (b) to participate in the activities of, or recruit members for, a political party; and
   (c) to campaign for a political party or cause.
   (2) Every citizen has the right to free, fair and regular elections for any legislative body established in terms of the Constitution.
   (3) Every adult citizen has the right-
   (a) to vote in elections for any legislative body established in terms of the Constitution, and to do so in secret; and
   (b) to stand for public office and, if elected, to hold office.*
rights are determined by legislation passed by instruction of the Constitution in order to give effect to the right. 34

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34 Examples in this regard include sections 9, 25, 32 and 33 of the Constitution of 1996.

Section 9 of the Constitution of 1996 reads as follows:

(1) “Everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3) National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.”

Section 25 of the Constitution of 1996 reads as follows:

“(1) No one may be deprived of property except in terms of law of general application, and no law may permit arbitrary deprivation of property.

(2) Property may be expropriated only in terms of law of general application— (a) for a public purpose or in the public interest; and (b) subject to compensation, the amount of which and the time and manner of payment of which have either been agreed to by those affected or decided or approved by a court.

(3) The amount of the compensation and the time and manner of payment must be just and equitable, reflecting an equitable balance between the public interest and the interests of those affected, having regard to all relevant circumstances, including— (a) the current use of the property; (b) the history of the acquisition and use of the property; (c) the market value of the property; (d) the extent of direct state investment and subsidy in the acquisition and beneficial capital improvement of the property; and (e) the purpose of the expropriation.

(4) For the purposes of this section— (a) the public interest includes the nation’s commitment to land reform, and to reforms to bring about equitable access to all South Africa’s natural resources; and (b) property is not limited to land.

(5) The state must take reasonable legislative and other measures, within its available resources, to foster conditions which enable citizens to gain access to land on an equitable basis.

(6) A person or community whose tenure of land is legally insecure as a result of past racially discriminatory laws or practices is entitled, to the extent provided by an Act of Parliament, either to tenure which is legally secure or to comparable redress.

(7) A person or community dispossessed of property after 19 June 1913 as a result of past racially discriminatory laws or practices is entitled, to the extent provided by an Act of Parliament, either to restitution of that property or to equitable redress.

(8) No provision of this section may impede the state from taking legislative and other measures to achieve land, water and related reform, in order to redress the results of past racial discrimination, provided that any departure from the provisions of this section is in accordance with the provisions of section 36(1).

(9) Parliament must enact the legislation referred to in subsection (6).”

Section 32 of the Constitution of 1996 reads as follows:

“(1) Everyone has the right of access to— any information held by the state; and (b) any information that is held by another person and that is required for the exercise or protection of any rights.

(2) National legislation must be enacted to give effect to this right, and may provide for reasonable measures to alleviate the administrative and financial burden on the state.”

Section 33 of the Constitution of 1996 reads as follows:
Within the context of applying section 36, reasonableness denotes that the law that confines a right should do so in a rational manner which does not exceed the purpose of the limitation.\(^{35}\) Therefore the need exists to prove the relationship between the limitation of the right and the intended benefits of the limitation.\(^{36}\) Academics and courts use the traditional metaphor of “balancing” to denote the weighing up of the purpose of the right against the objective of the limitation.\(^{37}\) The limitations scrutiny frequently entails the courts’ having to choose between “incommensurable goods” that, by definition, do not have any shared metric of value.\(^{38}\)

The general limitation clause is qualified by the word “general” because it applies to each and every right in the Bill of Rights, as well as stipulating that all said rights are limited through the application of the same standard.\(^{39}\) An inquiry into whether a right has been unjustly limited initially establishes whether a law of general application infringes any right in the Bill of Rights.\(^{40}\) Put differently, the limitation of any right has to be authorised by law.\(^{41}\)

The phrase “law of general application” is an expression of the basic principle of “liberal political philosophy and of constitutional law,” which is seen by many people as being the rule of law.\(^{42}\) This condition comes from an important standard of the


\(^{36}\) Mswela 122.

\(^{37}\) Woolman & Bishop 14.

\(^{38}\) Woolman & Bishop 14.

\(^{39}\) Currie & De Waal 152. It is also interesting to note that the United States Constitution does not contain a limitation clause. The German Bill of Rights does not have a “general limitation clause” but has a particular limitation for each right. The Canadian Charter of Rights and Freedoms, on the other hand, has a general limitation clause.

\(^{40}\) Makwanyane case, paragraph [98].

\(^{41}\) Mswela 121.

\(^{42}\) Currie & De Waal 155. Also see Mswela 121. It appears that there are two connotations to this rule. Firstly, the rule indicates that the authority and control which the government possess derives from the law. To this end, the government ought to have lawful power
rule of law, which explicitly state that rules must be expressed in a clear and accessible manner.\textsuperscript{43} It is apparent from case law that a “law of general application” takes account of common law\textsuperscript{44} and statutory law, on condition that the statute is clear.\textsuperscript{45} The work practices of companies do not meet the requirement of the law of general application,\textsuperscript{46} and neither does unauthorised conduct by a public official.\textsuperscript{47}

In \textit{Khala v Minister of Safety and Security},\textsuperscript{48} the court explained the word law as including legislation, common law and customary law. “Law” in the phrase “law of general application” has been understood to encompass all types of both original and subordinate legislation.\textsuperscript{49} This was stipulated in the case of \textit{Larbi-Odam v MEC for Education} where the Constitutional Court held that, in South Africa, subordinate legislation amounts to “law of general application”.\textsuperscript{50} In addition, common law, public and private rules and customary law all equally qualify as “laws of general application”. In the case of \textit{Hoffmann v South African Airways},\textsuperscript{51} the court stated that a policy or practice does not meet the standard of law. The aforementioned case was brought against the South African Airways policy of rejecting HIV-positive applicants for the position of cabin attendant.\textsuperscript{52}
The term "general application" in "law of general application" means that it must apply equally to every person affected by it. In the President of the Republic of South Africa v Hugo case, Makgoro J reflected on the phrase in broad terms and stated that the rule in question would qualify as a law of general application only if it is accessible, precise and generally applicable. The majority of the judges refrained from taking a position in this regard. However, in August v Electoral Commission, the majority ruling held that an empowering legislative provision is a minimum prerequisite for meeting the requirements of law of general application.

The nature of the right affected by an alleged infringement is an additional factor to consider, as stipulated in section 36(1)(a). The phrase "the nature and importance of the right" appears to have arisen for the first time in the constitutional case of S v Makwanyane. The phrase has since been carried over into post-1996 limitations jurisprudence, possibly on the supposition that the elements in section 36(1) are a re-composition of the limitations jurisprudence established by the Constitutional Court.

The weighting of rights is not entirely equal since the more important a specific right is to an open and democratic society based on human dignity, equality and freedom, "the heavier the burden of proof convincing the justification for the restriction of the particular right". The importance of the rights to human dignity, equality, and freedom and security of the person is clear in light of South Africa’s history of apartheid and violence.

As shown in previous chapters, the rights to human dignity, equality, and freedom and security of the person in the context of albinism undoubtedly call for strong...
justification of both the causes and effects of conduct which violates these rights. The appropriate recognition of these rights is clearly critical to the advancement of the objective of the Constitution “to create an open and democratic society.” The inquiry entails determining the extent of the infringement of the right, in other words, whether the violation of the right exceeds the scope of the purpose of the limitation. In *S v Manamela* the judge explicitly noted that:

> [t]he level of justification required to warrant a limitation upon a right depends on the extent of the limitation. The more invasive the infringement, the more powerful the justification must be.

In reviewing the legitimacy of a restriction of a right, reference ought to be made to the following paragraph as found in *S v Makwanyane*:

The limitation of constitutional rights for a purpose that is reasonable and necessary in a democratic society involves the weighing up of competing values, and ultimately an assessment based on proportionality. This is implicit in the provisions of section 33(1). The fact that different rights have different implications for democracy, and in the case of our Constitution, ‘for an open and democratic society based on freedom and equality,’ means that there is no absolute standard which can be laid down for determining reasonableness and necessity. Principles can be established, but the application of those principles to particular circumstances can only be done on a case-by-case basis. This is inherent in the requirement of proportionality, which calls for the balancing of different interests. In the balancing process, the relevant considerations will include the nature of the right that is limited, and its importance to an open and democratic society based on freedom and equality; the purpose for which the right is limited and the importance of that purpose to such a society; the extent of the limitation, its efficacy, and particularly where the limitation has to be necessary, whether the desired ends could reasonably be achieved through other means less damaging to the right in question. In the process regard must be had to the provisions of a section 33(1), and the underlying values of the Constitution, bearing in mind that as a Canadian Judge has said, ‘the role of the court is not to second-guess the wisdom of policy choices made by legislators’.

The importance of the right has not been expressly included as a factor for consideration under section 36. In a majority judgement in the *National Coalition for Gay and Lesbian Equality v Minister of Justice*, Ackermann J held that:

> [a]lthough s 36(1) does not expressly mention the importance of the right, this is a factor which of necessity must be taken into account in any proportionality enquiry.

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62 Mswela 123.
63 *Manamela* case, paragraph [34].
64 *Makwanyane* case, paragraph [4].
65 *National Coalition for Gay and Lesbian Equality v Minister of Justice* 1999 (1) SA 6 (CC), paragraph [34].
Section 36(1)(b) of the Constitution states that the importance of the purpose of the limitation should be reflected upon during the review of an infringed right. The reason for the limitation must serve a crucial purpose. Such a reason needs to be transparent in order for it to be seen as reasonable. In order for the reason for the restriction to be regarded as reasonable, it must be founded on the principle of a democratic society based on human dignity, equality and freedom.

The importance of the purpose for the limitation entails two separate enquiries. The reason for the restriction of the right must be examined, followed by an assessment of the importance of the reasons for the limitation.

The nature and extent of the limitation requires that the court evaluate the manner in which the limitation infringes the right in question. This necessitates an inquiry into the extent of violation of the right. Put differently, an inquiry into whether the infringement of the right exceeds the extent of the reason for the limitation is necessary. In the Manamela case, the judge fittingly observed that the level of justification required to warrant a limitation of a right depends on the extent of the limitation. The more invasive the infringement, the more powerful the justification must be.

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66 Rautenbach 2233. Rautenbach notes that: "...proportionality involves more than just providing reasons for the sake of accountability regardless of whether they are good or silly reasons. In very general terms it is usually also stated that the reasons given must be ‘plausible’ or ‘proper’ reasons, and whatever ‘plausible’ or ‘proper’ might mean, these qualifications mean that proportionality inevitably also has a substantive meaning.”

67 Currie & De Waal 166-167.

68 Currie & De Waal 166-167.

69 Rautenbach 2240.

70 In the Makwanyane case, paragraphs [662]; [669]; [717-718]; and [129-130], three important rights were violated. The State had to prove whether the purpose for limiting the three rights was vital in an open and democratic society based on human dignity, equality and freedom. The State argued that the death sentence served three functions which could not be served by any other type of penalty. In the first place, it was said to serve as a deterrent to violent crime; secondly, it was said to prevent the repetition of violent crime so that a murderer would not murder again; and thirdly, it was seen as serving the purpose of retribution for violent crime. The third purpose, however, was disputed on the grounds that retribution is not aligned to the principle of Ubuntu and the standards of reconciliation.

71 Currie & De Waal 168.

72 Currie & De Waal 168.

73 Mswela 123.

74 Manamela case, paragraph [34].
In simple terms, the “relation between the limitation and its purpose”, as stipulated in section 36(1)(d), means that the grounds for the encroachment of a right must be compelling and there should be an essential link between the law and its purpose.\(^75\)

Less restrictive ways of achieving the purpose, as stipulated in section 36(1)(e), concern the element of proportionality in the sense that a limitation is regarded as reasonable if a less invasive means is employed to realise the same end.\(^76\) Where there is more than one appropriate way of advancing the purpose of a limitation effectively, the one that encroaches least on the right to be limited should be chosen.\(^77\) Such a less invasive way will either not limit the affected right(s) in any way or will not limit the right(s) to the same extent as a more invasive way.\(^78\)

It is clear from the discussion above that our constitutional framework envisages circumstances where rights protected in the Constitution are capable of being limited, and sets a high standard in terms of when such restrictions of rights would be justifiable. Section 38\(^79\) of the Constitution stipulates that any person listed in this section has a right to direct their allegation of an infringement of a right to any competent court, and such court may grant the proper relief. Against the backdrop of the constitutional framework discussed in chapter three and the theoretical introduction to the limitation clause given above, the discussion now turns to a critical evaluation of the killing of persons living with albinism. This will be followed by an inquiry into the rationality of the stigma and discrimination faced by people living with albinism.

\(^{75}\) Currie & De Waal 169. Also see Mswela 124.
\(^{76}\) Klatt & Meister 9.
\(^{77}\) Klatt & Meister 9.
\(^{79}\) Section 38 of the Constitution of 1996 reads as follows:

“Anyone listed in this section has the right to approach a competent court, alleging that a right in the Bill of Rights has been infringed or threatened, and the court may grant appropriate relief, including a declaration of rights. The persons who may approach a court are:

a. anyone acting in their own interest;
b. anyone acting on behalf of another person who cannot act in their own name;
c. anyone acting as a member of, or in the interest of, a group or class of persons;
d. anyone acting in the public interest; and
e. an association acting in the interest of its members.”
4.3 Limitation of the right to life among persons with albinism under constitutional scrutiny

From the discussions in chapters one and three, it is apparent that the mystification of albinism is instrumental in posing a threat to the right to life. This thesis has highlighted the mistaken cultural beliefs, stereotypes and myths about albino body parts having magical powers and how such beliefs have led to hundreds of albinos being killed and their body parts being sold by unscrupulous dealers in Africa. It has been indicated that these killings have a range of physical as well as psychological effects on persons with albinism and have established albinos around the world as a vulnerable group.

Muti killings violate the right to freedom and security of the person, the right to human dignity as well as the right to life (where death is a direct result). Victims of muti murder die during or after the attack from pain, haemorrhages and surgical shock.\(^{80}\) Violent acts that result in death or grave physical harm undoubtedly encroach on a person’s right to life and physical integrity.\(^ {81}\) The Constitution, in section 12(1(c), specifically protects the right to be free from all forms of violence “from either public or private sources.” Further protection is found in section 12(1)(d) which addresses the right not to be tortured in any way, while section 12(1)(e) provides for the right not to be treated or punished “in a cruel, inhuman or degrading way.”\(^{82}\)

The South African vision of a society founded on the recognition of human rights means that everyone is obliged to value the right to life and the right to dignity.\(^{83}\) In

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\(^{82}\) Section 12 of the Constitution of 1996, reads as follows: “12.(1) Everyone has the right to freedom and security of the person, which includes the right—
(a) not to be deprived of freedom arbitrarily or without just cause;
(b) not to be detained without trial;
(c) to be free from all forms of violence from either public or private sources;
(d) not to be tortured in any way; and
(e) not to be treated or punished in a cruel, inhuman or degrading way.”

\(^{83}\) Makwanyane case, paragraph [24].
the landmark case of *S v Makwanyane and Another,* Judge Langa made reference to South Africa’s dark history in which the value of life and human dignity were ‘demeaned’. He cited political, social and other factors as having created an environment of aggression, resulting in a culture of ‘retaliation and vengeance’. In the process, reverence for life and for the intrinsic worth of everyone was the major loss. By retaining a punishment which failed to hold the dignity of the person and the value of human life in high regard, the State played a part in this disintegration. Considering that the State is a role model for society, in the new constitutional context the State is obliged to guide society to respect the law and to demand that killing come to an end and human life and dignity be honoured. By implication, the State must say no to the destruction of a criminal’s right to life and dignity.

Recent years have seen an escalation in *muti* murders across South Africa. It is very probable that some of the children who have vanished without a trace have been victims of *muti* murders, although this remains speculation. The case of the missing South African albino child referred to in chapter one leads to speculation about possible victimisation, considering the number of African countries that have witnessed such *muti* murders.

Chapter one cited various reasons for the killing of persons with albinism for *muti* purposes. Different body organs are thought to be used for a variety of purposes. In the mining industry for example, the legs, bones and blood of albinos are used in concoctions which are sprinkled over mining sites for the purpose of locating precious minerals. The bones of albinos are also ground and buried underground.

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84 *Makwanyane* case, paragraph [18].
85 *Makwanyane* case, paragraph [18].
86 *Makwanyane* case, paragraph [18].
87 *Makwanyane* case, paragraph [18].
89 *Makwanyane* case, paragraph [22].
by miners who believe that they will be transformed into diamonds. The genitals of albinos are used in treatments to boost sexual potency. Wealthy city dwellers are amongst those who believe that potions made from albino body parts are particularly powerful.

The use of albino body parts for muti is part of a broader practice of using human body parts for muti, and considering how rife muti murder is in South Africa, it is important to examine the reasons for these occurrences, regardless of whether they involve people with albinism or not. Many reasons for these killings have been suggested. In the belief that body parts have extraordinary powers, numerous people have resorted to harvesting certain body parts with the expectation that these will help them become rich. With the current economic situation in South Africa, the desperate need to escape poverty may play a role in the incidence of these aggressive crimes.

Ordinary people consult inyangas for the purpose of obtaining muti to overcome their problems, accomplish their goals or “get the better of their enemies”. Some, though not all, inyangas kill or contract killings for the purposes of human muti. 

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94 Burke 64. In a recent case heard in the North Gauteng High Court, Mogaramedi v S 2015 (1) SACR 427 (GP), paragraph [4], "The appellant had been practicing as a Sangoma for ten (10) years prior to the offence. As part of his final initiation, he had to obtain the genital organ of a close female relative. He therefore lured his younger sister, (the deceased), to his home under the false pretense that they would conduct a ritual for their incarcerated brother. He waited for the deceased to fall asleep whereupon he hit her twice on her head with an axe. He then stabbed her with a knife on the chest and waited for her to pass away. He then cut off the deceased’s genital organ with an axe. He was arrested whilst in possession of the said genital organ.”


The following are further reasons given for the harvesting of body parts for *muti*
purposes in South Africa:

- Blood improves vitality.
- The eye will make an important business venture succeed or give farsightedness.
- The ear will make people listen to the views of the owner of a business.
- The breast will make customers dependent on the business owner (as the infant is dependent upon the breast), and will also ensure fertility.
- While a young girl’s vagina is said to bring productivity and wealth to a business venture, testicles are often used for the purpose of enhancing sexual prowess and performance.
- The skull of a human built into the foundation of a new building will ensure good business.
- The hands, or parts of the hand such as the fingers, are regarded as talismans that will assist in attracting many clients. It is also believed that ritual murderers can hypnotise their victims by showing them a human hand.
- Genitals and the placenta are often harvested for fertility spells.¹⁰¹

Most of the reasons cited above and elsewhere in this thesis seem to be motivated by greed and the desire for both personal and financial gain. This confirms the deeply held belief that *muti* solves problems and brings financial gain.¹⁰² The desire for financial gain also drives individuals to sell body parts harvested from humans while they are alive.

Roelofse, a criminologist, observes as follows:

> In many instances of privately initiated *muti* murders, the deeply held belief in *muti* to solve problems as well as financial gain by selling body parts, drive individuals to commit

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It has been understood from researching this thesis that the majority of murders of persons with albinism are committed for muti purposes. As opposed to human sacrifice where the purpose of the murder is death, in muti related killings it is possible that death is an unintended result of the harvesting of albino organs since it is frequently considered ideal that the victim remain alive during the harvesting procedure. The assumption is that when body parts are harvested while the victim is still alive, the power of the resulting medicine is extensively boosted. Referring to victims of muti murder in South Africa, Carstens explains that death caused by the harvesting of body parts is the result of victims dying during or after the procedure as a result of pain, haemorrhages and surgical shock.

The nature of these killings is brutal. Knives and machetes are the objects reportedly used to cut off limbs, breasts and other body parts from the helpless screaming victims. Some albinos have been beheaded and their heads circumspectly cut and preserved as gruesome good luck charms or for use in rituals. There is clearly no space for the age old concept of humanness, Ubuntu, in such violent behaviour. These brutal murders are in conflict with the principle of Ubuntu since they fail to honour the primary Ubuntu values of life and human dignity. It is self-evident that there is no dignity in dying this way.

While specific attacks on albinos seem to be a fairly new phenomenon in certain African countries, the muti trade in general has always existed as a clandestine practice in South Africa and this severely and unjustifiably undermines the rights of certain members of society to life and to freedom and security of the person.

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107 Le Roux at http://www.isrcl.org/Papers/LeRoux.pdf (visited 22 July 2015). Le Roux defines Ubuntu as a culture in which communality and the interdependence of the members of a community are emphasised. An outstanding feature of Ubuntu is the value it puts on life and human dignity. The notion that the life of another person is at least as valuable as one’s own, is emphasised.
4.4 Unfair discrimination of persons with albinism under constitutional scrutiny

Section 9 of the Constitution does not include health status as a ground for protection against unfair discrimination. However, in the ground breaking case of Hoffmann v South African Airways the court ruled that unfair discrimination on the basis of HIV status encroaches on constitutional prohibitions in terms of unfair discrimination, despite the fact that the ground is not specifically stipulated. The court construed HIV status to be a prohibited ground of discrimination under the South African Constitution, despite it not being one of the prohibited grounds of unfair discrimination listed under section 9(3). This decision entailed an interpretation of the equality clause.

At a minimum, reasonableness entails that the limitation of a right must serve some important purpose. The reasons for the limitation of the right in question have to be worthwhile and important in a constitutional democracy. The close analysis conducted in this study shows that unfair discrimination against persons living with albinism is a consequence of lack of education and poor understanding of the medical facts behind the condition.

Referring to HIV, Judge Ngcobo notes that:

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108 Section 9 of the Constitution of 1996 reads as follows:
“9(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.
(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.
(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.
(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.
(6) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.”

109 Hoffmann case, paragraphs [39]; [40]; and [41].

110 Hoffmann case, paragraphs [40]; and [41].

111 Hoffmann case, paragraph [22].

Rautenbach IM "Policy and Judicial Review – Political Questions, Margins of Appreciation and the South African Constitution" (2012) 1 Tydskrif vir die Suid-Afrikaanse Reg 20-34 at 32.

The same can be said about albinism. Much of the intolerance towards persons with albinism is due to general ignorance about the condition. Fear of the unknown, exacerbated by minimal contact with albinos, continues to fuel the harmful cultural beliefs, stereotypes and false perceptions that surround albinism. This perhaps explains why albinism is believed to be a secret condition, despite its obviousness. As a result of fear and ignorance, this group of people is isolated from the rest of society, which contributes to the perpetuation of existing myths, stereotypes and false perceptions regarding the condition. Persons living with albinism generally keep a low social profile out of fear that they may be harmed.

In the *Hoffmann* case, Judge Ngcobo made the following remark about harmful stereotypes:

> Our constitutional democracy has ushered in a new era – it is an era characterised by respect for human dignity for all human beings. In this era, prejudice and stereotyping have no place.\(^\text{115}\)

In his thesis entitled, *The Selfless Constitution: Experimentation & Flourishing as the Foundations of South Africa’s Basic Law*, Woolman notes the following:

> Imagine, for example, that your reflections on the cruelty perpetrated on people of color by discriminatory laws have led you to subscribe to principles of racial equality. Yet, adopting those beliefs, even if secretly, would clash with your previous identity as a member of a community that accepts its privileged position as a deserved entitlement. Accepting the new belief requires you not only to give up previously-held racist notions, but also to reject a host of other intertwined beliefs and relationships. The difficulty of changing one’s beliefs is compounded when one seeks to change one’s behavior on account of a change in beliefs. Recent social psychology scholarship illustrates that because our modes of behavior in relating to others are mediated through subconscious stereotypes, simply changing our conscious, overt beliefs about racism or class-based discrimination is often insufficient to eliminate patterns of behavior that result in racially or class-based discriminatory outcomes, such as avoiding areas with

\(\text{114}\) *Hoffmann* case, paragraph [28].

\(\text{115}\) *Hoffmann* case, paragraph [28]. A person who alleges unfair discrimination has to prove that such differentiation is likely to impair their dignity. The burden of proving that dignity is likely to be impaired is not an easy one, as illustrated by the following cases: *Jordan & Others v S* 2002 (6) SA 642 (CC); and *Volks NO v Robinson & Others* 2005 (5) BCLR 446 (CC). McConnachie C provides a brilliant discussion on the courts’ approach to human dignity in his article entitled “Human dignity, ‘Unfair Discrimination’ and Guidance” (2014) 34 (3) *Oxford Journal of Legal Studies* 609–629 at 609-629. McConnachie criticises Justice Ackermann’s view that a profound reflection on and understanding of human dignity can provide South African courts with clear guidance in ascertaining what constitutes unfair discrimination.
large number of poor residents... To successfully combat the effects of existing patterns of discrimination requires both individual reflection, changes in belief and gradual alterations in the patterns of social practices.\textsuperscript{116}

Woolman demonstrates how folk-psychology descriptions of the self and the social obstruct a better understanding of who we are as human beings.\textsuperscript{117} He attacks the principles of folk-psychology that continue to control our descriptions of the self, the social and the political with the hope that, by undermining folk psychology, an incorrect explanation of the self, the social and the political, we may perhaps attain a ‘better understanding of who we are and what we need to do’. \textsuperscript{118}

Chapter one of this thesis highlights the role of the media, and particularly popular culture as a medium of communication in aggravating existing stereotypes and myths about albinism by portraying the oculocutaneous albino as a villainous character who is out of the ordinary, mystical and cruel.\textsuperscript{119} Such stereotyping of and prejudice against vulnerable members of society is an assault on their dignity and poses a direct threat to their right to equality.

Albinism-related stigma and discrimination adversely affects the exercise of practically every human right, not only the right to be free from discrimination. The

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\textsuperscript{116} Woolman SC “The Selfless Constitution: Experimentation & Flourishing as the Foundations of South Africa's Basic Law” 2007 Thesis submitted in fulfilment of the requirements for the Degree Doctor of Law in the College of Law at the University of Pretoria 1-319 at 112.
\textsuperscript{117} Woolman “The Selfless Constitution: Experimentation & Flourishing as the Foundations of South Africa's Basic Law” 266.
\textsuperscript{118} Woolman “The Selfless Constitution: Experimentation & Flourishing as the Foundations of South Africa's Basic Law” 266.
\textsuperscript{119} In the modern capitalist world, the mass media have become a major source of popular culture. The media do not merely entertain and inform, they also convey the stereotypes, beliefs and values of the general public to create the existing order of social life. In his theory of ideological state apparatuses, Louis Althusser states that schools and families, as well as religions, play the role of ideological state apparatuses which imperceptibly teach and transmit the leading “hegemonic ideology” of society into the minds of people in order to be able to control them. Gataullina adds the media to this list as yet another Althusserian ideological apparatus which directs the minds of the masses in the contemporary capitalist world. What is manufactured by the media, i.e. popular culture, typifies the way in which people live. Popular culture needs to be on a level that people can understand. See Gözdem A & Tüzün G “Popular Culture, Mass Media and the Spatial Perception” Paper Presented at the 42\textsuperscript{nd} International Society of City Regional Planners (ISoCaRP) Congress, 2006, 1-5 at 3; Schneider DJ The Psychology of Stereotyping (2004, New York: The Guilford Press) at 351; Fourie PJ Media Studies, Media History, Media Society (2007, Cape Town: Juta) at 133; and Mswela MM “The Evil Albino Stereotype in Film: An Impediment to the Right to Equality” (2013) 32 (1) Medicine and Law 79-93 at 79-93. Also see Lily Gataullina “Stereotypes in Media” at http://serendip.brynmawr.edu/local/scisoc/sports03/papers/lgataullina.html (visited 27 August 2015).
\end{flushright}
rights to privacy, health, freedom of movement, education, housing, freedom from inhuman or degrading treatment, life, liberty and security are also affected.

The most effective way of addressing discrimination against persons living with albinism is to ensure that the condition is properly understood. Schools, community centres and other avenues should be used to educate communities about the causes of albinism and how the condition can be managed to the maximum benefit of persons living with albinism. While the harmful effects of ignorance about the condition have been clearly illustrated above, being valued and appreciated as a “whole person” is the basis for a lifetime of self-esteem and personal strength.\(^{120}\)

4.5 Conclusion

While chapter three discusses the internal limitations clause analysis in the context of socio-economic rights, this chapter focuses on the specific aspects of the general limitation clause, namely whether a limitation pursues a legitimate aim, whether a limitation is capable of realising its aim, whether an action limits a right, and the balancing stage which determines whether the objective of the limitation outweighs the limitation imposed. This constitutional scrutiny exercise has focused particularly on the right to life and the right to equality. It is clear from the discussion above that the right to life and the right to equality cannot be limited unreasonably and unjustifiably. The brutal and indefensible murder of persons with albinism remains irrational and fails to value life and human dignity, while unfair discrimination against persons with albinism remains unjustifiable.

\(^{120}\) Owen IR Talk, Action and Belief: How the Internality Model Combines Attachment-Oriented Psychodynamic Therapy and Cognitive Behavioural Therapy (2009, Bloomington: iUniverse) at 14; 61; 189; and 335.
CHAPTER 5: ALBINISM AND DISABILITY: A COMPARATIVE ANALYSIS

“It is of little solace to a person denied employment to know that the employer's view of his or her condition is erroneous. To such a person, the perception of the employer is as important as reality”.¹

PART I

5.1 Contextual background and significance of the chapter

The question of whether albinism is classified as a disability or not is a controversial legal one that does not always have a straightforward answer. A literature search indicates that in South Africa no comprehensive and analytical study has been carried out on the subject of albinism and disability. This chapter anticipates addressing this gap within a legal perspective. The objective of such an analysis is to understand whether people with albinism qualify for the protection which is afforded to people with disabilities; eligibility for governmental programmes and eligibility for protection by legislation. Such an analysis is also of interest since it has fundamental implications for measuring the prevalence of disability.

Following an inquiry into the status of people with albinism in South Africa by the United Nations High Commissioner for Human Rights in Geneva, the South African Human Rights Commission responded as follows:²

In South Africa, persons with albinism are considered as persons with disabilities. In many communities within South Africa, disability is still generally seen as an illness, shame or curse despite the fact that both section 9 of the Constitution, Act No. 108 of 1996 and the Promotion of Equality and Prevention of Unfair Discrimination Act, No. 4 of 2000, prohibit unfair discrimination on the basis of disability.

No reasons have been brought forward to explain the South African Human Rights Commission’s classification of albinism as a disability, and this classification has resulted in uncertainty regarding the status of persons with albinism in South Africa.³

¹ EE Black Ltd v Marshall 497 F. Supp. 1088, paragraph [1098].
Early this year, the Acting Assistant Labour Commissioner of Swaziland, Stukie Motsa, who herself lives with albinism, came down hard on the countries classification of people with albinism under the disability category and commented that the classification was unwarranted because persons with albinism are not disabled. In her own words:

I personally think it is wrong for people with Albinism to be classified as People with disabilities because they are not. They are just normal people and should be treated this way. They are just ill-placed in this category.

A pocket guide on disability equity in South Africa states that although albinism does not amount to a disability per se, persons living with albinism associate themselves with disabled people for the reason that they face the same discrimination. This view is also found in the Ekurhuleni Metropolitan Municipality’s Policy Guidelines for People with Disabilities. It is apparent that there is evidence of ambiguity around the status of people with albinism in terms of disability. In the discussion that follows, the

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5 Ntiwane at http://www.observer.org.sz/news/69308-albinism-classification-is-discriminatory.html (visited 19 September 2015). Kenya has taken steps to improve the lives of people with albinism including the ongoing effort to explicitly include albinism in its laws on disability. In 2010, persons living with albinism in Kenya submitted a petition to Parliament, requesting that:
(1) they be categorised as persons with a disability;
(2) changes be made to the current Kenyan Disability Act or a specific Act drafted to provide for the needs of persons living with albinism; and
(3) accessibility, as well as affordability, of sunscreen lotions be guaranteed.
This appeal was well-received and subsequently handed over to the Department of Justice and Constitutional Affairs. The Committee for Equal Opportunities in Kenya has been tasked with following up and implementing the matter. At the writing of this thesis no further information was available regarding progress in the implementation of this appeal. The ongoing determinations to amend the definition of disability in the current Persons with Disability Act (2003) so as to include persons with albinism are being done for the purpose of requiring reasonable accommodation of persons with disabilities in key locations such as schools and the workplace. See Albinism Society of Kenya “Human Rights of Persons with Albinism” at https://www.google.co.za/url?url=https://uprdoc.ohchr.org/uprweb/downloadfile.aspx%3Ffilename%3D1483%26file%3DEnglishTranslation&rct=j&frm=1&q=&esrc=s&sa=U&ei=834IVdfiOcG6Ub6RgcAK&ved=0CB0QFjAA&usg=AFQjCNEuYdGnvM3fUer7-FVVXuqzYfW7A (visited 10 October 2015).

6 Disabled People of South Africa, Parliamentary Office 1st ed, Pocket Guide on Disability Equity, December 2000. The guide on disability equity further states that albinos routinely develop visual disabilities that affect their participation in life activities.

thesis examines the relevant legislative framework regulating disability in South Africa in the context of albinism. To turn a blind eye to comparative law and international human rights law when writing on a matter that is inherently a global human rights phenomenon, would be to neglect one’s constitutional duty. Foreign case law and international human rights law could shed new light on this longstanding grey area or stimulate the development of novel legal analytical strategies.

Part I of this chapter is a comparative analysis which specifically explores whether albinism is considered a disability in South Africa and in the United States of America. In South Africa, the current working definition of disability stems from the IMATU & Another\(^8\) case which relied significantly on a foreign precedent; the Sutton v United Airlines\(^9\) case. This definition constitutes an extremely narrow concept of disability.\(^10\) It will be argued that the Sutton v United Airlines decision, referred to by our courts, is based on an insufficiently inclusive definition of disability. Specific cases that relied on the Sutton v United Airlines decision as a persuasive authority in determining whether albinism is a disability or not, will also be examined. While the United States of America has struck down the decision in the Sutton v United Airlines and amended its legislation to include a broader and less restrictive definition of disability, which includes present as well as past conditions and a subjective component of perceived disability,\(^11\) the South African definition of disability still remains narrow and less inclusive. The United States of America’s amended legislation does not contain an exhaustive definition of disability; rather, an equality-based framework was chosen which considers changing biomedical, social and technological developments.\(^12\) Such a framework of disability includes a socio-political aspect which places emphasis on human dignity, respect and the right to

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\(^8\) IMATU & Another v City of Cape Town 2005 (11) BLLR 1084 (LC) 1091 (hereinafter referred to as the IMATU & Another case).
\(^12\) Bryan WV Socio-Political Aspects of Disabilities (2010, Illinois: Charles Thomas) at 5-17.
equality.\textsuperscript{13} As a result, a physical limitation, a condition, a perceived disability or a combination of these, can be defined as a disability. Against this background, the comparative analysis raises specific issues that deserve attention, in particular that the unique disadvantages and negative stereotyping suffered by people with albinism should be recognised as unlawful conduct against people with disabilities as defined by legislation. Put differently, the discussion calls for a broader approach that includes both a social and a human rights perspective.

There have been several calls by people with albinism for access to the Disability Grant.\textsuperscript{14} Part II of this chapter examines whether persons with albinism qualify for a grant under the South African Social Assistance Act.\textsuperscript{15}

### 5.2 The legislative framework regulating disability in South Africa

South Africa does not have centralised disability legislation prescribing the basis on which a person can claim to be disabled. Rather, there are diverse policies and legislation regulating disability matters.\textsuperscript{16}

Since the dawn of democracy in South Africa, the situation with regard to disabled people has changed very little apart from a few modifications to legislation.\textsuperscript{17} Disabled persons are protected in the Constitution against unfair discrimination. The Constitution provides the framework for non-discrimination against people with disabilities.\textsuperscript{18} Legislation such as the Promotion of Equality and Prevention of Unfair

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\textsuperscript{13} Brayn 5-17 and 215-252.
\textsuperscript{15} Social Assistance Act 13 of 2004.
\textsuperscript{16} These are, for example, the Social Assistance Act 13 of 2004 (hereinafter referred to as the Social Assistance Act); the Employment Equity Act 55 of 1998 (hereinafter referred to as the Employment Equity Act); and the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (hereinafter referred to as the Promotion of Equality and Prevention of Unfair Discrimination Act) which specifies disability as a ground of discrimination but does not define what disability means.
\textsuperscript{17} Department of Local Government, Disability Framework for Local Government, 2009-2014, 1-59 at 16.
\textsuperscript{18} Section 9 of the Constitution of the Republic of South Africa, 1996 (hereinafter referred to as the Constitution of 1996) reads as follows:
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Discrimination Act, the Employment Equity Act and the Labour Relations Act,\(^{19}\) give effect to section 9 of the Constitution which provides for the enactment of national legislation to prevent unfair discrimination and promote the achievement of equality among all people, including those with disabilities. Such legislation exists to enable progress towards a democratic society that is integrated in its diversity and manifested in relationships that express care and concern for disabled people.\(^{20}\) These statutes are guided by the constitutional principles of equality, fairness, equity, social progress, justice, human dignity and freedom.\(^{21}\)

The way in which we think about equal opportunities in the context of disability is inextricably linked to how disabled people are categorised as a protected class.\(^{22}\) Defining who qualifies as a disabled person is a challenge, since disability in itself is a contested concept, comprising “very fluid or porous boundaries”.\(^{23}\) There is no agreed upon general standard for establishing who qualifies under the protected class of disability for the purposes of non-discrimination.\(^{24}\) Cases of racial, sex or gender discrimination are easily identifiable in the sense of determining whether a petitioner falls in the protected class.\(^{25}\) The distinctive attributes of race, such as

\(^{(2)}\) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken.\(^{19}\)

\(^{(3)}\) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.\(^{20}\)

\(^{(4)}\) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.\(^{21}\)

\(^{(5)}\) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.” Also see Department of Local Government, *Disability Framework for Local Government*, 2009-2014, 1-59 at 21.

\(^{19}\) Labour Relations Act 66 of 1995.


\(^{21}\) Degener 152. Also see Department of Local Government, *Disability Framework for Local Government*, at 10; 11; 15; and 20.

\(^{22}\) Dupper O & Garbers C *Equality in the Workplace: Reflections from South Africa and Beyond* (2009, Cape Town: Juta) at 189.

\(^{23}\) Dupper & Garbers 189.


\(^{25}\) Dupper & Garbers 189. See for example, *Minister of Finance and Other v Van Heerden* 2004 (6) SA 121 (CC); *City Council of Pretoria v Walker* 1998 (2) SA 363; *Lesbian and Gay
phenotype, or sex or gender which distinguish between the biologically defined male and female, are generally regarded as readily ascertainable and determinative.\textsuperscript{26} Disability, in contrast, is not, and has been treated in different ways by the legislature.\textsuperscript{27}

There is no common legal definition of what “disability” is.\textsuperscript{28} When investigating unfair discrimination based on disability, the outcome of each case will depend on the context within which it occurs.\textsuperscript{29} Section 9 of the Constitution, which was discussed in detail in chapter 3, affords persons with disability constitutional protection against unfair discrimination. However, the South African Constitution provides no framework for the definition of disability.\textsuperscript{30} It merely lists disability as a ground for protection from

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\textit{Equality Project and Eighteen Others v Minister of Home Affairs 2006 (1) SA 524 (CC); The Sex worker Education and Advocacy Taskforce v Minister of Safety and Security and Others 2009 (6) SA 513 (WCC); and President of the Republic of South Africa and Another v Hugo 1997 (4) SA 1 (CC).}
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\textit{Dupper & Garbers 189.}
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\begin{flushright}
\textit{Dupper & Garbers 189. The definition of disability under the Social Assistance Act will be discussed in part II of this chapter (within the context of the social security grant which is offered to people with disabilities). The Social Assistance Act recognises a person with a disability as a person who, owing to a physical or mental disability, is unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance. In the Employment Equity Act, disability is defined in terms of the capability of the disabled person to be usefully employed. The South African Revenue Services has shed additional light on the legal definition of disability. Section 18(3) of the Income Tax Act 58 of 1962 defines the term disability at length as a moderate to severe limitation of a person’s ability to function or perform daily activities as a result of physical, sensory, communication, intellectual or mental impairment, if the limitation – (a) has lasted or has a prognosis of lasting more than a year; and (b) is diagnosed by a duly registered medical practitioner in accordance with criteria prescribed by the Commissioner. The Commissioner for SARS set out a prescribed form (ITR-DD Confirmation of Diagnosis of Disability for the purposes of the Income Tax Act) which explores vision, hearing, communication or speech, physical, intellectual and mental disability. This form also indicates what is considered to be disability in each of the previously stipulated areas. The Mental Health Care Act 17 of 2002 defines a severe or profound intellectual disability as meaning “a range of intellectual functioning extending from partial self-maintenance under close supervision, together with limited self-protection skills in a controlled environment through limited self-care and requiring constant aid and supervision, to severely restricted sensory and motor functioning and requiring nursing care”. See also Bick L “South Africa: Definitions of Disability and the 2011 Census” at http://www.mondaq.com/x/147254/Arbitration+Dispute+Resolution/Definitions+Of+Disability+And+The+2011+Census (visited 10 September 2015).}
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\textit{Renteln 62.}
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\textit{IMATU & Another case, paragraph [22]}
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unfair discrimination.\textsuperscript{31} In the \textit{Hoffmann} case, there was a challenge to engage the Constitutional Court on the definition of disability as a listed ground. \textsuperscript{32} The courts refused to provide a definition since it was able to decide the case on an analogous ground. The present working definition of disability in South Africa derives from the interpretation of the Employment Equity Act.\textsuperscript{33}

5.3 Disability as an insufficiently inclusive concept under the Employment Equity Act 55 of 1998

The Employment Equity Act is designed for the implementation of constitutional equality in the workplace and to regulate disability in two major ways. Firstly, similarly to the Constitution, the Employment Equity Act lists disability as one of the grounds for protection in section 6(1).\textsuperscript{34} Secondly, chapter 3 of the Act stipulates that disabled persons are part of the target groups for affirmative action.\textsuperscript{35} Persons with disabilities, as well as black persons and women, are advanced by affirmative action.\textsuperscript{36}

The Employment Equity Act\textsuperscript{37} defines disabled persons as:

\begin{quote}
people who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into, or advancement in, employment.
\end{quote}

It is clear that this definition of disability is centered on the actual existence of an impairment and on the degree of impairment.\textsuperscript{38} To qualify under the protected class,

\begin{enumerate}
\item[Dupper & Garbers 189. Also see the \textit{Hoffmann v South African Airways} 2001 (1) SA 1 (CC) (hereinafter referred to as the \textit{Hoffmann} case).]
\item[Hoffmann case, paragraph [40].]
\item[Hoffmann case, paragraph [40].]
\item[Section 6(1) of the Employment Equity Act reads as follows: “(1) No person may unfairly discriminate, directly or indirectly, against an employee, in any employment policy or practice, on one or more grounds, including race, gender, sex, pregnancy, marital status, family responsibility, ethnic and social origin, color, sexual orientation, age, disability, religion.”]
\item[Chapter 1 of the Employment Equity Act defines designated groups as black people, women and people with disabilities who are citizens of the Republic of South Africa either by birth or descent, or became citizens of the Republic of South Africa by naturalization before 27 April 1994 or after 26 April 1994 and who would have been entitled to acquire citizenship by naturalization prior to that date but were precluded by apartheid policies. Section 13 of the Employment Equity Act stipulates that a designated employer must implement affirmative action measures for designated groups to achieve employment equity.]
\item[Dupper & Garbers 189.]
\item[Section 1 of Employment Equity Act.]
\item[Dupper & Garbers 189.]
\end{enumerate}
such impairment ought to cause significant restriction in the competence required to carry out the inherent purpose of the job.\textsuperscript{39} The definition is based on the consequences of the impairment, in that it has to limit the complainant’s admission into, or progression in, employment.\textsuperscript{40}

\textbf{5.3.1 Standard Bank of South Africa v Commission for Conciliation, Mediation and Arbitration and Others}

In the case of \textit{Standard Bank of South Africa v Commission for Conciliation, Mediation and Arbitration and Others},\textsuperscript{41} Deirdre Ferreira, who had worked for Standard Bank for 17 years, sustained injuries in a motor accident whilst on duty. She developed back pain and was later diagnosed with fibromyalgia. The court had to determine on review whether Standard Bank rightfully dismissed Ferreira and whether the compensation awarded to Ferreira was reasonable. The \textit{Standard Bank} case emphasises that the Constitution protects employees with disabilities as a vulnerable group, as they are a minority with attributes that are different from mainstream society.

It was also held in the same case that the primary inquiry in an incapacity examination is whether a person’s disability is a long-term recurring physical or mental impairment that significantly restricts the person’s prospects of admission into, or progress, in employment.\textsuperscript{42} Defining disability in the employment context shifts the consideration from the diagnosis of the disability to the consequences of the disability for both the employee’s capability to work as well as their ability to find work.\textsuperscript{43}

Despite the fact that this is a rational definition in terms of affirmative action, it is excessively restrictive for non-discrimination purposes as it misses the rationale for addressing disability-related discrimination. The central limitation of such a definition is that it does not take cognisance of the fact that many disabled people are not

\begin{itemize}
\item \textsuperscript{39} Section 1 of the Employment Equity Act. Also see Dupper & Garbers 189.
\item \textsuperscript{40} IMATU & Another case, paragraphs [89-90].
\item \textsuperscript{41} \textit{Standard Bank of South Africa v Commission for Conciliation, Mediation and Arbitration and Others} (2008) 4 BLLR 356 (LC) (hereinafter referred to as the \textit{Standard Bank} case).
\item \textsuperscript{42} \textit{Standard Bank} case, paragraph [58].
\item \textsuperscript{43} \textit{Standard Bank} case, paragraph [58].
\end{itemize}
severely impaired or that they manage these impairments to the extent that they no longer require protection from unfair discrimination.44

5.3.2 IMATU & Another v City of Cape Town

In the groundbreaking case of IMATU45, the meaning of disability as contained in section 6 of The Employment Equity Act was construed very narrowly. This case concerns a complex but significant question relating to whether the City of Cape Town’s imposition of a blanket ban on the employment of diabetics as fire-fighters amounted to unfair employment discrimination.46 In this case, a law enforcement officer working for the Cape Town City Council applied to be transferred to the firefighting unit.47 He was turned down because it was believed that his diabetes (an illness that can result in a coma) could be dangerous to himself and others.48 The plaintiff claimed that in his thirteen years as a voluntary firefighter, his diabetes had never endangered anyone’s life.49 He further argued that he was no more of a risk than other employees who could suffer from unexpected strokes, embolisms or fits.50 Statistics show that diabetics are employed in emergency services around the world.51

The court held that the onus was on the employer to prove that its policy of a blanket ban on insulin-dependent diabetics was not discriminatory.52 In the court’s view, the employer was unable to supply this proof.53 The court further held that the employee’s condition did not constitute a disability in terms of the Employment Equity Act54 but the employee’s dignity had nonetheless been negatively affected which meant there was unfair discrimination.55 The employer was also unable to persuade the court that its policy on diabetes sufferers was based on the inherent

44 Dupper & Garbers 195.
45 IMATU & Another case, paragraphs [89-91]; and Dupper & Garbers 195.
46 IMATU & Another case, paragraph [1].
47 IMATU & Another case, paragraph [8].
48 IMATU & Another case, paragraphs [8-11].
49 IMATU & Another case, paragraph [20].
50 IMATU & Another case, paragraph [65].
51 IMATU & Another case, paragraph [52].
52 IMATU & Another case, paragraph [81].
53 IMATU & Another case, paragraph [112].
54 IMATU & Another case, paragraphs [91-92].
55 IMATU & Another case, paragraphs [92-93].
requirements of the job.\textsuperscript{56} The court concluded that the employer’s policy generalised unnecessarily and unfairly and that diabetes sufferers should be tested individually to establish whether they are fit for certain jobs.\textsuperscript{57}

As an expert witness in this case, Professor Bonnici testified that Type 1 diabetes is a long-term physical impairment.\textsuperscript{58} There is no cure for it and it is a lifetime disease. People who suffer from Type 1 diabetes are dependent on insulin that has to be self-administered or administered by others for the rest of their lives.\textsuperscript{59} They cannot function without it, and will in fact die if they do not receive insulin.\textsuperscript{60} There is therefore no doubt that Type 1 diabetes is a long-term physical impairment. The Respondent’s expert witness, Dr Carstens, confirmed this.\textsuperscript{61}

However, in the court’s opinion the matter did not end there. Item 5.1 of the Employment Equity Act requires that before being classified as a person with disabilities, an applicant must satisfy all the criteria in the definition. Hence, in addition to showing a long-term physical impairment, applicants need to show that such impairment substantially limits their prospect of entry into or advancement in employment. In terms of item 5.1.3(i), an impairment is substantially limiting if, in its nature, duration or effects, it substantially limits the person’s ability to perform the essential functions of the job for which they are being considered. Cognisance was taken of subsection (ii) of item 5.1.3 as some impairments are easily controlled, corrected or lessened to the point that they have no limiting effects. For example, a person who wears spectacles or contact lenses does not have a disability, unless the person’s vision is substantially impaired even with spectacles or contact lenses. Consideration must be given to the medical treatment or devices which could control or correct the impairment so that its adverse effects are prevented or removed. The court’s finding accords with the view that diabetics have of themselves, as many prefer not to be stigmatised as “disabled”.

\textsuperscript{56} IMATU & Another case, paragraph [119].
\textsuperscript{57} IMATU & Another case, paragraph [98].
\textsuperscript{58} IMATU & Another case, paragraph [107].
\textsuperscript{59} IMATU & Another case, paragraph [107].
\textsuperscript{60} IMATU & Another case, paragraph [107].
\textsuperscript{61} IMATU & Another case, paragraph [107].
The court was of the view, particularly in the light of the medical evidence, that fast-acting, analogue insulin controls or corrects the long-term physical impairment, diabetes mellitus, so that its adverse effects in the working environment are significantly reduced or disappear entirely. Indeed, that was the applicant’s case. It follows that although diabetes mellitus can be accurately described as a long-term impairment, a person who suffers from this ailment is not regarded as a person with a disability under the Employment Equity Act. According to the court, the plaintiff lived a normal life apart from his medication regime, and there was no substantial limitation of his ability to carry out tasks.\textsuperscript{62} The applicant therefore did not fall within the definition of “people with disabilities” in the Code of Good Practice.

In the \textit{IMATU} case, the court took a foreign precedent; \textit{Sutton v United Airlines}, as credible and persuasive authority.\textsuperscript{63} The court noted as follows:

\begin{quote}
My finding in this regard, I would venture, accords with the view taken by diabetics of themselves. Many surely would prefer not to be stigmatised by the brand “disabled”. A similar conclusion was reached by the US Supreme Court in \textit{Sutton v United Airlines Inc} 527 US 471 (1999) which held that the determination of whether an individual is disabled under the ADA Disability Standard requires consideration of the individual’s impairment in its mitigated, or medicated state.\textsuperscript{64}
\end{quote}

The \textit{Sutton v United Airlines} case was decided by the United States of America Supreme Court under the Americans with Disabilities Act of 1990. The definitional construct of disability under the Americans with Disabilities Act of 1990 will be explored next in order to provide a meaningful understanding of disability in the American context as well as a better understanding of the American courts’ normative responses to disability discrimination claims.

\begin{footnotes}
\item[62] \textit{IMATU & Another} case, paragraph [91].
\item[63] \textit{IMATU & Another} case, paragraph [98].
\item[64] \textit{IMATU & Another} case, paragraph [91].
\end{footnotes}
5.4 The legal interpretation of disability under the Americans with Disabilities Act of 1990: A case study

5.4.1 Sutton v United Airlines

The Americans with Disabilities Act of 1990 contains a three-pronged approach to the definition of disability which has been retained in the Americans with Disabilities Amendment Act:

The term disability means, with respect to an individual:
(A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
(B) a record of such an impairment; or
(C) being regarded as having such an impairment (as described in paragraph(3)).

The first component of this definition of disability refers to a physical or mental impairment that substantially limits one or more major life activities of an individual, while the second component refers to a record of such impairment. In addition, the definition provides for the protection against discrimination of individuals who are regarded as having an impairment. An individual can therefore be covered by the definition of disability in three ways.

In the case of Sutton v United Airlines, the court considered the application of the third component of this definition of disability. The United States Supreme Court found that the determination of “disability” under the Americans with Disabilities Act of 1990 requires an inquiry into any mitigating or corrective measures. The case focused on the question of whether the determination of disability under the Americans with Disabilities Act should be made with consideration of any corrective measures for the impairment. The key question was whether the appellants, the twin Sutton sisters who suffered from severe myopia, had been unfairly discriminated against in being refused positions as global airline pilots for a major commercial

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65 Section 4 of the Americans with Disabilities Amendment Act of 2008.
66 Lawrence & Gostin 2232.
67 Sutton case, paragraph [68].
68 Sutton case, paragraph [1].
The sisters met the stipulated employment criteria such as age, education, experience and FAA certification.\textsuperscript{69}

Subsequent to the submission of their applications, United Airlines invited the sisters to attend interviews and to take the relevant flight simulator tests,\textsuperscript{71} but when they arrived they were told that there had been a mistake because they did not meet the airline’s minimum vision requirement. The minimum requirement specified by the employer and accepted as an inherent requirement for the job was 20/100 uncorrected visual acuity or better.\textsuperscript{72} The sisters failed to meet this requirement for the reason that they both had visual acuity of 20/200 or less in the right eye and 20/400 or less in the left eye, although their corrected visual acuity was 20/20 or better.\textsuperscript{73}

The discrimination claim brought by the sisters was dismissed because it failed to state a claim upon which relief could be granted.\textsuperscript{74} The court noted that the plaintiffs were not actually and substantially limited in any major life activity since their vision impairments could be fully corrected.\textsuperscript{75} The court further noted that their claim did not specify that they were disabled in the meaning of the Americans with Disabilities Act and that there was insufficient allegation that the airline regarded the sisters as having an impairment that substantially limits a major life activity. Their claim only alleged that the airline regarded them as incapable of meeting the specific job requirements.\textsuperscript{76}

The judge noted that that the Americans with Disabilities Act did not define what is meant by “substantially limits”, and that this could be achieved through consulting dictionaries as well as turning to the interpretive guidance of the Equal Employment Opportunity Commission (EEOC).\textsuperscript{77}

\textsuperscript{69} Sutton case, paragraphs [1-6].
\textsuperscript{70} Sutton case, paragraph [4].
\textsuperscript{71} Sutton case, paragraph [4].
\textsuperscript{72} Sutton case, paragraph [4].
\textsuperscript{73} Sutton case, paragraph [4].
\textsuperscript{74} Sutton case, paragraph [6].
\textsuperscript{75} Sutton case, paragraph [6].
\textsuperscript{76} Sutton case, paragraph [4].
\textsuperscript{77} Sutton case, paragraph [35].
The dictionaries suggest that “substantially” means something that is “considerable”, “specified to a large degree”, “ample” or of “considerable amount, quantity or dimensions”.

The judge also referred to the Equal Employment Opportunity Commission’s explanation of “substantially limits” in the following terms:

Significantly restricted in the ability to perform either a class of jobs or a broad range of jobs in various classes as compared to the average person having comparable training, skills, and abilities. The inability to perform a single, particular job does not constitute a substantial limitation in the major life activity of working.

On appeal, the Court of Appeals for the Tenth Circuit affirmed the District Court’s decision. Whilst the appellants were prohibited from being international pilots, there were a number of other jobs from which they were not excluded as they could still be employed as regional pilots or pilot instructors. It is apparent from this case that where a corrective measure allows a person to participate in the major life activity of working, it cannot be said that the person is substantially limited, notwithstanding the fact that the person could not perform a particular job without the corrective measure.

The discussion now turns to court cases in the United States of America that have specifically dealt with the question of whether albinism is a disability or not. The judges in these cases have treated the *Sutton v United Airlines* case as a persuasive authority in coming to their respective judgements.

### 5.4.2 Manz v Gaffney

In the *Manz v Gaffney* case, the plaintiff had ocular albinism and his disability claim was based upon this visual condition. The plaintiff was hired to work for the County in 1995. In 1997, he was tested for promotion to the position of “caseworker trainee” and scored 95 out of a possible 100 points in the promotion examination.

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78 *Sutton* case, paragraph [35].
79 *Sutton* case, paragraph [35].
80 *Sutton* case, paragraph [37].
82 *Manz* case, paragraph [211].
83 *Manz* case, paragraph [211].
Manz's complaint stated that he was interviewed for the caseworker trainee position on several occasions between November 1997 and March 1999 but was never offered the promotion. He also asserted that during the period in which he was interviewed for the job, the County hired fifty caseworker trainees. He claimed that the failure to promote him was based upon his disability, namely ocular albinism.

The plaintiff filed a Notice of Claim against the County in May 1998. In June 1998 he asked his supervisor for leave so that he could attend a meeting with a County attorney to discuss his disability discrimination claim. The plaintiff alleged that after the June 1998 meeting, he received a poor performance evaluation. According to the plaintiff, this evaluation as well as the failure to promote him that followed his filing of the Notice of Claim and the June 1998 meeting were acts taken in retaliation for his disability discrimination claim.

Manz had a driver's licence since 1994 and he stated that he was able to drive using an adaptive aid provided by his physician. The use of this corrective aid, together with his doctor's certification that he was able to see well enough to drive, allowed Manz to bypass the eye test which is required for all driver's license applicants. Manz attested that he could not see signs from afar and stated that if this turned out to be an on-the-job dispute, he would perhaps have to use binoculars. Manz also asserted that he was capable of reading although slowly. While observing that he had to be close to things than others, which they might easily see from further away, Manz did not experience any other visual limitation. He also submitted an affidavit detailing his limitations in the activities of hunting, watching television and reading. He emphasised that when hunting, he “sits in a deer stand and waits for the animal

84 Manz case, paragraph [211].
85 Manz case, paragraph [211].
86 Manz case, paragraph [211].
87 Manz case, paragraph [211].
88 Manz case, paragraph [211].
89 Manz case, paragraph [211].
90 Manz case, paragraph [211].
91 Manz case, paragraph [211].
92 Manz case, paragraph [211].
93 Manz case, paragraph [215].
94 Manz case, paragraph [215].
95 Manz case, paragraph [216].
96 Manz case, paragraph [216].
97 Manz case, paragraph [216].
to approach him." When watching television, he attested that he could only see "appropriate detail" if he sat no more than eight feet away from a four foot screen, that he could read only a section of a newspaper at a time due to eye fatigue, and that he required a magnifying device to read small print.99

Dr Marc Epstein, an ophthalmologist for the Plaintiff since 1992, pointed out that the plaintiff's corrected visual acuity was 20/60 but submitted that with the help of "telescopic magnification," he was able to see 20/20.100 Dr Epstein further stated that Menz had very little trouble driving with the exception of driving in environments with "extraordinarily bright lights", but could compensate for his problem by wearing sunglasses.101 Manz alleged that his vision constituted an impairment that limits the major life activities of seeing, reading, and driving.102

The defendant, the County, contended that the plaintiff was not disabled within the meaning of the Americans with Disabilities Act.103 This contention was backed up by the argument:

1) that Plaintiff did not suffer from a physical impairment and 2) that Plaintiff suffered no substantial limitation in the performance of any major life activity. In this regard it was argued that driving has been rejected as constituting a "major life activity" within the meaning of the ADA.104

The court found that the prerequisite that a plaintiff prove that a "major" life activity was affected by his impairment confirms that only important impairments are protected.105 The court further stated that major life activities are functions such as caring for oneself, performing manual tasks, seeing, hearing, speaking and breathing, while activities such as playing golf, shopping and executing household chores do not amount to major life activities.106

98 Manz case, paragraph [216].
99 Manz case, paragraph [216].
100 Manz case, paragraph [216].
101 Manz case, paragraphs [216-217].
102 Manz case, paragraph [212].
103 Manz case, paragraph [212].
104 Manz case, paragraph [212].
105 Manz case, paragraph [212].
106 Manz case, paragraph [212].
In answering the question of whether the plaintiff’s condition constituted a disability within the meaning of the Americans with Disabilities Act, the court noted that the plaintiff suffered from a "physical impairment" and that such impairment limited his ability to see, which is clearly a major life activity under the Americans with Disabilities Act.¹⁰⁷

The inquiry did not end there. A further question critical to the investigation of whether the plaintiff’s condition was a disability under the Americans with Disabilities Act, was whether the plaintiff was in fact “substantially” limited in the major life activity of seeing.¹⁰⁸ Persons who are substantially limited in major life activities are either incapable of performing such actions or significantly restricted as to the way in which or the length of time for which an activity can be performed.¹⁰⁹

In considering whether there is a substantial limitation, the court considered:

1) the nature and severity of the impairment,
   2) the duration or expected duration of the impairment, and
   3) the permanent or long term impact of the impairment.¹¹⁰

The individual analysis that is central to the substantial limitation inquiry also necessitates that the court consider the effect of corrective measures on the plaintiff’s condition.¹¹¹ This includes the use of devices such as eyeglasses, contact lenses and medication.¹¹² The body’s specific coping systems need to be considered when determining the extent of any limitation.¹¹³ The degree of improvement afforded by the use of such aids may lead to the conclusion that the impairment does not qualify as a substantial limitation of the major life activity as claimed.¹¹⁴ The substantial limitation question has to be deliberated on a case by case basis.¹¹⁵

Such individual inquiry bars a court from concluding that all people with a certain condition automatically suffer from a disability under the Americans with Disabilities

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¹⁰⁷ Manz case, paragraph [216].
¹⁰⁸ Manz case, paragraph [217].
¹⁰⁹ Manz case, paragraph [212].
¹¹⁰ Manz case, paragraph [212].
¹¹¹ Manz case, paragraph [214].
¹¹² Manz case, paragraph [214].
¹¹⁴ Manz case, paragraph [214].
¹¹⁵ Manz case, paragraph [217]; and Albertsons case, paragraphs [11-12].
Act.\textsuperscript{116} The court in this case noted that it is “insufficient” to come to a conclusion that several people with ocular albinism are substantially limited in their ability to see.\textsuperscript{117} Reasonably, the determination should be whether a specific plaintiff suffers from a considerable limitation in the ability to see.\textsuperscript{118}

The court in the \textit{Manz} case referred to the \textit{Albertsons} case where the Supreme Court noted that the visual impairment suffered by the plaintiff is suffered by a number of individuals in varying degrees.\textsuperscript{119} The court held that the plaintiff’s own testimony, as well as his doctor’s report were evidence that the plaintiff used a number of ameliorative devices to allow him to function.\textsuperscript{120} Spectacles and other visual aids made it possible for him to drive a car, read and perform his duties at work.\textsuperscript{121} The court held that the reasoning of the plaintiff’s doctor that the plaintiff’s vision was correctable to 20/20 and that such corrective measures were "artificial" 20/20, was meaningless, stating that

\[\text{every near-sighted person who wears eyeglasses has their vision "artificially" corrected to 20/20 while they remain myopic. Every person whose high blood pressure is "corrected" by the use of medication still suffers from hypertension. Similarly, Plaintiff has his vision artificially improved to 20/20 while still suffering from ocular albinism. Any distinction between a "real" and "artificial" correction is simply semantic.}\]

In light of the above, the court came to the conclusion that the plaintiff does not suffer from a disability within the meaning of the Americans with Disabilities Act and as a result dismissed the claim that he was discriminated against on the basis of a disability.\textsuperscript{123}

\begin{footnotes}
\item[116] \textit{Manz} case, paragraph [217]; and \textit{Albertsons} case, paragraphs [11-12].
\item[117] \textit{Manz} case, paragraph [217].
\item[118] \textit{Manz} case, paragraph [217].
\item[119] \textit{Manz} case, paragraph [217]; and \textit{Albertsons} case, paragraph [11].
\item[120] \textit{Manz} case, paragraph [217].
\item[121] \textit{Manz} case, paragraph [217].
\item[122] \textit{Manz} case, paragraph [217].
\item[123] \textit{Manz} case, paragraph [218].
\end{footnotes}
5.4.3 *Barta v Sears*

In the case of *Barta v Sears*,\textsuperscript{124} the plaintiff Nancy Barta, who suffers from albinism, brought an application to the court for determination whether she is a "disabled person" under the Americans with Disabilities Act.\textsuperscript{125}

On 7 October 1999, the plaintiff found a casual job as a replenisher at Sears, Roebuck and Co through the Virginia Department for the Blind and Visually Handicapped.\textsuperscript{126} She worked in the stockroom, unloading and packing commodities on the sales floor.\textsuperscript{127} On 21 March 2001, the defendant unilaterally changed the Plaintiff's job position from replenisher to sales associate.\textsuperscript{128} She worked in the ladies department of one of the defendant's stores from April 2001 until she resigned on 28 January 2002. On 1 July 2001, the defendant allegedly registered the plaintiff as disabled in the Accommodation and Leave Log.\textsuperscript{129}

In the spring of 2001, the plaintiff completed a standard assistant’s availability form wherein she specified her availability as 16 hours per week.\textsuperscript{130} Her available hours were allegedly limited by access to transportation.\textsuperscript{131} Part-time associates at the company were not guaranteed a minimum number of working hours per week, hence the scheduling of working hours was the obligation of the department or unit manager.\textsuperscript{132}

A sales associate’s duties include working with customers, helping them in product selection and concluding sales transactions, as well as restocking merchandise.\textsuperscript{133} Since the plaintiff reported herself as having a visual limitation, she was at no time obligated to use the cash register as part of her job as a sales assistant.\textsuperscript{134} The plaintiff contended that she informed a number of managers that she could not read the computer monitors and that the Department for the Blind and Visually

\textsuperscript{124} *Barta v Sears, Roebuck and Co*, 307 F. Supp. 2d 773 (E.D. Va. 2004) (hereinafter referred to as the *Barta case*), paragraph [778].

\textsuperscript{125} *Barta case*, paragraph [778].

\textsuperscript{126} *Barta case*, paragraph [776].

\textsuperscript{127} *Barta case*, paragraph [777].

\textsuperscript{128} *Barta case*, paragraph [777].

\textsuperscript{129} *Barta case*, paragraph [777].

\textsuperscript{130} *Barta case*, paragraph [777].

\textsuperscript{131} *Barta case*, paragraph [777].

\textsuperscript{132} *Barta case*, paragraph [777].

\textsuperscript{133} *Barta case*, paragraph [777].

\textsuperscript{134} *Barta case*, paragraph [777].
Handicapped could be approached to provide the defendant with whatever might be required for her to perform her job, such as a talking register, a bigger monitor or Zoom text loaded onto the computer.\textsuperscript{135} The plaintiff contended that the defendant turned down her proposal regarding free tools for the visually impaired,\textsuperscript{136} and she was not allowed to make use of the cash register as part of her job.\textsuperscript{137} She was also not offered store training on the use of the register.\textsuperscript{138}

The plaintiff's hours remained consistent until January 2002.\textsuperscript{139} The decrease in her working hours after that date, as well as the rationale behind the decrease were central to the plaintiff's discrimination claim under the Americans with Disabilities Act.\textsuperscript{140} The defendant claimed that the plaintiff and all other casual sales associates had their working hours decreased in January 2002.\textsuperscript{141} The plaintiff allegedly worked 45.5 hours in December 2001, but did not work at all for the first two weeks in January 2002 and was only scheduled for one day from 9:00 am to 12:30 pm in the entire month of January.\textsuperscript{142} Following an objection by Ms Jill Dewey, one of her managers, the plaintiff was allegedly allowed to work two further non-scheduled days during January.\textsuperscript{143}

The plaintiff asserted that Ms Dewey demanded that she undergo training on the computers and start using the sales registers. She again tried to explain her visual impairment to Ms Dewey, and the fact that supplementary aids were accessible through the Department for the Blind and Visually Handicapped.\textsuperscript{144} Ms Dewey refused to consider accommodating the plaintiff's condition and declared that the plaintiff would not be scheduled for work again until she took the computer training and learned to work the register.\textsuperscript{145} The plaintiff alleged that her direct manager tried to give her other unscheduled working hours, which Ms Dewey challenged.\textsuperscript{146}

\textsuperscript{135} Barta case, paragraph [777].
\textsuperscript{136} Barta case, paragraph [777].
\textsuperscript{137} Barta case, paragraph [777].
\textsuperscript{138} Barta case, paragraph [777].
\textsuperscript{139} Barta case, paragraph [777].
\textsuperscript{140} Barta case, paragraph [777].
\textsuperscript{141} Barta case, paragraph [777].
\textsuperscript{142} Barta case, paragraph [777].
\textsuperscript{143} Barta case, paragraph [777].
\textsuperscript{144} Barta case, paragraph [777].
\textsuperscript{145} Barta case, paragraph [777].
\textsuperscript{146} Barta case, paragraphs [777-778].
The plaintiff also alleged that at this stage she asked Ms Dewey to complete a rental calculation form for her landlord and Ms Dewey refused. The plaintiff resided in Section VIII housing partly funded by the Housing and Urban Development (HUD), and her monthly rent varied based on her monthly earnings.\textsuperscript{147} She had previously routinely had the form completed by supervisors at Sears, Roebuck and Co, and without the updated information for January 2002, her rent would be calculated based on the 45.5 hours she worked in December.\textsuperscript{148} The plaintiff alleged that she tried to explain her rental arrangements to Ms Dewey and again requested that she complete the form. Ms Dewey again declined.\textsuperscript{149}

On 28 January 2002, the plaintiff submitted a handwritten notice of resignation from her position with Sears, Roebuck and Co with immediate effect. She asserted that she resigned because she felt it was the only way to have her rent decreased by reporting her income.\textsuperscript{150} A charge of discrimination under the Americans with Disabilities Act was brought before the court and the court requested to determine whether the Plaintiff was a "disabled person" under the Americans with Disabilities Act.\textsuperscript{151}

The plaintiff contended that her eyesight is a physical impairment \textit{per se}, automatically making her a disabled person under the Americans with Disability Act.\textsuperscript{152} She also specified that she falls under the category of "statutory blindness" as per the Social Security Administration's definition. Under the Social Security Regulations, one is categorised as statutorily blind if one has "central visual acuity of 20/200 or less in the better eye with the aid of a correcting lens".\textsuperscript{153} The plaintiff furthermore claimed that the medical records from her medical practitioner, Dr Jacey reflected that she has a visual acuity of below 20/200 which can only be adjusted to 20/200 with corrective lenses.\textsuperscript{154} The plaintiff in addition contended that her physical condition is permanent and that it is evident that she cannot see certain things

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{147} Barta case, paragraph [778].
\item \textsuperscript{148} Barta case, paragraph [778].
\item \textsuperscript{149} Barta case, paragraph [778].
\item \textsuperscript{150} Barta case, paragraph [778].
\item \textsuperscript{151} Barta case, paragraph [778].
\item \textsuperscript{152} Barta case, paragraph [778].
\item \textsuperscript{153} Barta case, paragraph [778].
\item \textsuperscript{154} Barta case, paragraph [779].
\end{itemize}
\end{footnotesize}
without the assistance of improving aids.\textsuperscript{155} The plaintiff depended on the affidavit of Dr Jacey and a letter from Ms Jennings\textsuperscript{156} of the Department for the Blind and Vision Impaired corroborate her submission that she had undergone a personal assessment of the effect of her condition on her life. Dr Jacey's affidavit stated that:

Ms Barta's daily life activities, which have been affected by her visual disability, are driving, sewing, and unable to read small print without the aid of a magnifying glass or visual aid readers.

The defendant referred to the Eleventh Circuit case of Chenoweth v Hillsborough County,\textsuperscript{157} which found that driving is usually not viewed as a major life activity.\textsuperscript{158} The defendant also referred to the Second Circuit case of Colwell v Suffolk County Police Department,\textsuperscript{159} which held that getting to and from work does not amount to a distinct major life activity. The defendant further argued that if driving is not seen as a major life activity then sewing should not be seen as a major life activity.\textsuperscript{160}

An applicant need meet only one of the three listed factors to substantiate that he or she is within the protected class under the Americans with Disabilities Act.\textsuperscript{161} The determination whether a person qualifies as a disabled person as defined by the Act necessitates an individual evaluation of the effect of the condition on the person’s major life activities.\textsuperscript{162}

Despite the fact that the term "substantially limits" is not defined in the law, regulations state that a comparison must be drawn between what a person is able to do or not as a result of their impairment and what a normal non-impaired person is

\begin{footnotes}
\item[155] Barta case, paragraph [779].
\item[156] "Ms. Jennings' letter does not explain the actual impact Plaintiff's impairment has had on her life activities but simply states that Plaintiff has been classified as statutorily blind by the Social Security Administration." See Barta case, paragraph [779].
\item[157] Chenoweth v Hillsborough County, 250 F.3d 1328 (11th Cir. 2001) (hereinafter referred to as the Chenoweth case).
\item[158] Chenoweth case, paragraph [7].
\item[159] Colwell v Suffolk County Police Dept, 158 F.3d 635 (2d Cir.1998) (hereinafter referred to as the Colwell case), paragraph [643].
\item[160] Barta case, paragraph [779]. In Faroh v Sedgwick County, 2002 WL 1627701, 2002 U.S. Dist. Lexis 13491 (D.Kan. July 12, 2002) it was held that that recreational activities such as fishing competitively, bow hunting, mountain biking, weight lifting and rollerblading are not considered to be major life activities.
\item[161] Barta case, paragraph [778].
\item[162] Barta case, paragraph [778]. Also see Toyota Motor, Mfg., Ky. v Williams, 534 U.S. 184, 198-99, 122 S.Ct. 681, 151 L.Ed.2d 615 (2002) (hereinafter referred to as the Toyota Motor Manufacturing Kentucky case).
\end{footnotes}
capable of doing.\textsuperscript{163} In the case of \textit{Toyota Motor Manufacturing Kentucky v William}, \textsuperscript{164} the Supreme Court explained that to be “substantially limiting”, an impairment has to be permanent or long-term and the impairment must impede or severely restrict the individual from performing activities that are important in the day-to-day lives of many people.\textsuperscript{165}

In circumstances where the plaintiff has been diagnosed with severe visual complications but is not always disabled, an individual investigation of their capability to compensate for the impairment is necessary.\textsuperscript{166} Nevertheless, the court explained that the burden of proof for individuals with severe visual impairments is not unduly heavy as they "ordinarily will meet the Act's definition of disability".\textsuperscript{167}

In the \textit{Barta} case, the court held the defendant to be correct in arguing that the activities documented in Dr Jacey's report do not qualify as major life activities.\textsuperscript{168} The Equal Employment Opportunity Commission lists major life activities as including:

\begin{itemize}
  \item caring for oneself, performing manual tasks, walking, seeing, hearing,
  \item speaking, breathing, learning, and working.\textsuperscript{169}
\end{itemize}

The court came to the conclusion that the plaintiff merely outlined her impairment without illustrating how the impairment affected her life.\textsuperscript{170} Therefore no sufficient evidence was brought to support a finding that the plaintiff was disabled as a matter of law.\textsuperscript{171}

\textsuperscript{164} \textit{Toyota Motor Manufacturing Kentucky} case, paragraph [681].
\textsuperscript{165} \textit{Toyota Motor Manufacturing Kentucky} case, paragraph [681].
\textsuperscript{166} \textit{Albertsons} case, paragraph [11 ].
\textsuperscript{167} \textit{Albertsons} case, paragraph [12].
\textsuperscript{168} \textit{Barta} case, paragraph [780].
\textsuperscript{170} \textit{Barta} case, paragraph [780].
\textsuperscript{171} \textit{Barta} case, paragraph [778].
5.4.4 Terri Bakker v Greyhound Bus Line Ray Robinson

In the case of Terri Bakker v Greyhound Bus Line Ray Robinson,\textsuperscript{172} the plaintiff claimed that she was discriminated against on the grounds of her being an albino. Her claim was dismissed with the reasoning that her albinism does not amount to a disability within the meaning of the then Americans with Disabilities Act of 1990.\textsuperscript{173} It was held that her albinism could not be described as a "cosmetic disfigurement" within the meaning of the definition of "physical or mental impairment".\textsuperscript{174}

5.4.5 Victor Hernández, Janice Del Valle, individually and as representatives of the minors Victor Hernández-Del Valle and Natalia Hernández-Del Valle v William Turner and Carib Christian School

The case of Victor Hernández, Janice Del Valle, individually and as representatives of the minors Victor Hernández-Del Valle and Natalia Hernández-Del Valle v William Turner and Carib Christian School\textsuperscript{175} was decided after the Americans with Disabilities Amendment Act was passed. The plaintiff, Janice Del Valle, alleged that Carib Christian School and its principal William Turner, refused her son, Víctor Hernández-Del Valle, who suffers from albinism, admission to the school in the year 2007-2008 because of his condition.\textsuperscript{176}

The court found that Title III of the Americans with Disabilities Act provides for equal opportunities for persons with physical or mental disabilities.\textsuperscript{177} Among other things, the rationale behind this provision is to give an obvious and all-inclusive public order for the suppression of discrimination against persons with disabilities.\textsuperscript{178}

The court examined the Americans with Disabilities Act in terms of the facts of the case and came to the conclusion that albinism does not constitute a disability.\textsuperscript{179}

\textsuperscript{172} Terri Bakker v Greyhound Bus Line Ray Robinson 240 F. Supp. 2d 454 (D. Md. 2003) (hereinafter referred to as the Terri Bakker case), paragraph [455].
\textsuperscript{173} Terri Bakker case, paragraph [455].
\textsuperscript{174} Terri Bakker case, paragraph [455].
\textsuperscript{176} Victor Hernández case, paragraph [6].
\textsuperscript{177} Victor Hernández case, paragraph [6].
\textsuperscript{178} Victor Hernández case, paragraph [6].
\textsuperscript{179} Victor Hernández case, paragraph [7].
Referring to albinism and the Terri Bakker v Greyhound Bus Line Ray Robinson case, the court held that

[It does not appear to be a "cosmetic disfigurement" within the meaning of the definition of physical or mental impairment.]

The court further held that the plaintiff’s grievance did not show that Victor was restricted in any way from participating in any major life activity. The claim was dismissed.

Eye conditions that are common in albinism have been seen to result in some form of disfigurement, such as an irregular rapid back and forth movement of the eyes, and strabismus, a muscle imbalance of the eyes, sometimes referred to as "crossed eyes". Prosthetic contact lenses are used for people with ocular disfigurement. Such lenses are said to provide visual and cosmetic enhancement.

5.5. The Americans with Disabilities Amendment Act of 2008 and the overturn of the decision in the Sutton case

In the United States of America the medical model has been the prevailing disability paradigm, even though the passing of the Americans with Disabilities Act of 1990 was largely understood as a conceptual departure from the medical model of

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180 Victor Hernández case, paragraph [7].
181 Victor Hernández case, paragraph [7].
182 Victor Hernández case, paragraph [7].
185 Steun et al 173.
disability. Rather than approaching physical impairments as individual problems, the Americans with Disabilities Act highlighted the social construction of disability by affording statutory recourse in the event of acts of employment discrimination. Despite the expectation that the Americans with Disabilities Act would bring about a transition to a social construction of disability, ongoing public examples of disability and the handling thereof by the federal courts have stood in the way of achieving this goal.

Court cases that require the application of the Americans with Disabilities Act are opportunities to advance awareness of social issues related to disability, such as access and discrimination. Through a series of court cases, the United States Supreme Court narrowed the protection afforded by the Americans with Disabilities Act with the result that people whom the Act was initially intended to protect have been excluded, namely people with epilepsy, diabetes and muscular dystrophy. The explanations of the Act given by the courts have for the most part functioned to place more and more restrictions on eligibility for protection under disability laws. For example, the cases discussed above in the context of albinism indicate that under the Americans with Disabilities Act an action against discrimination should provide proof of a disability that substantially limits one or more major life activities. Such proof involves a detailed medical diagnosis. It must also be shown that all possible corrective measures have been utilised, and lastly, that discrimination has in fact occurred. The preoccupation with the medical definition of disability diverts attention from the real societal problems that the Americans with Disabilities Act had intended to address. It is sometimes easier for defendants to make an assertion

187 Areheart 191.
188 Areheart 184.
that a claimant does not in fact have a disability or that the claimant failed to take sufficient corrective measures, than to argue that discrimination did not take place.\(^{193}\)

The Americans with Disabilities Amendment Act of 2008 overturned the controversial key ruling in the *Sutton* case which involved a stringent construal of “substantially limits”.\(^{194}\) The redefinition of disability has broadened the number and types of persons who are protected under the Americans with Disabilities Act.\(^{195}\) The amendments highlight the fact that the emphasis must be on whether discrimination occurred rather than adherence to a strict definition of disability.\(^{196}\)

The Americans with Disabilities Amendment Act of 2008 introduced a new resolution whereby the interpretation of “substantially limits” and “major life activities” was totally expunged and replaced with additional findings that result in a more inclusive standard.\(^{197}\) The question of whether a person has a disability was seen as a basic threshold concern, but the legislative history of the Americans with Disabilities Amendment Act reveals a considerably lower threshold for ascertaining whether a person has a disability.\(^{198}\)

The holding that a substantial limitation of a major life activity should relate to activities of central significance to daily life was determined to be in conflict with the purpose of the Americans with Disabilities Act.\(^{199}\) The definition of “major life activities” has since been well-defined and extended to include “major bodily functions.”\(^{200}\) The Americans with Disabilities Amendment Act instructs the courts to

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\(^{194}\) Charles & Scott 95; and Lawrence & Gostin 2232.
\(^{195}\) Lawrence & Gostin 2232.
\(^{197}\) Benfer 4; and Lawrence & Gostin 2231-2234.
\(^{200}\) Legal Information Institute, 29 CFR Part 1630, Appendix to Part 1630 – Interpretive Guidance on Title I of the Americans with Disabilities Act at
provide protection “to the maximum extent permitted” and offers a non-exhaustive list of “major life activities,” including caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating and working.

The Americans with Disabilities Amendment Act notes that an impairment that substantially limits one major life activity does not have to limit other major life activities in order to be accepted as a disability.

The Americans with Disabilities Amendment Act requires courts to decide if a person is disabled without reference to the ameliorative effects of mitigating measures (with the exclusion of ordinary eyeglasses or contact lenses). These modifications to the original Act of 1990 must make it easier for individuals to qualify as disabled for purposes of the law and for deliberations to focus on whether or not discrimination occurred.


Section 4(4)(A) of the Americans with Disabilities Amendment Act reads as follows: “The definition of disability in this Act shall be construed in favor of broad coverage of individuals under this Act, to the maximum extent permitted by the terms of this Act.”

Section 4(2)(1) of the Americans with Disabilities Amendment Act reads as follows: “Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working”.

Section 4(4)(C) of the Americans with Disabilities Amendment Act reads as follows: “An impairment that substantially limits one major life activity need not limit other major life activities in order to be considered a disability.”

Section 4(4)(E) of the Americans with Disabilities Amendment Act reads as follows: “The determination of whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures such as—
(l) medication, medical supplies, equipment, or appliances, low-vision devices (which do not include ordinary eyeglasses or contact lenses), prosthetics including limbs and devices, hearing aids and cochlear implants or other implantable hearing devices, mobility devices, or oxygen therapy equipment and supplies;
(ii) use of assistive technology;
(iii) reasonable accommodations or auxiliary aids or services; or
(iv) learned behavioral or adaptive neurological modifications.

(i) The ameliorative effects of the mitigating measures of ordinary eyeglasses or contact lenses shall be considered in determining whether impairment substantially limits a major life activity.

(iii) As used in this subparagraph—
(l) the term ‘ordinary eyeglasses or contact lenses’ means lenses that are intended to fully correct visual acuity or eliminate refractive error; and
(ii) the term ‘low-vision devices’ means devices that magnify, enhance, or otherwise augment a visual image.” Also see Lawrence & Gostin 2232.

Elliott 395-420.
Under the Americans with Disabilities Amendment Act persons with diabetes and other chronic illnesses; which the original Americans with Disabilities Act was evidently intended to cover, now fall under the Act’s umbrella of protection.\(^{206}\) By following the *Sutton* case, South African courts have adopted a restrictive approach, which has now become questionable in light of the fact that the decision in the *Sutton* case was overturned.

### 5.6 Albinism and disability in the context of the South African Employment Equity Act 55 of 1998

The question of whether a person living with albinism can succeed with a discrimination claim based on disability under the Employment Equity Act is considered next.

It is apparent from the clinical overview of albinism in chapter two that albinism is associated with various life-long physical impairments due to its effect on the skin and vision. Persons with albinism routinely develop visual disabilities that have a profound impact on their participation in life activities. As discussed in chapter two, the symptoms of albinism in early childhood comprise poor vision, sensitivity to bright light, nystagmus and strabismus.\(^{207}\) Vision may vary from normal in albinos who are moderately affected, to legal blindness or complete blindness in people with the more severe types of albinism.\(^{208}\) Usually, those with the least pigmentation have the poorest vision.\(^{209}\) Where albinism affects the hair, eyes and skin, it results in pale, white to chalky coloured skin, sandy to yellow hair and light brown or blue eyes.\(^{210}\) Because their skin is extremely fair, people with this form of albinism suffer from photo-ageing cancer and greater prevalence of all types of skin cancer.\(^{211}\)

As stated in chapter two, some writers are of the view that there should be a differentiation between a genetic trait and a genetic disease, submitting that the term

\(^{206}\) Lawrence & Gostin 2232.
\(^{208}\) Dominguez 14.
\(^{209}\) Dominguez 14.
\(^{211}\) Marks R *et al* *Clinical Signs and Procedures in Dermatology* (1993, London: Martin Dunitz) at 17.
genetic disease may be used if a trait results in medical problems.\textsuperscript{212} Effects of albinism which are cosmetic only may perhaps be called generic traits,\textsuperscript{213} in which case colouration in albinism would be seen as a cosmetic trait.\textsuperscript{214} With this in mind, it is submitted that in cases where albinism results in medical visual and skin problems, it may be associated with life-long impairment. Considering that most of the medical problems associated with albinism appear at birth and others during childhood, one could regard them as life-long, particularly in light of the fact that many of the said visual problems and skin cancers cannot be corrected. To date, there is no “cure” for albinism.

Persons living with albinism are dependent on sunscreen with a high (SPF),\textsuperscript{215} and have to protect their bodies by means of protective clothing\textsuperscript{216} and sunglasses with a high UV protection screen to relieve light sensitivity.\textsuperscript{217} They also have to wear glasses prescribed for the treatment of infertile nystagmus to correct eyesight problems, such as eye position.\textsuperscript{218} Persons living with albinism cannot function without taking these precautions. If they do not use sunscreen, they are prone to skin cancer while some cannot see unless they wear spectacles.

As held by the court in the \textit{IMATU} case, the matter does not end with an inquiry as to whether there is a physical impairment. The applicants must show that such impairment substantially limits the prospects of entry into or advancement in employment of a person with albinism. It is only where albinism limits a person’s ability to perform the essential functions of the job for which they are being considered (for example, legal blindness\textsuperscript{219}) and where the medical condition cannot be easily controlled, corrected or lessened, that an employer may dismiss a person.

\begin{thebibliography}{9}
\bibitem{Richards35} Richards 35.
\bibitem{Richards35} Richards 35.
\bibitem{Mcgarry2013} McGarry KA & Tong IL \textit{The 5-Minute Consult Clinical Companion to Women’s Health} (2013, Philadelphia: Lippincott Williams & Wilkins) at 224.
\bibitem{Horobin29} Horobin 29.
\bibitem{Brodsky2010} Brodsky MC \textit{Paediatric Ophthalmology} (2010, New York: Springer) at 405.
\bibitem{Bedinghaus2015} “Being legally blind means that your best seeing eye cannot be corrected with glasses or contact lenses any better than 20/200”; see Bedinghaus T “What does it mean to be Legally Blind” at http://vision.about.com/od/faqs/f/What-Does-It-Mean-To-Be-Legally-Blind.htm (visited 9 October 2015).
\end{thebibliography}
with albinism on the ground of disability. Where a person living with albinism can easily control, correct or lessen the severity of their medical condition to the extent that it has no limiting effects, as in the Standard bank case, it may be concluded that the medical condition does not limit a person’s ability to perform. For instance, should an albino correct her vision by wearing glasses, an employer cannot limit advancement in employment or entry into employment unless the person’s vision is still substantially impaired even with the use of spectacles or contact lenses.

As mentioned before, the main shortcoming of the definition under discussion is that it excludes many disabled people from protection on the grounds that their impairment is not severe enough or that they are coping satisfactorily with the impairment to the point that they no longer require protection from discrimination. It is apparent that persons living with albinism who do not suffer from a severe impairment as a result of their condition are therefore not protected against unfair discrimination on the basis of disability. This narrow approach does not take into account instances where persons are discriminated against as a result of social constructions with regard to disability.

The court in the Standard Bank case remarked that if disability is construed restrictively instead of purposively, the very intention of preventing unfair discrimination may be thwarted.\footnote{Standard bank case, paragraph [59].} The court explained that protection against discrimination would be lost to many disabled people in instances such as where:\footnote{Standard bank case, paragraph [59].}

- a severely myopic job candidate is refused a position as a pilot as a result of being regarded as not being disabled because she wears spectacles to correct her sight; or
- a diabetic is not regarded as a person with a disability because he controls his condition with medication.
5.7 Albinism as a perceived disability under the Americans with Disabilities Amendment Act of 2008 and the Convention on the Rights of Persons with Disabilities

While the South African Employment Equity Act is silent on the subject of perceived disability, the third component of the definition of disability in the Americans with Disabilities Amendment Act focuses less on the extent of a person’s actual impairment and more on how others perceive the individual and the effect of such perceptions on attitudes towards and assumptions about their abilities. This subcategory of the definition of disability protects those who are "perceived" as having a disability from employment decisions grounded on stereotypes or mistaken beliefs about disability.

With the purpose of providing a fitting recourse for all people who experience discrimination on the basis of disability, it is necessary to explicitly recognise that there are individuals who do not consider themselves disabled and would not be

222 Section 4 of the Americans with Disabilities Amendment Act amends section 3 of the Americans with Disabilities Act of 1990 to read as follows:
"Definition of disability.
As used in this Act:
(1) Disability.—The term ‘disability' means, with respect to an individual -
(A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
(B) a record of such an impairment; or
(C) being regarded as having such an impairment (as described in paragraph (3)).
(2) Major life activities.—
(A) In general.—For purposes of paragraph (1), major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.
(B) Major bodily functions.—For purposes of paragraph (1), a major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.
(3) Regarded as having such an impairment.—For purposes of paragraph (1)(C):
(A) An individual meets the requirement of 'being regarded as having such an impairment' if the individual establishes that he or she has been subjected to an action prohibited under this Act because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.
(B) Paragraph (1)(C) shall not apply to impairments that are transitory and minor. A transitory impairment is impairment with an actual or expected duration of 6 months or less."
Also see Mish 159.
Mish 159.
viewed as disabled by a number of people, but who are subjected to the same disparate treatment as "the disabled". 224

Some individuals who may be categorised as disabled under the Americans with Disabilities Amendment Act due to the presence of a genetic marker, should definitely not be expected to think of themselves as disabled. 225 Although there may be some uneasiness about being categorised as disabled, it is important to be aware that no one with a disability, visible or not, wishes to experience the stigma and discrimination which still persist around those whom society considers disabled. 226
There are people who do not consider themselves disabled but who still experience discrimination, 227 and the Americans with Disabilities Amendment Act offers such individuals legal recourse. 228

The question of whether a person with a genetic trait is covered by the definition of disability is immaterial. 229 Any person with a genetic trait who has experienced discrimination based on their physical or mental capabilities may take advantage of the Americans with Disabilities Act to remedy the situation.

The “regarded as a disability” component applies whether or not a person has an impairment since its sole intention is to protect persons who are treated as having a physical or mental impairment that substantially limits a major life activity. 230 Accordingly, the “regarded as” protection does not require proof of an actual “disability” as it applies to the following groups:

(1) the non-disabled but actually impaired group, those who have an impairment which is not substantially limiting as to a major life activity but are perceived by the employer as having a substantially limiting impairment and

230 Senn 835.
the non-disabled and non-impaired group, they have no impairment at all but are regarded by the employer as having a substantially limiting impairment.\textsuperscript{231}

In order to be protected by the American with Disabilities Amendment Act it is sufficient that a person be mistakenly “regarded” or “perceived” by an employer as having an actual or real disability.\textsuperscript{232} “Regarded as” cases focus on the employer’s subjective perception of the individual, rather than on the individual’s actual abilities.\textsuperscript{233}

Where an employer asserts that an employee is incapable of performing a particular job without providing supporting medical evidence other than a diagnosis, this may be in violation of the Americans with Disabilities Act, particularly if employers base their judgement on assumptions, stereotypes, fears or myths rather than material medical evidence.

In the case of \textit{Equal Employment Opportunity Commission v Heartway Corporation},\textsuperscript{234} the plaintiff Edwards was dismissed from her position as cook at a nursing home after her employer became aware that she was receiving treatment for Hepatitis C. Upon finding out about her condition, Edwards’ supervisor made the following statements:

\begin{quote}
How would you like to eat food containing her blood, if she ever cut her finger?
\end{quote}

and

\begin{quote}
… if this got out to the clients they [...] would have a mass exodus from the nursing home.\textsuperscript{235}
\end{quote}

The Tenth Circuit Court of Appeals stated that these remarks indicated that the supervisor’s subjective view was that Edwards was substantially limited in her ability to work in that he believed she should not be employed in any kitchen. Consequently, the court found that although Edwards’ Hepatitis C diagnosis did not in fact render her disabled, a realistic jury could reach the conclusion that her

\begin{itemize}
\item \textsuperscript{231} Senn 833.
\item \textsuperscript{232} \textit{Wysong v Dow Chemical Company} 503 F.3d 441, 451 (6th Cir. 2007), paragraphs [8-9].
\item \textsuperscript{233} \textit{Wilson v Phoenix Specialty Manufacturing Company, Incorporated} 513 F.3d 378, 385 (4th Cir. 2008), paragraph [9].
\item \textsuperscript{234} \textit{Equal Employment Opportunity Commission v Heartway Corporation} 466 F.3d 1156 (10th Cir. 2006) (hereinafter referred to as the \textit{Heartway Corporation} case), paragraphs [1158-1160].
\item \textsuperscript{235} \textit{Heartway Corporation} case, paragraphs [1159-1160].
\end{itemize}
supervisor considered her to be substantially limited in the main life activity of working and incapable of performing a wide range of jobs. As a result, Ms Edwards was protected under the Americans with Disabilities Act’s “regarded as” component. This case reveals that judgements by employers about disability in the workplace must be based on objective medical information and not on preconceptions or inferences concerning the effects of a disability.

Although public perceptions of disability are not regulated under the Employment Equity Act, in November 2007 South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPWD). The Convention on the Rights of Persons with Disabilities is the most recent significant international human rights instrument relating to disability. The Convention on the Rights of Persons with

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236 Heartway Corporation case, paragraph [1167].
237 Heartway Corporation case, paragraph [1168]. In the case of Equal Employment Opportunity Commission v. E.I. DuPont de Nemours & Co., 480 F.3d 724 (5th 2007), the Fifth Circuit Court of Appeal found that E.I. DuPont de Nemours & Co violated the Americans with Disabilities Act following the termination of an employee who it regarded as substantially limited in walking. Barrios, the employee, had several medical conditions that resulted in his having difficulty when walking. Following a functional capacity evaluation, DuPont’s surgeon elected to restrict Barrios from walking anywhere in the plant. DuPont construed such a step to mean that Barrios was incapable of evacuating the plant on his own in the event of an emergency. DuPont regarded independent evacuation as an inherent job requirement. As a result DuPont put Barrios on temporary disability leave and later permanent disability leave. Seven years later, upon Barrios’ confirming that she could follow the evacuation path without assistance, DuPont nevertheless refused to reemploy her. The Federal Court found that DuPont regarded Barrios as substantially limited in the major life activity of walking for the reason that DuPont assumed that her impairment extended to all aspects of her life. Consequently the court found that DuPont violated the Americans with Disabilities Act when it forced Barrios to take disability leave. This case illustrates the danger of employers taking exceedingly far-reaching decisions as to an employee’s restrictions without sufficient medical evidence. Employers have a duty under the Americans with Disabilities Act to ensure that emergency evacuation procedures take the needs of people with disabilities into account as well as to offer reasonable accommodations in assisting individuals to evacuate a facility in the event of an emergency. DuPont failed to do this and forced Barrios to take disability leave, and also refused to reinstate her after it was shown that she could evacuate the facility and perform her job functions. For these reasons, DuPont was found to have violates the Americans with Disabilities Act.

Disabilities came into force on 3 May 2008 with the purpose of protecting the fundamental rights and integrity of Persons Living with Disabilities (PLWD).

The United Nations Convention on the Rights of Persons with Disabilities marked the beginning of a new era in disability rights and was the culmination of a 30 year struggle by people in the disability rights movement and advocates of human rights to gain acknowledgment that everyone, regardless of impairment, must enjoy all human rights and fundamental freedoms.\textsuperscript{239} It altered the playing field for people universally by giving official acknowledgment that disability is a rights issue\textsuperscript{240} on the one hand and a social development issue on the other.\textsuperscript{241}

The Convention on the Rights of Persons with Disabilities covers most aspects relating to the daily lives of children and adults with disabilities, such as the rights of children and adults to attend schools and to receive inclusive education. The Convention also requires that the State provide disabled children and adults with vocational education, rehabilitation, and the same range, quality and standard of free or affordable health services provided to other persons.

As seen from the above, at the level of the Employment Equity Act there seems to be a noticeable inconsistency between the South African framework on disability and the framework of the Convention.

The United Nations Convention on Persons with Disabilities advances an alternative way in which persons with albinism may be protected from discrimination. The Convention’s definition is ideal for the South African disability sector.\textsuperscript{242} It may not be

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\textsuperscript{239} Rioux M H “Disability Rights and Change in a Global Perspective” (2011) 14 (9) Sport in Society 1094–1098 at 1094.

\textsuperscript{240} Rioux 1094.

\textsuperscript{241} Rioux 1094.

\textsuperscript{242} Part (e) of the preamble of the Convention on the Rights of Persons with Disabilities of 2008 defines disability in the following way: “Disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environment barriers that hinders their full and effective participation in society on an equal basis with others.” Also see Bick L “South Africa: Definitions Of Disability And The 2011 Census” at http://www.mondaq.com/x/147254/Arbitration+Dispute+Resolution+Definitions+Of+Disability+And+The+2011+Census (visited 6 July 2012). Tanzania has signed and ratified the Convention on the Rights of Persons with Disabilities and is therefore bound to the provisions of this Convention in as far as they relate to the rights of persons with albinism. Since Tanzania has ratified the CRPWD as well as the Optional Protocol, persons living with albinism in Tanzania can bring any complaints to the Committee.
practicable to find an entirely acceptable common description of disability, but the
four essentials stipulated in the Convention on the Rights of Persons with Disabilities
offer a basis upon which everyone can evaluate and take action on disability.

The Convention on the Rights of Persons with Disabilities establishes the right of
people with disabilities to enjoy their lives in the same way as other people, to
access justice, and to enjoy the rights to freedom, privacy and security.\(^{243}\) The
Convention also prohibits all forms of discrimination against persons with disabilities,
both direct and indirect discrimination, and recognises that accommodation of
persons with disabilities is regularly required to expedite the achievement of
equality.\(^{244}\) In addition, the Convention obliges states parties to perform certain


\(^{244}\) Articles 3, 4 and 5 of the Convention on the Rights of Persons with Disabilities of 2008 read
as follows:

“Article 3: The principles of the present Convention shall be:

a. Respect for inherent dignity, individual autonomy including the freedom to make one’s own
   choices, and independence of persons;
b. Non-discrimination;
c. Full and effective participation and inclusion in society;
d. Respect for difference and acceptance of persons with disabilities as part of human
diversity and humanity;
e. Equality of opportunity;
f. Accessibility;
g. Equality between men and women;
h. Respect for the evolving capacities of children with disabilities and respect for the right of
   children with disabilities to preserve their identities.”

Article 4: General Obligations:

1. States Parties undertake to ensure and promote the full realization of all human rights and
   fundamental freedoms for all persons with disabilities without discrimination of any kind on the
   basis of disability. To this end, States Parties undertake:
   a. To adopt all appropriate legislative, administrative and other measures for the
      implementation of the rights recognized in the present Convention;
b. To take all appropriate measures, including legislation, to modify or abolish existing laws,
      regulations, customs and practices that constitute discrimination against persons with
      disabilities;
c. To take into account the protection and promotion of the human rights of persons with
      disabilities in all policies and programmes;
b. To refrain from engaging in any act or practice that is inconsistent with the present
      Convention and to ensure that public authorities and institutions act in conformity with the
      present Convention;
c. To take all appropriate measures to eliminate discrimination on the basis of disability by any
      person, organization or private enterprise;
d. To undertake or promote research and development of universally designed goods,
   services, equipment and facilities, as defined in article 2 of the present Convention, which
   should require the minimum possible adaptation and the least cost to meet the specific needs
   of a person with disabilities, to promote their availability and use, and to promote universal
   design in the development of standards and guidelines;
e. To undertake or promote research and development of, and to promote the availability and
   use of new technologies, including information and communications technologies, mobility
affirmative duties, including taking legislative and administrative measures that promote the human rights of persons with disabilities, eradicate discrimination and ensure that the public and private sectors respect persons with disabilities.

In view of the fact that definitions of disability may change over time, the Convention states that:

... disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and

aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
f. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
g. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.
2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.
3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.
4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.
5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

Article 5: Equality and Non-Discrimination:
1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 27 (Work and Employment) obligates states parties to:
a. Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures...
environment barriers that hinders their full and effective participation in society on an equal basis with others.\textsuperscript{246}

The Preamble and article one of the Convention affirm the social construction of disability by stating that the definition of disability ought to be advanced from the social perspectives which generate attitudinal and physical barriers preventing persons with disabilities from effectively contributing to society, and not from the viewpoint of the supposed medical condition of such individuals.\textsuperscript{247} The Convention looks beyond the question of “access to the physical environment” and tackles concerns of equality and the elimination of legal, social and attitudinal obstructions to the involvement of people with disabilities.\textsuperscript{248}

Social exclusion and inclusion consist of the multidimensional social relations between those at the centre and those on the periphery.\textsuperscript{249} By generating barriers, society creates disablement.\textsuperscript{250} The debate on the “social inclusion” and “social exclusion” of disability seldom revolves around the rights or needs of persons with disabilities.\textsuperscript{251}

The advantages of social approaches to disability are that they shift the focus from individuals and their physical or mental deficits to the manner in which society embraces or rejects them.\textsuperscript{252} Instead of disability being seen as unavoidable it is viewed as a product of social arrangements that can be reduced or perhaps even eliminated.\textsuperscript{253} The purpose of the social model is therefore to move society away from treating persons with incapacities as “defective” and to render it more inclusive.\textsuperscript{254} The Convention on the Rights of Persons with Disabilities embraces the

\textsuperscript{246} Part (e) of the preamble of the Convention on the Rights of Persons with Disabilities of 2008.
\textsuperscript{248} Scott 514.
\textsuperscript{251} Rioux 64.
\textsuperscript{253} Shakespear 12.
\textsuperscript{254} Hurpur "Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities“ 3.
social model idea that society causes the disablement of persons with impairments.  

Comparisons of social interpretations of the notion of disability are interesting and instructive. For example, in the United States case of School Board of Nassau County, Florida v Arline, the court stated that “society's accruing myths and fears about disabilities are as handicapping as the physical limitations that flow from actual impairment.”

In another United States case, University of Maryland v Boyd, the court held that a police officer's skin condition amounted to a handicap under the Maryland statutes. The relevant police officer suffered from pseudofolliculitis as a result of shaving, leading to skin irritation, sores and scarring. The court held that the police officer was a “handicapped individual, because of his skin condition and its interference with the major life activity of socialisation”. The court based its decision on substantiated evidence that the officer's skin condition was the reason for the discomfort that made him isolate himself from the general public and which also destroyed his marital relationship.

The Boyd case, as well as the flexible and more inclusive understanding of disability embodied in the Convention on the Rights of Persons with Disabilities, offers a more realistic framework for addressing the common loss suffered by persons living with albinism. Socialisation is, however, not listed as a major life activity in the Americans with Disabilities Amendment Act. The list of major life activities in the Act is however not absolute or restricted. The listed major life activities are basic life functions, and socialisation is arguably just as imperative as learning and working.

Because persons living with albinism have a lifelong physical impairment, they are continuously required to navigate circumstances arising from their distinctiveness.

256 School Board of Nassau County, Florida v Arline 480 U.S. 273 (1987), paragraph [3].
257 University of Maryland v Boyd 93 Md. App. 303 (1992) 612 A.2d 305 (hereinafter referred to as the University of Maryland case), paragraph [3].
258 University of Maryland case, paragraph [2].
259 University of Maryland case, paragraph [3].
260 University of Maryland case, paragraph [3].
261 Scott 514.
Hence, “normal socialisation” is not only challenging for albinos, but potentially impossible to achieve.\textsuperscript{262} The court in the \textit{Boyd} case recognised the significance of socialisation in an individual’s life. Like the plaintiff in the \textit{Boyd} case who suffered from a skin condition which inhibited his interaction with others, persons living with albinism are significantly impaired in the activity of socialisation and should be able to access the same form of protection offered in the \textit{Boyd} case.\textsuperscript{263} The social perceptions around albinism make normal socialisation of persons with albinism seem unattainable due to the stigma attached to the condition.

The Convention on the Rights of Persons with Disabilities appears to take a middle road between the individual impairment model and the social model,\textsuperscript{264} and it reflects a flexible and inclusive definition of disability.\textsuperscript{265} The definition recognises that whilst there might be a myriad interpretation of disability, a juridical definition of disability for equality and non-discrimination purposes must at least imply impairment as a point of departure.\textsuperscript{266} At the same time, the definition must be responsive to socio-economic barriers as constituent elements of disability.\textsuperscript{267} The Convention accepts that impairment and the environment interact to produce the experience of disability when people with impairments cannot participate in society on an equal basis.

The agenda for disability advocacy is frequently at the practical level where the basic rights of individuals need to be guaranteed.\textsuperscript{268} The social model advances disability rights by removing obstructions in society, but then again the social construction of disability can overlook the barriers of disabilities that are not created by society.\textsuperscript{269} The restriction of the social construction of disability means that studies which adhere strictly to this model have occasionally failed to effectively factor in the impact of obstructions that are not created by society.\textsuperscript{270} The human rights model takes this...
further step and crafts a governing policy framework that guarantees that persons with disabilities can exercise all their human rights. Advocacy on disability needs to support people in dealing with the impact of their impairment while at the same time fighting to stop society from generating barriers.

In order for disabled people to exercise their human rights, it is essential that there be constant dialogue and consensus about disability rights among the public, Government and the private sector as well as a commitment to implement the spirit and moral intent of the Convention on the Rights of Persons with Disabilities. This dialogue has to accept how conventional philosophies around disability focused on individuals and their impairments as well as how this has fundamentally disadvantaged persons with disabilities. It must express solidarity with people who have been marginalised in their social participation.

Signatories to the Convention on the Rights of Persons with Disabilities are mandated to observe the provisions of the Convention by using them to drive domestic law and policy reforms. The Convention requires that states undertake to adopt immediate, effective and appropriate measures:

a) to raise awareness about people with disabilities throughout society, including at family level, and to foster respect for the rights and dignity of persons with disabilities;

b) to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

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and the removal of barriers largely through civil rights statutes. The social model does not focus on redressing the problems caused by past discrimination or addressing the problem where persons with impairments could not fully function even if universal design were embraced. For example, even if all architectural barriers were removed, a person with quadriplegia would require an electric wheelchair and additional medical support, and a person without eyesight would require training and a mobility aid such as a guide dog or white cane. The social model advances disability rights substantially from the medical model but fails to ensure all persons with disabilities can exercise their human rights." Also see Hurpur P "Time to be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change" (2011) 45 Valparaiso University Law Review 1271-1283 at 1278.

Hurpur "Time to be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change" 1278.


Rioux 90.

Rioux 90.
c) to promote awareness of the capabilities and contributions of persons with disabilities.\textsuperscript{275}

The Convention on the Rights of Persons with Disabilities obliges states to take positive action to promote an extensive disability rights-based agenda. The expected interventions are not restricted to merely changing laws, but include broader community education.\textsuperscript{276} Persons with albinism are often victims of a misunderstood genetic condition, and of unpleasant and unwarranted discrimination. Where such discrimination lurks in the work environment, the Employment Equity Act must afford a degree of legal protection for persons with albinism. The Employment Equity Act should take a firm position on employers who unfairly discriminate against persons with albinism. At the very least, the Act should include a broad definition of a protected disabled person.

Even a strict law can do nothing if there is not a transformation in the mind-set of people as well as a readiness to accept and respect the disabled.\textsuperscript{277} There is a prevailing attitude of associating disabled people with their disabilities rather than their abilities.\textsuperscript{278} Society must be sufficiently dynamic to accept all differences, considering that the world survives precisely because of its variances and the natural

\textsuperscript{275} Article 8 (1) of the Convention on the Rights of Persons with Disabilities of 2008 reads as follows:

"1. States Parties undertake to adopt immediate, effective and appropriate measures:
   (a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
   (b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
   (c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:
   (a) Initiating and maintaining effective public awareness campaigns designed:
      (i) To nurture receptiveness to the rights of persons with disabilities;
      (ii) To promote positive perceptions and greater social awareness towards persons with disabilities;
      (iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
   (b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
   (c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
   (d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities."

\textsuperscript{276} See Article 8 (1) of the Convention on the Rights of Persons with Disabilities of 2008.

\textsuperscript{277} Isaac R \textit{et al} "Integrating people with disabilities: their right – our responsibility" (2010) 25 (5) \textit{Disability and Society} 627-630 at 630.

\textsuperscript{278} Isaac 630.
balance between them. It is also ultimately the responsibility of every individual to respect the uniqueness and rights of all members of society.

PART II

5.8 Albinism: Does it qualify as a disability under the Social Assistance Act 13 of 2004?

5.8.1 Theoretical observations

Apart from the rights to health care services, education, access to shelter and housing, and the right to sufficient food and water, section 27 of the Constitution provides that everyone has the right to have access to social security. This includes proper social assistance for citizens who are not capable of supporting themselves, as well as their dependants. The state has an additional duty to take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of the right to social security.

Social security consists of both social insurance as well as social assistance. Social insurance more often involves personal as well as contributory plans, such as “occupation retirement insurance”, whilst social assistance is a state-offered non-contributory fund, membership of which is normally determined by the so-called means test.

The objectives of the Social Assistance Act are to:

279 Isaac 630.
280 Isaac 630.
281 Section 27(1)(c) of the Constitution of 1996 reads as follows: “Everyone has the right to have access to - (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.”
282 Section 27(2) of the Constitution of 1996 reads as follows: “The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.”
284 “Social insurance, which entails a joint contribution by employers and employees to pensions or provident funds,” see the Child Health Policy Institute & the South African Federal Council on Disability, Report Prepared for the Committee of Inquiry into a Comprehensive Social Security System at 6.
a) provide for the administration of social assistance and payment of social
grants;

b) make provision for social assistance and determine the qualification
requirements in respect thereof;

c) ensure that minimum norms and standards are prescribed for the delivery of
social assistance; and

d) provide for the establishment of an inspectorate for social assistance.285

The disability grant is intended to offer additional income to people with disabilities
who are not able to work. There are two kinds of disability grants, namely:

- the permanent grant which lasts for five years, and
- the temporary grant which lasts for six months to a year.286

5.8.2 Qualifying for the social security grant

The Social Security Agency lists the following requirements that have to be met in
order to qualify for a disability grant. Applicants must be:

(1) South African citizens /permanent residents or refugees;
(2) resident in South Africa;
(3) 18 to 59 years of age;
(4) submit a medical/assessment report confirming disability;
(5) medical assessment must not be older than three months at date of
application;
(6) spouse must meet the requirements of the means test;
(7) not be maintained or cared for in a state institution;
(8) not be in receipt of another social grant in respect of him- or herself.287

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285 Section 3 of the Social Assistance Act 13 of 2004. This was also confirmed in the fairly recent
case of *Ngalo v South African Social Security Agency* (SASSA) (2740/11) [2013] ZAECMHC
(visited 10 October 2015).

286 GNRe 898 of 22 August 2008: Regulations relating to the application for and payment of social
assistance and the requirements or conditions in respect of eligibility for social assistance

287 GNRe 898 of 22 August 2008: Regulations relating to the application for and payment of social
assistance and the requirements or conditions in respect of eligibility for social assistance
(*Government Gazette* No 31356). Also see, Strydom EML *Essential Social Security Law et al*
(2006, Cape Town: Juta) at 8.
5.8.3 The definition of disability in terms of the Social Assistance Act 13 of 2004

In the Social Assistance Act\textsuperscript{288} a disabled person is defined as a person contemplated in section 9(b), the latter reading as follows:

Disability grant.—A person is, subject to section 5, eligible for a disability grant, if he or she—
(a) has attained the prescribed age; and
(b) is, owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance.

From the above one may conclude that a disability is a physical or mental impairment which has such an immense impact on a person’s earnings that their income is insufficient to provide for their maintenance. It is apparent that in this definition disability is approached from a medical viewpoint which merely looks at the physical or mental impairment and its extent or severity in terms of the ability to work for a living.\textsuperscript{289}

5.8.4 The definition of disability in the Social Security Amendment Act 5 of 2010

Before promulgated, the Social Security Amendment Bill defined disability as follows:

Disability, in respect of an applicant, means a moderate to severe limitation to his or her ability to function as a result of a physical, sensory, communication, intellectual or mental disability rendering him or her unable to—
(a) obtain the means needed to enable him or her to provide for his or her own maintenance; or
(b) be gainfully employed.\textsuperscript{290}

\textsuperscript{288} Section 1 of the Social Assistance Act 13 of 2004.
\textsuperscript{290} Social Assistance Amendment Bill (\textit{As introduced in the National Assembly (proposed section 76); Bill published in Government Gazette No. 32986 of 1 March 2010} (The English text is the official text of the Bill). The Social Assistance Amendment Bill was approved by the
The Bill stipulated that a definition of “disability” was included for the purpose of providing clarity regarding eligibility for a disability grant. This in itself demonstrates that the Social Assistance Act was not clear on who qualifies as a disabled person. Regrettably, the proposed definition of disability has not been included in the Act that was subsequently promulgated. One can only hope for a reconsideration and possibly revision of the current definition of disability, particularly given that it has been difficult for members of the public to determine whether or not they qualified as disabled.

5.8.5 The means test

Access to social assistance is restricted to persons who qualify in terms of the “means test”. The means test entails that the institution responsible for the administration of social assistance funds evaluates the income and assets of the applicant in order to determine whether their means are below a stipulated amount, in which case they would qualify for assistance. In South Africa’s welfare system, access to state assistance in respect of health care, old age pensions, disability grants and child grants is subject to the means test.

5.8.6 The right to social security in the context of albinism

The Integrated National Disability Strategy acknowledges that in South Africa people with disabilities are excluded from mainstream society, and experience several challenges in accessing fundamental rights. The vision of the Integrated National Disability Strategy is to transform South Africa into a society for all where disability concerns are integrated into all government development strategies, planning and

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President on 16 September 2010. It is now an Act and the Act’s citation is The Social Assistance Amendment Act No 5 of 2010. Unfortunately the proposed definition of disability is not incorporated in the Act.

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291 Social Assistance Amendment Bill (As introduced in the National Assembly (proposed section 76); Bill published in Government Gazette No. 32986 of 1 March 2010) (The English text is the official text of the Bill).

292 Strydom 8.

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294 Strydom 8.

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programmes, including health care, rehabilitation, public education, barrier free access, transport, communications, data collection and research, employment, human resources development, social welfare and community development, social security, housing, and sport and recreation. In terms of employment specifically, the focus is on promoting participation by people with disabilities in small enterprises. If the above-mentioned areas are addressed, the rights of people with disabilities will clearly be recognised.

South Africa currently uses the medical model to establish eligibility for access to disability grants. Such a model is not effective because it leaves large groups of people unable to benefit from the social security system.

With the high rate of HIV and AIDS in South Africa, accessible health care and social security schemes are strained to the limit, and for many access to such schemes is decreasing.

Besides the growing need for social assistance for disabled persons, it is apparent from the definition of disability in the medical model that only those who are medically certified as disabled to the extent that they cannot work and provide for themselves, will qualify for the disability grant. The question arising is whether persons living with albinism qualify for the disability grant. To date, albinos have never been classified as disabled in terms of social security legislation. To qualify under the Social Assistance Act, a person living with albinism has to meet both medical requirements and those of the means test. The grants needed by persons with albinism for the purposes of improving their health, for instance by having access to sunscreen lotion and regular visits to a dermatologist, as well as general consultations, only appear to be available in circumstances where they are unable to work and provide for themselves.

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Advanced cancer may cause a person to become severely ill and consequently be unable to work for a living. Since persons living with albinism are at a high risk of developing cancer and in combination with other health considerations, it is submitted that this vulnerable group should be considered as candidates for a disability grant. Taking into account the complexity of the medical test and means test requirements, government should consider introducing a chronic disease grant, as was proposed during the briefing on the Social Security Amendment Bill held by the Department of Social Development.\footnote{Botha Y “Social Assistance Amendment Bill [B5-2010]: Briefing by the Department of Social Development” at https://pmg.org.za/committee-meeting/11437/ (visited 30 October 2015).} According to the Treatment Action Campaign, a chronic disease\footnote{“A chronic disease is one that is long-lasting but manageable with the right treatment and lifestyle. HIV is a chronic disease because antiretroviral drugs (ARVs) allow people to live long and healthy lives. Other examples of chronic diseases are diabetes and heart disease.” Silber G “A Chronic Disease Grant for South Africans” at http://www.tac.org.za/community/files/file/etmag/ET27English.pdf (visited 15 July 2015).} grant would cover costs specifically related to chronic illness.\footnote{Silber at http://www.tac.org.za/community/files/file/etmag/ET27English.pdf (visited 15 July 2015).} Not only would this provide financial assistance for various additional categories of people, but it would also contribute to reducing the misunderstandings and stigma surrounding disability.\footnote{Silber at http://www.tac.org.za/community/files/file/etmag/ET27English.pdf 9 (visited 15 July 2015).} The chronic disease grant would reinforce the right to health by making it possible for those with chronic ailments to properly manage their diseases.\footnote{Silber at http://www.tac.org.za/community/files/file/etmag/ET27English.pdf 9 (visited 15 July 2015).}

The approval of such a grant will benefit persons with albinism who are diagnosed with cancer, but there is also the question of how albinos who do not have cancer can be socially assisted. One can only hope for the construction of a broader definition of disability that covers more “moderate” physical or mental impairments. Persons living with albinism who are not legally blind but still visually impaired might be included in this definition.

\footnote{Botha Y “Social Assistance Amendment Bill [B5-2010]: Briefing by the Department of Social Development” at https://pmg.org.za/committee-meeting/11437/ (visited 30 October 2015).}
\footnote{“A chronic disease is one that is long-lasting but manageable with the right treatment and lifestyle. HIV is a chronic disease because antiretroviral drugs (ARVs) allow people to live long and healthy lives. Other examples of chronic diseases are diabetes and heart disease.” Silber G “A Chronic Disease Grant for South Africans” at http://www.tac.org.za/community/files/file/etmag/ET27English.pdf (visited 15 July 2015).}
"We would like persons with albinism to be considered as a specific group with particular needs that must be given special attention in international human rights law." ¹

6.1 Introduction

Section 39 of the South African Constitution states that a court, tribunal or forum is required to promote the values that underlie an open and democratic society based on human dignity, equality and freedom (subsection (a)), must consider international law (subsection (b)) and may consider foreign law (subsection (c)).²

Section 231 of the Constitution states that a treaty binds South Africa after it has been approved by the National Assembly and the National Council of Provinces, except if it is self-executing, or of a technical, administrative or executive nature. ³

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² Section 39 of the Constitution of the Republic of South Africa, 1996 (hereinafter referred to as the Constitution of 1996), reads as follows:

“(1) When interpreting the Bill of Rights, a court, tribunal or forum –
(a) must promote the values that underlie an open and democratic society based on human dignity, equality and freedom;
(b) must consider international law; and
(c) may consider foreign law.
(2) When interpreting any legislation, and when developing the common law or customary law, every court, tribunal or forum must promote the spirit, purport and objects of the Bill of Rights.
(3) The Bill of Rights does not deny the existence of any other rights or freedoms that are recognised or conferred by common law, customary law or legislation, to the extent that they are consistent with the Bill.”

³ Section 231 of the Constitution of 1996 reads as follows:

“(1) The negotiating and signing of all international agreements is the responsibility of the national executive.
(2) An international agreement binds the Republic only after it has been approved by resolution in both the National Assembly and the National Council of Provinces, unless it is an agreement referred to in subsection (3).
(3) An international agreement of a technical, administrative or executive nature, or an agreement which does not require either ratification or accession, entered into by the national executive, binds the Republic without approval by the National Assembly and the National Council of Provinces, but must be tabled in the Assembly and the Council within a reasonable time.
(4) Any international agreement becomes law in the Republic when it is enacted into law by national legislation; but a self-executing provision of an agreement that has been approved by Parliament is law in the Republic unless it is inconsistent with the Constitution or an Act of Parliament.
addition, section 232 of the Constitution determines that customary international law is law in South Africa, unless it is inconsistent with the Constitution or legislation. Under Section 233 of the Constitution, South African courts are obliged to prefer any reasonable interpretation of legislation that is consistent with international law over any alternative interpretation that is inconsistent with international law.

Provisions from international and regional human rights instruments relevant to the issues faced by persons with albinism, highlighted in this thesis, are briefly explored in this chapter. Although the focus of the chapter is limited to international human rights obligations relevant to South Africa in the context of persons with albinism, it will also briefly allude to the position in Tanzania, referred to in chapter one, to provide a comparative perspective. Tanzania, as discussed earlier, faces very specific challenges regarding the treatment of persons with albinism.

6.2 Treaty based systems

6.2.1 International Covenant on Civil and Political Rights (ICCPR)

As suggested by its name, the International Covenant on Civil and Political Rights (ICCPR) guarantees the protection of civil liberties such as physical integrity, justice, equality before the law and freedom from discrimination, as well as human rights which are associated with political involvement. The International Covenant on Civil and Political Rights was drafted in 1966, together with the International Covenant on Economic, Social and Cultural Rights (ICESCR), but it formally came into force in 1976 in accordance with article 49. South Africa ratified this treaty on 10 December 1998.

(5) The Republic is bound by international agreements which were binding on the Republic when this Constitution took effect

Section 232 of the Constitution of 1996 reads as follows:
“Customary international law is law in the Republic unless it is inconsistent with the Constitution or an Act of Parliament”.

Section 232 of the Constitution of 1996 reads as follows:
“When interpreting any legislation, every court must prefer any reasonable interpretation of the legislation that is consistent with international law over any alternative interpretation that is inconsistent with international law”.


Article 49 of the International Covenant on Civil and Political Rights of 1976 reads as follows:

Both the South African and Tanzanian governments are obliged to protect the rights of their citizens as enshrined in the International Covenant on Civil and Political Rights. The measures taken by the Tanzanian government have been criticised for inadequately protecting the rights of albinos, in particular their right to security of the

\begin{quote}
"1. The present Covenant shall enter into force three months after the date of the deposit with the Secretary-General of the United Nations of the thirty-fifth instrument of ratification or instrument of accession.
2. For each State ratifying the present Covenant or acceding to it after the deposit of the thirty-fifth instrument of ratification or instrument of accession, the present Covenant shall enter into force three months after the date of the deposit of its own instrument of ratification or instrument of accession."
\end{quote}
person, right to life and freedom from discrimination. Murders have deprived persons with albinism of their right to security of their person as protected in terms of article 9 of the International Covenant on Civil and Political Rights.

Although article 9 of the Covenant deals mainly with arrest and detention issues, the provision is relevant to the protection of persons with albinism in all African countries that have ratified the Convention. It is clear that albinos live in fear of their lives because of these murders. Such fear may force them to become housebound as they feel unsafe on the streets. As a result, many parents of children with albinism do not allow their children to walk to school.

The murders also constitute an infringement of the right to life of albinos as embodied in article 6 of the International Covenant on Civil and Political Rights.

13 Alum et al 5-13. Article 9 of the International Covenant on Civil and Political Rights of 1976 reads as follows:

1. Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.

2. Anyone who is arrested shall be informed, at the time of arrest, of the reasons for his arrest and shall be promptly informed of any charges against him.

3. Anyone arrested or detained on a criminal charge shall be brought promptly before a judge or other officer authorized by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release. It shall not be the general rule that persons awaiting trial shall be detained in custody, but release may be subject to guarantees to appear for trial, at any other stage of the judicial proceedings, and, should occasion arise, for execution of the judgement.

4. Anyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings before a court, in order that that court may decide without delay on the lawfulness of his detention and order his release if the detention is not lawful.

5. Anyone who has been the victim of unlawful arrest or detention shall have an enforceable right to compensation.

14 Article 6 of the International Covenant on Civil and Political Rights of 1976 reads as follows:

1. Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

2. In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgement rendered by a competent court.

3. When deprivation of life constitutes the crime of genocide, it is understood that nothing in this article shall authorize any State Party to the present Covenant to derogate in any way from any obligation assumed under the provisions of the Convention on the Prevention and Punishment of the Crime of Genocide.

4. Anyone sentenced to death shall have the right to seek pardon or commutation of the sentence. Amnesty, pardon or commutation of the sentence of death may be granted in all cases.
which affords every human being “the inherent right to life”. The principle of equality and non-discrimination is one of the fundamental components of international human rights law. This principle requires that everyone be treated equally before the law, without prejudice.

Article 26 of the International Covenant on Civil and Political Rights further protects everyone, including persons with albinism, from all forms of discrimination. The relevance of article 26 for this study is that it places an obligation upon member states to put in place legislation which prohibits any discrimination. Such laws must guarantee equal and effective protection against discrimination on any of the following grounds; race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Elsewhere in this thesis reference was made to the negative perceptions regarding albinism which result in severe and harmful forms of discrimination.

It is contended by state parties that there is considerable overlap between the provisions of article 26 of the International Covenant on Civil and Political Rights and article 2 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). The committee responsible for these treaties is of the view that the

5. Sentence of death shall not be imposed for crimes committed by persons below eighteen years of age and shall not be carried out on pregnant women.  
6. Nothing in this article shall be invoked to delay or to prevent the abolition of capital punishment by any State Party to the present Covenant."

“1. Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.  
2. Where not already provided for by existing legislative or other measures, each State Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such laws or other measures as may be necessary to give effect to the rights recognized in the present Covenant.  
3. Each State Party to the present Covenant undertakes:  
(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;  
(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent
International Covenant on Civil and Political Rights still finds application even if the equality and non-discrimination issue is referred to in other conventions, notably the Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Elimination of all Forms of Discrimination Against Women, as well as the International Covenant on Economic, Social and Cultural Rights.\textsuperscript{20} Despite the fact that the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights were drafted against the backdrop of a common history, it remains necessary for the committee to apply each individual convention fully to member states.\textsuperscript{21}

The question of what constitutes unfair discrimination under international law is unfortunately outside the scope of this study. It is instructive to note, however, that under international law, an infringement of the right to equality arises where equal cases are treated differently, especially where there is no objective and reasonable justification for this differential treatment or no proportionality between the aim sought and the means employed.

In an attempt to rectify past discrimination in terms of opportunities, the principle of equality and non-discrimination obliges state parties to implement affirmative action. Under General Comment 18,\textsuperscript{22} the Human Rights Committee states this obligation, as does the Committee on Economic, Social and Cultural Rights, therefore state parties are obliged to take affirmative action.\textsuperscript{23}

\begin{flushright}
\textsuperscript{20} Brye & Byfield 252. \\
\textsuperscript{21} Brye & Byfield 252. \\
\textsuperscript{22} Section 10 of the United Nations, General Assembly, \textit{General Comment 18 Non-discrimination}, U.N. Doc. HRI/GEN/1/Rev.1, 1994, reads as follows:  "The Committee also wishes to point out that the principle of equality sometimes requires States parties to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination prohibited by the Covenant. For example, in a State where the general conditions of a certain part of the population prevent or impair their enjoyment of human rights, the State should take specific action to correct those conditions. Such action may involve granting for a time to the part of the population concerned certain preferential treatment in specific matters as compared with the rest of the population. However, as long as such action is needed to correct discrimination in fact, it is a case of legitimate differentiation under the Covenant." \\
\end{flushright}
6.2.2 International Covenant on Economic, Social and Cultural Rights (ICESCR)

South Africa signed the International Covenant on Economic, Social and Cultural Rights in 1994, and ratified this important international covenant in January 2015.24 The eventual ratification of this Covenant was a timely tribute to former President Nelson Mandela who originally signed the International Covenant on Economic, Social and Cultural Rights on his first visit to the United Nations in New York in 1994, thereby taking a courageous step in demonstrating South Africa's intention to join the rest of the world in upholding socio-economic rights.25 The resolution to ratify the International Covenant on Economic, Social and Cultural Rights is commendable as it ensures that South Africa is finally able to honour its international duties and to consolidate its commitment to alleviate poverty and guarantee social justice for everyone.26

The International Covenant on Economic, Social and Cultural Rights affords the most comprehensive provisions in terms of the right to the enjoyment of the highest attainable standard of health.27 Advocacy for the highest possible attainable standard of health of vulnerable members of society entails recognising the obstacles that stand in the way of good healthcare for vulnerable and disadvantaged persons.28

This Covenant recognises the health needs of the vulnerable and defenceless members of society and recommends steps that signatory states have to take in

27 Article 12(1) of the International Covenant on Economic, Social and Cultural of 1976 reads as follows: “1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”
28 Chatrejee C & Sheoran G Vulnerable Groups in India, Centre For Enquiry into Health and Allied Themes (2007, Mumbai: Satam Udyog) at 25.
order to achieve healthcare goals.\textsuperscript{29} This naturally has implications for the health of the general population, as well as that of the particular vulnerable groups.\textsuperscript{30}

\textbf{6.2.3 Convention on the Rights of the Child (CRC)}

The adoption and coming into force of the Convention on the Rights of the Child (CRC) was an important historic event.\textsuperscript{31} The philosophy underpinning the Convention on the Rights of the Child derives from resistance to the nineteenth-century view of children as mere property, entirely submissive to their fathers and treasured only in economic terms.\textsuperscript{32}

Before the adoption of this Convention, a number of international instruments and organisations expressed the need for an instrument that would regulate the rights of the child, culminating in the drafting of the Convention on the Rights of the Child.\textsuperscript{33} One of these was the International Labour Organisation (ILO), which deals with issues such as minimum employment age, working hours and other conditions of employment for children and the protection of children who work under very dangerous conditions.\textsuperscript{34} Various other multilateral agreements also protect the rights of children.\textsuperscript{35}

The protection provided by the Convention on the Rights of the Child applies to children \textit{per se} and not children as constituent members of a family or other social

\textsuperscript{29} Article 12(2) of the International Covenant on Economic, Social and Cultural Rights of 1976 reads as follows:

\begin{quote}
"The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
(b) The improvement of all aspects of environmental and industrial hygiene;
(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness."
\end{quote}

\textsuperscript{30} Chatrejee & Sheoran 25.


\textsuperscript{33} Mower 12.

\textsuperscript{34} Mower 12.

\textsuperscript{35} Mower 12.
Under the Convention, a child is recognised as an independent person separate from all other persons or groups of persons. A child is not only recognised as possessing such rights but as having the capacity to assert such rights in national judicial and administrative proceedings.

A self-governing body of experts monitors the Convention on the Rights of the Child by assessing state reports, and in turn, compiling recommendations. The Convention on the Rights of the Child does not have an individual complaint mechanism. The political will of the state party as reviewed by the committee of the Convention on the Rights of the Child determines the enforcement of the Convention.

Many albino murder victims are children, as they are the most fragile and vulnerable. Such killings are a gross violation of the child’s right to life. Article 6 of the Convention on the Rights of the Child is of particular importance for children living with albinism. This provision obligates state parties to recognise children’s inherent right to life. In addition, it obliges state parties to ensure the maximum survival and development of the child.

The killing of children with albinism also constitutes a violation of their right to education as these children may be prevented from attending school or afraid to do so, as has been reported in Tanzania, out of fear of being killed. The right to education is recognised under article 28 of the Convention on the Rights of the Child.

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36 Verhellen 4.
37 Verhellen 4.
38 Verhellen 4.
39 Verhellen 4.
40 Alum et al 42-44.
41 Alum et al 42-44.
42 Alum et al 42-44.
44 Alum et al 42-44.
45 Article 28 of the Convention on the Rights of the Child reads as follows:
“1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:
(a) Make primary education compulsory and available free to all;
The Tanzanian government has introduced special measures to protect children living with albinism in the form of police escorts to accompany them to school.\textsuperscript{46} Such efforts are aimed at ending the violent murder of children living with albinism,\textsuperscript{47} and suggest that the Tanzanian government is aware of its commitment to the Convention on the Rights of the Child.\textsuperscript{48} As far as could be determined in this study, no similar initiative exists in South Africa; certainly not one initiated by the South African government.

Poor school attendance is found in other jurisdictions on the African continent. For example, the United Nations Children’s Fund (UNICEF) has joined forces with authorities in Burundi in an attempt to improve protection for children living with albinism.\textsuperscript{49} The United Nations Children’s Fund has condemned the attacks and made it clear that these children will attend school.\textsuperscript{50}

The right to equality and freedom from discrimination is the most important right for children living with albinism.\textsuperscript{51} Non-discrimination is important and has been acknowledged by the Convention on the Rights of the Child as one of the four core principles underpinning the implementation of the Convention. The principle of non-
discrimination has received special emphasis for the reason that it is fundamental to
the implementation of all other rights. Under this Convention, it is the duty of a state
party to eliminate the stigma and discrimination associated with albinism.

6.2.4 Universal Declaration of Human Rights (UDHR)

The adoption of the Universal Declaration of Human Rights (UDHR) in 1948 marked
the introduction of a declaration of human rights and fundamental freedoms by a
structured community of nations. The Universal Declaration of Human Rights is
comprised of 30 articles which set forth the civil, political, economic, social and
cultural rights to which all human beings are entitled without partiality.

Article 1 of the Universal Declaration of Human Rights provides that all human
beings are born free and equal in dignity and rights. Given that all human beings
have a sense of right and wrong, they should act in a spirit of brotherhood.
Persons living with albinism, as part of society, are entitled to protection from all forms of
human rights infringements, such as the killings and torture in Tanzania referred to
above.

Article 2 of the Declaration provides that everyone is entitled to all the rights and
freedoms set forth in the Declaration, without distinction of any kind, including race,
colour, sex, language, religion, political or other opinion, national or social origin,
property or birth. Read against the backdrop of the discussion of the equality clause
in chapter three above, article 2 makes it clear that albinism may not be a factor that
restricts the rights of persons living with this condition.

The right to life, liberty and security of the person are guaranteed in article 3 of the
Universal Declaration of Human Rights. Chapters one and three of this thesis refer
have referred to the murder of albinos and the trade in their body parts. These

52 Children's Rights Alliance “United Nations Convention on the Rights of the Child at
http://www.childrensrights.ie/childrens-rights-ireland/un-convention-rights-child (visited 10
October 2015).
53 Ntinda 249.
Dissertation submitted in partial fulfilment of the requirements of the Degree LLM (Human
Rights and Democratisation in Africa) at the Faculty of Law, Centre for Human Rights,
University of Pretoria 1-47 at 15.
55 Salewi 15.
practices violate the inherent right to life embodied in article 3 of the Universal Declaration of Human Rights.

Persons living with albinism should enjoy the benefit of protection of their rights through a range of human rights instruments by virtue of their being members of the human race.\textsuperscript{56} South Africa has an obligation to educate its citizens about their entitlement to human rights in order to uphold and honour these rights and freedoms.

6.2.5 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)

The Convention on the Elimination of All Forms of Discrimination against Women is often described as a global bill of rights for women that protects women who are at risk of facing discrimination.\textsuperscript{57} The treaty generally serves two purposes, namely:

- to establish the principle of non-discrimination with respect to the enjoyment of all human rights for women; and

- to the extent required, to provide specificity to the general provisions against discrimination in the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, tailoring the anti-discrimination clauses more specifically for women.\textsuperscript{58}

The Convention on the Elimination of All Forms of Discrimination against Women offers a foundation for realising equality between women and men by ensuring that women have equal access to opportunities within the public and political sphere.

It is significant to note that Tanzania has indicated a commitment to the Convention on the Elimination of All Forms of Discrimination against Women through taking appropriate measures to realise equal political opportunities for women with albinism by appointing a woman with albinism to a special seat in Parliament.\textsuperscript{59} South Africa should consider implementing similar measures for the purpose of ensuring that

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{56} Salewi 14.
\item \textsuperscript{57} The Convention on the Elimination of All Forms of Discrimination (1249 UNTS 13 entered into force on 13 September 1981).
\item \textsuperscript{58} See the preamble of the Convention on the Elimination of All Forms of Discrimination of 1981.
\end{itemize}
\end{footnotesize}
vulnerable women with albinism can enjoy their human rights and fundamental freedoms. As South Africa is a party to the Convention on the Elimination of All Forms of Discrimination against Women, it is legally bound to put into practice the provisions of the Convention. Although one can argue that persons living with albinism are no different from other women with certain conditions and health risks, such as HIV/AIDS, the thesis submits that none of these other health conditions cause their sufferers to be targeted in the very unique way that albinos are. This thesis has specifically drawn attention to the dangerous cleansing myth that affects young girls and women living with albinism. Young girls and women with albinism are at a very high risk of being raped by ignorant HIV-infected men. The stigmatisation of and discrimination against HIV-positive persons are severe but not as dangerous as those relating to persons living with albinism who have special needs such as focused trauma counselling for victims of assault, discrimination, rape and amputation in addition to cancer.

6.2.6 International Convention on the Elimination of All Forms of Racial Discrimination (CERD)

Persons living with albinism are protected by the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) which seeks to eliminate discrimination based on race, colour, descent, or national or ethnic origin.\(^{60}\) This Convention is obviously of value within the context of discrimination against persons living with albinism.\(^{61}\) As discussed in this thesis, these people suffer discrimination for the reason that they belong to a category of people regarded as a curse in the majority of African communities.\(^{62}\) The Convention prohibits:

any form of distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.\(^{63}\)


\(^{61}\) Salewi 16.

\(^{62}\) Salewi 16.

\(^{63}\) Article 1 of the Convention on the Elimination of All Forms of Racial Discrimination of 1969.
The Convention on the Elimination of All Forms of Racial Discrimination strives to ensure that persons living with albinism enjoy and exercise the human rights which are fundamental to their freedom in the same way as all other members of society. The disabling social stereotypes and mystification surrounding albinism are obstacles to the social integration of persons with albinism and as a result, they are denied a variety of opportunities in life. The Convention stipulates the need for measures to secure adequate protection against such discrimination.  

Article 2; 3; and 4 of the Convention on the Elimination of All Forms of Racial Discrimination of 1969 read as follows:

Article 2
"1. States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races, and, to this end: (a) Each State Party undertakes to engage in no act or practice of racial discrimination against persons, groups of persons or institutions and to ensure that all public authorities and public institutions, national and local, shall act in conformity with this obligation; (b) Each State Party undertakes not to sponsor, defend or support racial discrimination by any persons or organizations; (c) Each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists; (d) Each State Party shall prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization; (e) Each State Party undertakes to encourage, where appropriate, integrationist multi-racial organizations and movements and other means of eliminating barriers between races, and to discourage anything which tends to strengthen racial division.

2. States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms. These measures shall in no case entail as a consequence the maintenance of unequal or separate rights for different racial groups after the objectives for which they were taken have been achieved."  

Article 3
"States Parties particularly condemn racial segregation and apartheid and undertake to prevent, prohibit and eradicate all practices of this nature in territories under their jurisdiction."  

Article 4
"States Parties condemn all propaganda and all organizations which are based on ideas or theories of superiority of one race or group of persons of one colour or ethnic origin, or which attempt to justify or promote racial hatred and discrimination in any form, and undertake to adopt immediate and positive measures designed to eradicate all incitement to, or acts of, such discrimination and, to this end, with due regard to the principles embodied in the Universal Declaration of Human Rights and the rights expressly set forth in article 5 of this Convention, inter alia: (a) Shall declare an offence punishable by law all dissemination of ideas based on racial superiority or hatred, incitement to racial discrimination, as well as all acts of violence or incitement to such acts against any race or group of persons of another colour or ethnic origin, and also the provision of any assistance to racist activities, including the financing thereof;
6.2.7 Vienna Declaration on Human Rights (VDHR)

The preamble of the Vienna Declaration on Human Rights emphasises that as:

[...] all human rights derive from the dignity and worth inherent in the human person, [...] the human person is the central subject of human rights and fundamental freedoms, and consequently should be the principal beneficiary and should participate actively in the realization of the rights and freedoms. The above provision aims to reaffirm what has already been stated in the UDHR of 1948, namely that all human beings are vested with human rights which are innate to them by virtue of being human.

The first paragraph of the Vienna Declaration also states that human rights and fundamental freedoms are the birth right of all human beings and that the protection and promotion of these rights and freedoms is the primary responsibility of Government.

This statement highlights the obligation of all governments to ensure the protection of its citizens’ human rights without exception. The Declaration stresses the critical role which states are required to play in guaranteeing that the rights and freedoms of all their citizens, including those of persons living with albinism, are protected and respected.


On 13 June 2013, the United Nations Human Rights Council in Geneva adopted a ground-breaking resolution at international level which identifies and addresses the attacks and discrimination faced by persons living with albinism in several countries. The United Nations Human Rights Council called on independent states to take appropriate measures to protect albinos.

(b) Shall declare illegal and prohibit organizations, and also organized and all other propaganda activities, which promote and incite racial discrimination, and shall recognize participation in such organizations or activities as an offence punishable by law;
(c) Shall not permit public authorities or public institutions, national or local, to promote or incite racial discrimination.”

In this Resolution, the Council categorically denounces attacks on persons living with albinism and urges states to take action against the criminals who target albinos.\textsuperscript{67} The Resolution calls for objective, swift and effective inquiries into attacks on persons living with albinism as well as appropriate remediation for family members.\textsuperscript{68} The text in this Resolution strongly condemns human rights violations against this vulnerable group and calls for firm respect of their fundamental rights and choices.\textsuperscript{69} The fact that this Resolution was taken in 2013 is evidence of the recognition of the importance of the special protection that persons living with albinism require from national governments.

6.3 Regional human rights system

6.3.1 African Charter on Human and Peoples’ Rights (ACHPR)

The African Charter on Human and Peoples’ Rights (ACHPR) is an African regional human rights instrument which was adopted by the Organisation of African Unity (OAU), now known as the African Union (AU), and came into effect on 21 October 1986.\textsuperscript{70}

No definition of “peoples” is found in the African Charter.\textsuperscript{71} The drafters may intentionally have decided not to define the concept.\textsuperscript{72} The legislative intention of the African Charter and the jurisprudence of the African Commission can offer some guidance in this regard.\textsuperscript{73} The drafters of the African Charter sought to give the Charter an African content.\textsuperscript{74} Characteristically, peoples’ rights are collective in that they apply to a body of people with a common differentiating characteristic.\textsuperscript{75}

\begin{itemize}
\item \textsuperscript{67} United Nations, General Assembly, Resolution A/HRC/RS/23/13, 13 June 2013, paragraph 2.
\item \textsuperscript{68} United Nations, General Assembly, Resolution A/HRC/RS/23/13, 13 June 2013, paragraph 2.
\item \textsuperscript{69} United Nations, General Assembly, Resolution A/HRC/RS/23/13, 13 June 2013, paragraph 4.
\item \textsuperscript{72} Dersso 360-364.
\item \textsuperscript{73} Dersso 360-364.
\item \textsuperscript{74} Dersso 360-364.
\item \textsuperscript{75} Dersso 360-364.
\end{itemize}
Peoples' rights as addressed in the African Charter are a powerful example of the African notion of society and a person. The status of an individual in society is hardly separated from the community to which they belong. Despite the fact that a person is an individual, such an individual exists principally by virtue of her affiliation with the group of her birth. In this sense, peoples' rights are imprinted with the shared character of African societies which is contrary to the Western individualistic approach.

The African Commission has not attempted to define the term “peoples” directly. The term “person” has been used by the Commission in different circumstances. The term “peoples” is used to denote all the inhabitants of a particular state rather than the entire African continent. When the African Commission heard cases of the violation of peoples' rights, the term “person” was used to denote a segment of the population of a country. Such an interpretation does not rule out an understanding that marginalised groups of people are protected by the African Charter. Dersso argues that this is predominantly true in cases where there is a “self-identifying minority.” The Katangese Congress v Zaire and the Social and Economic Rights Action Center and Center for Economic and Social Rights v Nigeria, African Commission on Human and Peoples’ cases are such examples.

In the Katangese case sub-state governance was advised as an alternative to “secession for independence.” The President of the Katangese people called for recognition of the independence of Katanga by the African Commission on the basis of article 20(1) of the African Charter. Based on article 20, the Commission held

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76 Dersso 360-364.
77 Dersso 360-364.
78 Dersso 360-364.
79 Dersso 360-364.
80 Dersso 360-364.
83 Katangese Peoples' Congress case, paragraph [1].
that all people have the right to self-determination and that there may possibly be a "controversy as to the definition of peoples and the content of the right". The Commission, in its concluding remarks, stated that the matter at hand had to do with the issue of self-determination for the Katangese and not self-determination for Zaire as a people. The Commission also held that there was no evidence to substantiate the allegation that Katangese people had been barred from taking part in Government under article 13(1). In its decision on the case, the African Commission referred to the Katangese as a people, without clarifying whether the Katangese consisted of one or more ethnic groups. In this case it is worth noting that although the Katangese make up just a fraction of the population of Zaire, they classify themselves as a people, and for this reason they fall within the ambit of peoples' rights under the African Charter.

The Ogoni case involved a claim regarding the environmental rights of people under the African Charter, as protected by article 24. In this case it was alleged that the military government of Nigeria was implicated in the production of oil through its state oil company, the Nigerian National Petroleum Company (NNPC). The government of Nigeria is said to have been the main shareholder in this company in association with Shell Petroleum Development Corporation (SPDC). Their operations were alleged to have shown no consideration for the living environment and health of the Ogoni people, with the result that the Ogoni were exposed to ecologically dangerous waste and developed health complications. The waste referred to included the disposal of toxic waste into neighbouring waterways, which also amounts to an infringement of certain international environmental standards. Such contamination of water, soil and air has severe short- and long-term health consequences, such as

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84 Katangese Peoples' Congress case, paragraph [2]. Also see Suski 30.
85 Katangese Peoples' Congress case, paragraphs [3-4]. Also see Suski 30.
86 Katangese Peoples' Congress case, paragraphs [3-4]. Also see Suski 30.
87 Dersso 366-367.
88 Dersso 366-367.
89 Dersso 366-367.
90 Ogoni case, paragraphs [1-9].
91 Ogoni case, paragraph [1].
92 Ogoni case, paragraph [1].
93 Ogoni case, paragraph [2].
94 Ogoni case, paragraph [2].
“skin infections, gastrointestinal and respiratory ailments, and increased risk of cancers, and neurological and reproductive problems”.  

The Commission found the Federal Republic of Nigeria to be in violation of articles 2, 4, 14, 16, 18(1), 21 and 24 of the African Charter on Human and Peoples' Rights, and made a petition to the government of Nigeria to guarantee the protection of the environment, health and livelihood of the people of Ogoniland.

The African Commission uses the word “people” interchangeably as referring to the Ogoni community and the Ogonis, apparently to emphasise the distinctiveness of a group with its own standing in Nigerian society. The intention of the distinction that the African Commission makes between the group (the Ogoni people) and the state of Nigeria appears to be to treat the group as being entitled to peoples’ rights and Nigeria as being the holder of the accountability imposed by these rights.

The relevance for this study of the cases discussed above is that the complainants are distinct communities with minority status. In addition to being a vulnerable group, persons living with albinism are similarly a minority group, particularly on the African continent.

The African Charter guarantees the right to life under article 4. Article 4 of the African Charter reads as follows:

> Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.

In regulating the right to life, unlike other international and regional instruments, the African Charter is not supported by protocols which prohibit the death penalty.

The African Charter on Human and Peoples' Rights explicitly and strongly condemns the taking of any human life in Africa. Persons living with albinism are also under the protection of this Charter and their lives are protected from any arbitrary killings.

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95 Ogoni case, paragraph [2].
96 Ogoni case, paragraphs [48] and [50-62].
97 Dersso 371.
98 Dersso 371.
Under the African Charter, the right to life is not merely described as the legal foundation of all other rights, but as a right that is associated with the moral, physical and spiritual existence of a human being.  

The African Commission on Human and Peoples’ Rights was instituted under article 30, with the authority to promote and protect human and peoples’ rights, as well as to interpret the provisions of the Charter. The Commission may possibly take into account personal complaints regarding a state party’s violation of human rights contained in the Charter.  

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101 Article 30 of the African Charter on Human and Peoples’ Rights of 1986 reads as follows: “An African Commission on Human and Peoples’ Rights, hereinafter called "the Commission", shall be established within the Organization of African Unity to promote human and peoples’ rights and ensure their protection in Africa.”

102 Article 45 (3) of the African Charter of 1986 reads as follows: “The functions of the Commission shall be: Interpret all the provisions of the present Charter at the request of a State party, an institution of the OAU or an African Organization recognized by the OAU.”

Concerned at the widespread of stigma, social exclusion and discrimination of people with albinism and recalling its mandate to ensure the protection of human and people’s rights under the African Charter on Human and Peoples Rights, the African Commission on Human and Peoples Rights adopted the Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism. The Resolution calls upon states to take appropriate measures to ensure the effective protection of people with albinism and to increase education and public awareness-raising activities. In collaboration with relevant regional and international organizations, State Parties are urged to promote, bilateral, regional and international initiatives aimed at protecting persons with albinism.

The Resolution also calls upon State Parties to ensure responsibility through impartial conduct, prompt and effective investigations into attacks against persons with albinism. State parties are also called upon to prosecute those responsible and to ensure that victims together with their families have access to appropriate remedies. The initiatives in the Resolution on Prevention of Attacks and Discrimination against Persons with Albinism places the primary responsibility in the hands of the state to protect persons with albinism and their family members. Resolution on Prevention of Attacks and Discrimination against Persons with Albinism, adopted at the African Commission on Human and Peoples’ Rights, meeting at its 54th Ordinary Session held from 22 October to 5 November 2013 in Banjul, The Gambia, see African Commission on Human and Peoples’ Rights “263 Resolution on Prevention of Attacks and at http://www.achpr.org/sessions/54th/resolutions/263/ (Visited 1 June 2016).

103 Article 55 of the African Charter of 1986 reads as follows: “Before each Session, the Secretary of the Commission shall make a list of the communications other than those of State parties to the present Charter and transmit them to the members of the Commission, who shall indicate which communications should be considered by the Commission.”
6.3.2 African Charter on the Rights and Welfare of the Child (ACRWC)


According to the African Charter on the Rights and Welfare of the Child, a child is a human being below the age of eighteen years. The Charter acknowledges the child’s distinctive and honoured position in African society and that children require protection against abuse and must be granted special care.

African children are notoriously exposed to various forms of maltreatment and deprivation such as economic and sexual abuse, gender discrimination within the educational system, the health care system and involvement in armed conflict.

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107 Article 2 of the African Charter on the Rights and Welfare of the Child of 1999 reads as follows: “Definition of a Child for the purposes of this Charter ‘a child means every human being below the age of 18 years.’”

108 Ekundayo at 147. “One of the reasons for having an Africa Children’s Charter was the feeling that Africa had been underrepresented during the drafting process of the CRC (only Algeria, Morocco, Senegal and Egypt participated meaningfully in the drafting process). A second reason was the thinking that Africa needed to have a charter for children which reflected the specifics of the African context.”

Additional issues affecting African children include child prostitution, migration, early marriages, child-headed households, street children and extreme poverty.\textsuperscript{110}

Earlier, this thesis stressed how children with albinism are victims of violence in the form of murder and being targeted for their body parts. An escalating number of children do not attend school due to the fear of violence and discrimination in schools. The African Charter on the Rights and Welfare of the Child is an important

\begin{quote}
\textit{distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status, RECALLING the Declaration on the Rights and Welfare of the African Child (AHG/ST.4 Rev.1) adopted by the Assembly of Heads of State and Government of the Organization of African Unity, at its Sixteenth Ordinary Session in Monrovia, Liberia, from 17 to 20 July 1979, recognized the need to take appropriate measures to promote and protect the rights and welfare of the African Child, NOTING WITH CONCERN that the situation of most African children, remains critical due to the unique factors of their socio-economic, cultural, traditional and developmental circumstances, natural disasters, armed conflicts, exploitation and hunger, and on account of the child's physical and mental immaturity he/she needs special safeguards and care, RECOGNIZING that the child occupies a unique and privileged position in the African society and that for the full and harmonious development of his personality, the child should grow up in a family environment in an atmosphere of happiness, love and understanding, RECOGNIZING that the child, due to the needs of his physical and mental development requires particular care with regard to health, physical, mental, moral and social development, and requires legal protection in conditions of freedom, dignity and security, TAKING INTO CONSIDERATION the virtues of their cultural heritage, historical background and the values of the African civilization which should inspire and characterize their reflection on the concept of the rights and welfare of the child, CONSIDERING that the promotion and protection of the rights and welfare of the child also implies the performance of duties on the part of everyone, REAFFIRMING ADHERENCE to the principles of the rights and welfare of the child contained in the declaration, conventions and other instruments of the Organization of African Unity and in the United Nations and in particular the United Nations Convention on the Rights of the Child; and the OAU Heads of State and Government's Declaration on the Rights and Welfare of the African Child.}''
\end{quote}


\textbf{Sexual Exploitation}

"1. States Parties to the present Charter shall undertake to protect the child from all forms of sexual exploitation and sexual abuse and shall in particular take measures to prevent:
(a) the inducement, coercion or encouragement of a child to engage in any sexual activity;
(b) the use of children in prostitution or other sexual practices;
(c) the use of children in pornographic activities, performances and materials."

\textbf{Protection against Harmful Social and Cultural Practices}

"1. States Parties to the present Charter shall take all appropriate measures to eliminate harmful social and cultural practices affecting the welfare, dignity, normal growth and development of the child and in particular:
(a) those customs and practices prejudicial to the health or life of the child; and
(b) those customs and practices discriminatory to the child on the grounds of sex or other status.
2. Child marriage and the betrothal of girls and boys shall be prohibited and effective action, including legislation, shall be taken to specify the minimum age of marriage to be 18 years and make registration of all marriages in an official registry compulsory."
instrument for the protection of the rights of children with albinism, as it emphasises the protection of children from violence, discrimination, ill-treatment, and negative social and cultural practices, including all forms of exploitation or sexual abuse and the kidnapping of and trafficking in children.

6.4 Conclusion

Persons living with albinism constitute a small and vulnerable group whose rights are constantly infringed upon without redress. The above discussion highlights the violation of such rights and submits that a more focused framework for the protection of the rights of albinos is required at international level. Every state has a duty to honour all the instruments and treaties which it has ratified.

South Africa, as a constitutional democracy with a progressive bill of rights and a history of inequality, violence and discrimination, should make a special effort to ensure that the life, dignity and equal worth of all citizens is respected, and that adherence to the above treaties and covenants becomes a priority, particularly in terms of advancing the rights of persons living with albinism.
CHAPTER 7: CONCLUSION AND RECOMMENDATIONS

“Another advocacy tool that can be used to raise awareness of the human rights situation of persons with albinism is through engaging artists in the endeavour, as they can reach out to a greater number of people through their voices and work. In that regard, it is noteworthy that, on 5 December 2013, Salif Keita, musician and advocate for the rights of persons with albinism, performed at the Palais des Nations in Geneva.”

7.1 Summary: Overview of chapters

Mistaken beliefs and myths, profoundly influenced by stereotypes, put the safety and lives of persons living with albinism in constant danger, not to mention the severe human rights violations faced by this group as a result of multiple forms of discrimination.

Despite legal provisions being in place to protect and promote human rights for all South Africans including albinos, such provisions are not implemented efficiently, with the result that insufficient protection is given to persons living with albinism.

Chapter one of this thesis addresses specific cultural beliefs, superstitions, myths and false perceptions which surround albinism and notes how most, if not all, of these beliefs are wrong and very harmful to the emotional, physical and psychological wellbeing of albinos. As pointed out in this chapter, albinism is mystified in popular culture, with albinos often depicted as figures of evil. This portrayal forms the backdrop against which the violation of their rights can be understood, and for this reason, chapter one briefly alludes to some of the fundamental rights, discussed in more detail later in the thesis, which are at risk of violation as a result of this depiction. The apex of the threat to albinos on the African continent finds expression in the lucrative trade in albino body parts and the intentional killing of persons living with albinism for whatever reason.

The vulnerability of persons living with albinism is heightened as a result of the unique health concerns associated with their condition. In order to provide a better understanding of the health needs of persons living with albinism and to contextualise the discussion of the fundamental rights at threat in chapter three,

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Chapter two explains some of the clinical aspects of albinism. The susceptibility of albinos to skin cancer leading to the premature death of many is one result of the lack of insight into the health needs of people with albinism. They are either unaware of this danger or only informed when the cancer has reached an advanced stage. Severe eye problems, which in many cases translate into blindness, are another health issue which is affecting persons with albinism.

In light of all the health problems associated with albinism, chapter three discusses the right of access to health care services enshrined in the Constitution. One of the recommendations made in this chapter is that the South African government should implement proper legislative and budgetary measures to improve the progressive realisation of this right for persons living with albinism. This would include access to essential subsidised items such as sunscreen, special sunglasses and low vision aids, to mention but a few. The vicious cycle of social ostracisation, stigmatisation and discrimination means that persons living with albinism are reluctant to seek medical help and even if they do, they may find themselves at the back of the queue for such services.

In chapter three, the core of this thesis, both skin colour and appearance are revealed as distinguishing traits that set persons living with albinism apart. This chapter cites examples of how skin tone bias affects a person’s social interaction with others, providing a platform for a discussion of the as yet scantily explored role of skin tone bias in South Africa and its legal implications. Inter- and intra-racial prejudicial treatment of people on grounds of skin tone in the context of albinism is addressed. The chapter also examines the possibility of redress for unfair discrimination relating to colour in terms of section 9(3) of the Constitution. It is asserted that discrimination redress for persons living with albinism should be possible on the basis of colour as a prohibited ground independent from race or ethnic considerations. In this regard, skin tone discrimination should be viewed as a distinct form of colour discrimination. Drawing from international case law and literature, it is submitted that persons living with albinism who are unfairly discriminated against on the basis of their unique skin colour should be able to rely on the Constitution’s equality clause which prohibits colour discrimination. This thesis acknowledges the sad reality that despite the protection afforded by the Constitution, persons living with albinism continue to suffer severe discrimination in both the
private and public sphere and as a result are not fully participating in society as they should.

Chapter three of the thesis also discusses the mistaken belief that albino body parts have magical powers and how this belief has led to the murder of hundreds of albinos and the sale of their body parts by unscrupulous dealers, particularly in Tanzania where trade in albino body parts for witchdoctor rituals is rife. In South Africa, there have been fewer albino muti murders than in Tanzania where the use of body parts taken from albinos is part of a broader practice of using human body parts for muti. It is also acknowledged that muti murder in South Africa does not only affect persons with albinism, but that muti murders in general are not new. The thesis also highlighted the prevalence of infanticide of newborns with albinism, which is still an underreported phenomenon.

The discussion of the intentional killing of albinos focuses on how the current legal framework, and in particular the protection of the right to life in terms of the Constitution, protects persons with albinism. The thesis argues that the courts should move away from judicial restraint and fulfil their constitutional mandate by further developing the right to life as encompassing the right to a “safe” life in situations where other specific entitlements fail to do so.

Chapter three also notes how a special school is an ideal setting for pupils affected by albinism. The thesis acknowledges the limited capacity of special schools, particularly in rural areas, and highlights the dropout of pupils with albinism which naturally results in illiteracy and low skills amongst this group of people. With this in mind, the thesis discusses the policy of inclusive education which incorporates a range of models to integrate school-going children with special needs into ordinary schools.

In addition, chapter three discusses the right to privacy in the context of albinism with particular reference to the issue of consent to medical procedures as well as privacy and confidentiality of health, genetic and genomic information.

While chapter three discusses the internal limitations clause analysis in the context of socio-economic rights, the constitutional scrutiny in chapter four particularly focuses on the right to life and the right to equality. Chapter four discusses section
36 of the Constitution, the limitations clause, in as far as it stipulates a test which a limitation of rights must meet to be considered reasonable and justifiable. This section emphasises two essential concepts, namely reasonableness and proportionality. Amongst other factors listed in section 36, any restriction of a right must be reasonable and justifiable in that the effect or extent of the limitation must correspond with the purpose of the limitation.

Whether or not albinism is a disability is explored in chapter five. The question whether persons living with albinism ought to contend their discrimination on the basis of disability is a question of fact which the thesis asserts should be founded on a clear understanding of what disability is. It is apparent from this thesis that South Africa has no centralised disability legislation since it is generally assumed that the range of diverse statutes and state department policies regulating disability matters are sufficient.

Chapter five provides evidence of how our courts have interpreted disability by adopting an excessively narrow guiding principle in terms of who qualifies as disabled. It is clear that this definition of disability is centered on the existence of an actual impairment and on the degree of impairment. To qualify under the protected class, such impairment must significantly restrict the competence required to carry out the inherent purpose of a job. The definition is based on the consequences of the impairment in that it has to limit the complainant’s admission into or progression in employment. The current working definition of disability stems from the IMATU & Another v City of Cape Town case which greatly relied on a foreign precedent, namely the case of Sutton v United Airlines. Through a series of court cases, the United States Supreme Court narrowed the protection afforded by the Americans with Disabilities Act, with the result that people whom the Act was initially intended to protect have been excluded, for example people with epilepsy, diabetes, muscular dystrophy and other conditions. The American court cases discussed in the context of albinism indicate that under the then Americans with Disabilities Act, an action against discrimination required proof of a disability that substantially limits one or

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2 IMATU & Another v City of Cape Town 2005 (11) BLLR 1084 (LC) 1091.
more major life activities. Such proof involves a detailed medical inquiry. It must also be shown that all possible corrective measures have been utilised, and lastly, that discrimination has in fact occurred. This preoccupation with the medical definition of disability diverts attention from the very real societal problems that the Americans with Disabilities Act was intended to address.

By following the Sutton case, South African courts have adopted a restrictive approach to disability which can be disputed in light of the fact that the decision in the Sutton case has since been overturned. The Americans with Disabilities Amendment Act of 2008 overturned the controversial key ruling in the Sutton case which involved a strict construal of “substantially limits”. This redefinition of disability has broadened the number and types of persons who are protected under the Americans with Disabilities Act, and highlights the fact that the emphasis must be on whether discrimination has occurred rather than a strict definition of disability.

South Africa’s narrow approach to disability, as pointed out, excludes many disabled people from protection on the grounds that their impairment is not severe enough in itself, or that they are coping so satisfactorily with the impairment that they no longer require protection from discrimination. This position stands irrespective of the merits of the victim’s discriminatory claim, and the victim is deprived of the opportunity to attest to unfair treatment in a court of law. This has had the adverse effect that persons who can mitigate their disabilities and are evidently capable of working are unable to rely on the Employment Equity Act\(^5\) for protection against disability discrimination.

This narrow approach does not take into account the social constructions of disability. In an attempt to obtain appropriate protection for persons living with albinism, this thesis further explores how South Africa’s current working definition of disability compares with the third prong of the definition of disability in the Americans with Disabilities Amendment Act. While the South African Employment Equity Act does not regulate “perceived disability”, the third component of the definition of disability in the Americans with Disabilities Amendment Act focuses less on the extent of a person’s actual impairment and more on how others perceive the

\(^{5}\) The Employment Equity Act 55 of 1998.
individual and the effect of such perceptions on attitudes towards and assumptions about their abilities.\textsuperscript{6} This subcategory of the definition of disability protects those who are "perceived" as having a disability from employment decisions grounded on stereotypes or mistaken beliefs about disability. The court cases that have presided over an enquiry into perceived disability discrimination point to the danger of employers taking exceedingly far-reaching decisions as to an employee’s restrictions without adequate medical justification.

In addition, chapter five discusses how the United Nations Convention on Persons with Disabilities advances an alternative way in which persons living with albinism may be protected against disability discrimination. The Convention asserts the social construction of disability by stipulating that the definition of disability ought to be advanced not from the viewpoint of the supposed medical condition of an individual, but from the perspectives of society which disable persons by generating attitudinal and physical barriers preventing them from effectively contributing to society. The Convention thus goes beyond the question of “access to the physical environment” and tackles the broader concerns of equality and the elimination of legal, social and attitudinal obstructions to the participation of people with disabilities. The thesis

\textsuperscript{6} Section 4 of the Americans with Disabilities Amendment Act Amends Section 3 of the Americans with Disabilities Act of 1990 to read as follows:

Definition of disability.

"As used in this Act:

(1) Disability.—The term ‘disability’ means, with respect to an individual—

(A) a physical or mental impairment that substantially limits one or more major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment (as described in paragraph (3)).

(2) Major life activities.—

(A) In general.—For purposes of paragraph (1), major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

(B) Major bodily functions.—For purposes of paragraph (1), a major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

(3) Regarded as having such an impairment.—For purposes of paragraph (1)(C):

(A) An individual meets the requirement of ‘being regarded as having such an impairment’ if the individual establishes that he or she has been subjected to an action prohibited under this Act because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.

(B) Paragraph (1)(C) shall not apply to impairments that are transitory and minor. A transitory impairment is impairment with an actual or expected duration of 6 months or less."

Mish RM “Regarded as Disabled” ADA Claims” (1998) 1 (1) Journal of Labour and Employment 159-175 at 159.
emphasises the Convention’s comprehensive definition of disability as it is responsive to socio-economic barriers as constituent elements of disability.

The question of whether albinism is a disability or not is also relevant in terms of whether persons living with albinism qualify for a social grant in South Africa. Since eligibility to the social security grant is based on many factors, the second part of chapter five gives a general overview of the requirements to qualify for the disability grant and contextualises this in terms of the position of persons living with albinism who advocate for support grants. In view of the fact that South Africa currently relies on the medical model for access to grants, and also considering that the grants needed by persons with albinism are for the purposes of improving their health, for example through access to sunscreen lotion and regular visits to dermatologists as well as general consultations, it appears that such funds are out of the reach of persons with albinism as they can only be accessed by persons who are medically certified as disabled to the extent that they cannot work and provide for themselves.

Chapter six of the thesis explores the international and regional instruments relevant to the protection of the rights of persons living with albinism. Finally, this chapter, chapter seven, presents the conclusion and recommendations of the study.

7.2 Recommendations

The study makes the following recommendations.

7.2.1 Recommendations for legislative reform on the definition of disability in the Employment Equity Act 55 of 1998

In light of the unwillingness of our courts to interpret the definition of disability in an inclusive manner, a reformulation of the Employment Equity Act’s definition of disability and the establishment of civil rights protection for South Africans who experience disability-based discrimination is long overdue. The recommendations emanating from this study are directly related to the amendments to the Americans with Disability Act, particularly the striking down of the restrictive interpretation of disability in the Sutton case which has been so regularly applied by our courts.

- The explanations given by the courts of what constitutes disability in terms of the Employment Equity Act have had the distressing effect of imposing more
and more restrictions on eligibility for protection. As a matter of legislative reform, the thesis proposes a new statutory definition of disability for the Employment Equity Act which does not require proof of substantial limitations in major life activities. This will direct attention away from the preoccupation with and adherence to a strictly medical definition of disability and focus attention on whether discrimination has occurred. In this regard it is recommended that the existence of a physical or mental impairment or health condition, or the perception of a physical or mental impairment or health condition be determined without factoring in any mitigating measures such as medication or auxiliary aids, since protection against discrimination has been lost to many disabled people in instances such as where they are coping satisfactorily as a result of using auxiliary aids. Such a definition will allow persons who demonstrate an impairment or health condition, or the perception of one, to raise the real issue of whether they have been treated unfairly or discriminated against on the grounds of the impairment or health condition.

- As a matter of legislative reform, people who are mistakenly perceived as disabled must under normal circumstances fall under the protection of laws prohibiting discrimination on the grounds of disability. The goal is to extend civil rights protection to the countless employees who experience discrimination due to the myths and stereotypes which society continues to associate with certain impairments, diagnoses or characteristics. In other words, sanctions against perceived disability discrimination, if taken seriously, can prevent subjective employer behaviour, which is demonstrably the main purpose for discrimination legislation. It is therefore suggested that the Employment Equity Act, which currently has no explicit provision for ‘perceived disability’, should extend the categories of persons protected by the Act to cater for individuals who are erroneously perceived as disabled. The recommended statutory reform would put perceived disability protection on an equal footing with the protection currently offered under the Employment Equity Act. This proposal, as shown in chapter five, is well grounded in the international approach to disability, the social construction of disability as enshrined in the United Nations Convention on the Rights of Persons with Disabilities and the Americans with Disability Amendment Act. Under the
Americans with Disabilities Amendment Act, this subcategory of the definition of disability protects those who are "perceived" as having a disability from employment decisions grounded on stereotypes or mistaken beliefs about disability. If implemented, such modifications to the definition of disability will assist in addressing its current restrictiveness. An employee with albinism would therefore be protected from discrimination emanating from misconceptions, myths and stereotypes about their condition.

- The question of who exactly qualifies under the class protected by perceived disability discrimination legislation is ultimately a policy consideration for legislative determination.

7.2.2 Recommendations with respect to albinism and disability in the context of the Social Assistance Grant

- Taking into account the complexity of the medical and means tests for accessing disability grants under the Social Assistance Act, the study recommends that Government should consider implementing a chronic disease grant. This would very likely benefit persons living with albinism considering that the Cancer Association of South Africa has acknowledged that these persons are prone to chronic ailments such as skin cancer. Such a grant would also help various other categories of people with chronic ailments to improve their health care.

- In light of the fact that there have been several calls by people with albinism for access to the Disability Grant for the purposes of improving their health, for example to use the grant to access sunscreen lotions and regular medical consultations as previously mentioned, what follows are recommendations regarding their deprived access to health care needs.

7.2.3 Recommendations relating to the access to health care needs of persons with albinism

- The Department of Health’s Strategic Plan for 2014-2019 covers a range of critical health issues, including the national health insurance scheme,

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tuberculosis, the damaging effects of smoking and alcohol abuse, and lifestyle diseases. The study recommends that the health concerns of persons living with albinism be added to this list of critical health issues.

- Against the backdrop of the right to health care services enshrined in the South African Constitution, this thesis proposes that persons living with albinism should take the first step as a group and approach the court to challenge the Government’s failure to progressively realise their right of access to health care services by neglecting to provide preventative services such as dermatological skin checks, eye checks and protective sunscreen lotion, as well as vision aids, and eye correction surgery, within its available resources. Although one can argue that persons living with albinism are no different from other classes of persons with health risks, such as diabetics or persons with hypertension, the thesis submits that none of these other health conditions cause their sufferers to be targeted in the very unique way that albinos are. The stigmatisation of and discrimination against HIV-positive persons are severe but not as dangerous as those relating to persons living with albinism who have special needs such as focused trauma counselling for victims of assault, discrimination, rape and amputation in addition to cancer.

- Building from the previous case study in chapter six on the eligibility of vulnerable groups to approach the African Commission on Human and Peoples’ Rights for the purpose of lodging a complaint on the violation of rights in the African Charter on Human and People Right, the thesis recommends that persons with albinism should approach the African Commission on Human and Peoples’ Rights should the South African courts fail to provide any interim or and long-lasting measures to circumvent the continued allegations of deprived access to their required health care needs. In its capacity as the supervisory body on the compliance with the African Charter on Human and Peoples Rights, the African Commission is obliged to act as the socio-political arm for this vulnerable group of people and should exert pressure to the government of South Africa to make every effort possible to ensure the availability of the required health care services.

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7.2.4 Recommendations on discriminatory conduct relating to persons with albinism

- Policy makers need to explore opportunities to review laws so that the predicaments facing persons living with albinism are addressed. If Government is to tackle the issue of unfair discrimination against persons with albinism effectively, it needs to take focused action to ensure the effective implementation of such equality and anti-discrimination laws. This thesis submits that historically, persons living with albinism have found themselves on the margins of society and that the time has come for proactive measures to attend to the challenges facing this very specific and unique vulnerable group. In spite of its long existence, colour discrimination has time and again been subsumed by racism because of the divides caused by distinctions based on skin colour during apartheid. Since colourism is associated with diverse stereotypes and stigma based on skin tone rather than ethnicity, the thesis recommends that it be recognised as a distinct type of discrimination not affiliated to race. Persons with oculocutaneous albinism who are victims of skin tone discrimination should challenge such discrimination by approaching the courts to seek redress, and the courts should extend the interpretation of colour as a ground of discrimination in order to protect these persons. The inclusion of colour separately from race in the constitution as grounds of protection from discrimination suggests that this may have been done to provide for extraordinary instances.

- Colourism, also known as skin tone discrimination, may be interracial or intra-racial. Intra-racial skin colour discrimination takes place when an affiliate of a particular racial group makes a distinction on the basis of skin colour between persons of the same racial group, while interracial colourism takes place when an affiliate of a particular racial group makes a distinction on the basis of skin colour between persons of another racial group. Given that there is evidence of colourism against albinos within racial groups, the study also recommends that there be greater engagement and research on intra-racial discrimination; a subject which has received scant attention in literature and in legal research due to the more common focus on comparisons between blacks and whites as racial groups.
Very few persons living with albinism are found in high profile positions in Africa. In Tanzania, President Jakaya Kikwete appointed Al-Shymaa John, an albino and member of the Tanzania Albino Society (TAS), as a Member of Parliament under the special seat category. South Africa could perhaps follow suit. By appointing persons with albinism in distinguished profile positions based on merit, the general public can be encouraged to realise that albinos pose no social threat and may even be seen as role models. It is hoped that equal access to socio-economic and political opportunities for persons with albinism will, in time, serve to lessen the myths, stereotypes and other false notions surrounding albinism.

7.2.5 Recommendations regarding the murder of person with albinism

- A new wave of evidence as recent as the 25th of September 2015 is indicative of the surge in violent crimes among persons with albinism. Two 19 year old men pleaded guilty in Vryheid regional court for the murder of a 20 year old albino woman and each were sentenced twenty years behind bars. The remains of the mutilated body of deceased were found in a shallow grave after the suspects confessed and led the police to the grave. The state of insecurity among persons with albinism requires immediate attention before it spirals out of control. If the lives of persons with albinism are to receive substantive meaning, the government must provide a safe and secure environment for this vulnerable group of people. In accordance with the discussion in chapter three which suggests that the right to life should be construed more broadly to incorporate the right to a “safe” life which should be

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extended to the protection of persons against fear, threats and the consequences of violent crime, the thesis recommends that the Minister of Safety and Security appoints a task team to work on a strategy for safety measures for persons with albinism. This strategy should be designed to put into practice effective prevention plans and programs with the purpose to stop the rising spread of violence and crime among persons with albinism. South Africa has put in place a National Strategy for the Safety and Security of the Rhinoceros Populations which was necessitated by the increased incidences of Rhino poaching.\textsuperscript{14} Following a number of new legislative measures and increased attention from police and wildlife investigators there has been a marked reduction in Rhino poaching.\textsuperscript{15} If such a strategy can be effectively implemented to conserve the rhino species, one can only hope for the same approach when it comes to one of the most vulnerable members of the human species.

- Despite the fact that various governments on the African continent have put measures in place to address the murder of albinos, there is a need for the general public to become involved in the protection of albinos, rather than relying solely on the police, non-governmental organisations and human rights associations. A joint effort on the part of all stakeholders is needed if effective solutions are to be found. A mere consciousness-raising or awareness campaign regarding the plight of persons with albinism alone is not sufficient. The thesis recommends that the general public should identify and implement common community oriented security and policing initiatives in areas with persons with albinism. However community oriented security and policing should not be regarded as a substitute for the required form of policing; rather the community oriented security could act as a complementary strategy.

- Protecting the life of every human being from the threat of infanticide at birth is a constitutional imperative. The lives of albino babies are devalued solely because of seemingly unalterable cultural beliefs about persons with albinism.

being evil or cursed. An effective government is one that demonstrates empathy for and protects the fragile and vulnerable members of the country. Accurate birth and death registrations, particularly with regard to persons with albinism, would be a good starting point for assessing more effectively the number of persons affected by albinism and their life expectancy. At present, the births and deaths of albinos are not accurately reported, for a number of reasons discussed in this thesis, with result that the real statistical position about albino infanticide or murders is obscured.

- The trafficking in body parts or organs of persons with albinism needs close scrutiny and care must be taken that the new Prevention and Combating of Trafficking in Persons Act\textsuperscript{16} is implemented insofar as it relates to the removal of body parts from persons with albinism. In particular, cross-border trade in body parts should be strictly monitored at South African border posts.

- While strict prosecution along with severe sentencing of the criminals responsible for albino murders should act as a deterrent, governments on the African continent must be more vigilant, particularly in Tanzania where the number of albino murders are far higher than elsewhere on the continent. Access to education in the rural areas may help to counter the illogical cultural beliefs that fuel the ritual practice of killing persons with albinism for their body parts\textsuperscript{17} and any existing community education campaigns in this regard should be strengthened.\textsuperscript{18} In countries such as South Africa where albino killings are not as common, such campaigns should be implemented. If not contained and effectively addressed in a specific jurisdiction, dangerous beliefs such as those pertaining to albinism can easily spill over into other jurisdictions where negative perceptions already exist, such as South Africa.

\textsuperscript{16} Combating of Trafficking in Persons Act 7 of 2013.
\textsuperscript{17} Dave-Odigie CP "Albino Killings in Tanzania: Implications for Security" (2010) 3 (1) Peace Studies Journal 68-75 at 73.
\textsuperscript{18} Dave-Odigie 73.
7.2.6 Recommendations on awareness about albinism

- As stated above, more than awareness and educational campaigns are required to bring an end to superstitious beliefs, discrimination and stigma.\(^{19}\) It is a daunting task to filter out all illogical and dehumanising elements in cultural backgrounds and belief systems.\(^{20}\) A substantial education campaign aimed at behaviour change is needed to address society’s lack of knowledge and to eradicate the common myths that being an albino is a curse and that the body parts of persons with albinism have the power to bring wealth.\(^{21}\) Such educational awareness campaigns should be both formal and informal in order to ensure that all members of society are reached.\(^{22}\) The successful transformation of minds rests on the acknowledgement that persons living with albinism are part of the human family.

- Public awareness as well as educational training with regard to human rights can be accomplished by means of media programmes and public meetings in addition to publishing easily understandable articles in journals and magazines or disseminating pamphlets.\(^{23}\) The mass media have a duty to educate their audience about albinism as a condition and the need to integrate and embrace persons living with albinism as a part of society.\(^{24}\) Amongst others, such campaigns should involve using positive and constructive names and condemning the use of belittling or humiliating words and names when referring to persons living with albinism.\(^{25}\) The mass media can be a very useful tool that is capable of serving as a vehicle for

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19 Dave-Odigie 73.
20 Dave-Odigie 73.
21 Dave-Odigie 73.
governments in Africa to guarantee respect, protection and the realisation of special rights for albinos.\textsuperscript{26}

- It is the duty of the media to broadcast and publish truthful and comprehensive stories and images of diverse groups of people.\textsuperscript{27} Programmes in which people, particularly minority groups, are represented should portray such people as “well-rounded” and authentic, not as caricatures. Stereotypical representations that are likely to influence public views must be avoided.\textsuperscript{28} Broadcasting corporations must cooperate to end negative and harmful stereotyping by putting into place and enforcing policies that take a strong stand against stereotypical and prejudicial films with the potential to influence the public mind.

- Moreover, stereotyped views can only be transformed if leading figures influence the way individuals perceive certain groups of people. Perceived differences and beliefs are not static and can perhaps be changed in response to diverse social demands. Education and the provision of user-friendly information at grassroots level about albinism and the genetics behind the condition, is indispensable.

- This thesis has specifically drawn attention to the dangerous cleansing myth that affects young girls living with albinism. The fact that young girls with albinism are at a very high risk of being raped by ignorant HIV-infected men, calls for the immediate establishment of a helpdesk for the provision of critical information about cultural and social issues such as health related matters, albinism, HIV/AIDS and indigenous medicines, to mention but a few.

\textbf{7.2.7 Recommendations regarding research on albinism in South Africa}

As this thesis has shown, there is a general paucity of research on albinism in South Africa. Chapter one of the study includes quantitative data on persons living with

albinism. These statistics are merely estimates of data collected several years back. Accurate reporting on the demographics relating to albinism is of critical importance in advocating for and managing the needs and interests of this group effectively. There is also a need for qualitative research on the experiences and perceptions of persons with albinism from different backgrounds. This will greatly enhance an understanding of the social context which foregrounds albinism.

7.2.8 Recommendations for non-governmental organisations

- Non-governmental organisations could assist persons living with albinism to establish their own organisations, be it at local, national and regional or national level, for the purpose of making their voices heard. With facilitation and capacity building, such associations run by persons with albinism may strengthen lobbying and advocacy efforts aimed at bringing about policy, legal and practice change on the African continent. Such networking and capacity building initiatives will also provide a platform for interventions by regional and international parties in instances of human rights violations by individual governments that are reported to for example, the African Commission on Human and Peoples’ Rights. Existing organisations working with persons living with albinism on the continent should also be strengthened by extending their reach into all rural and urban communities.

- Increased funding from international organisations ought to be geared towards the well-being, education and health of persons living with albinism, for example by providing sun screen lotion, special sunglasses and visual aids. Funding for micro-enterprises for persons living with albinism will also assist by providing income-generating projects aimed at alleviating the severe poverty associated with albinism.

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7.2.9 Recommendations on special educational needs of learners with albinism

- South Africa needs to improve the current access of persons living with albinism to special schools. Some of the measures recommended in this study are that children with albinism receive special consideration in schools. It is particularly the social aspect of education that may be challenging for children living with albinism. Children are generally not very tolerant of children who are different from them. Learners with oculocutaneous albinism unavoidably stand out as a result of their physical appearance and the modifications required to compensate for low vision sometimes exacerbate the albino child’s feeling of isolation. For this reason, teachers should avoid drawing attention to learners with albinism. Teachers play an exceedingly vital role in the lives of children living with albinism. Apart from the immediate families of these children, teachers should be responsible for helping them to develop, learn and cope with the challenges that their condition brings. The special needs of children or students with albinism should be added to the curriculum of teacher training programmes at tertiary institutions, specifically with regard to the social and clinical aspects of albinism. The study puts forward a range of recommendations with regard to changes in the classroom itself that may promote and facilitate the right to education of children living with albinism. These children need a suitable, appropriately enhanced learning environment for the effective realisation of their right to education in South Africa. Awareness programmes at schools will help both teachers and learners to cope with the challenges associated with albinism.

7.3 Concluding remarks

Government and civil society should be sensitised to the unique position of the special minority group of persons living with albinism. The first and most important step in providing adequate legal protection to this marginalised segment of society, is to raise awareness about the condition and the severe disadvantages, obstacles, threats and limitations that persons affected by albinism face on a daily basis.
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ANNEXURE A

HUMAN RIGHTS COUNCIL ADVISORY COMMITTEE QUESTIONNAIRE ON THE SITUATION OF HUMAN RIGHTS OF PERSONS LIVING WITH ALBINISM
Human Rights Council Advisory Committee

The situation of human rights of persons living with albinism

QUESTIONNAIRE

As part of the consultations undertaken by the Human Rights Council Advisory Committee with States, national human rights institutions and non-governmental organizations, with a view to preparing a study on the situation of human rights of persons living with albinism, pursuant to Council resolution 24/33.

Background

In its resolution 24/33, the Human Rights Council requested the Advisory Committee to prepare a study on the situation of human rights of persons living with albinism, and to present a report thereon to the Council at its twenty-eighth session.

It is therefore in this context that the Advisory Committee decided, at its twelfth session held in February 2014, to appoint a drafting group\(^1\) in charge of the preparation of this study. The drafting group will present a progress report at the thirteenth session of the Committee in August 2014, before its submission to the twenty-eighth session of the Council (March 2015).

In this connection, the drafting group decided, in its preparation of the report, to seek views and inputs from different stakeholders dealing with the issue of the situation of human rights of persons living with albinism. The drafting group therefore elaborated the hereunder questionnaire for States, national human rights institutions and non-governmental organizations.

QUESTIONNAIRE

1. What is the human rights situation of persons living with albinism in your country or in any country you are familiar with? Are they considered a particular social group? Are they considered disabled? Are they considered to belong to another category?

   a. In South Africa, persons with albinism are considered as persons with disabilities. In many communities within South Africa, disability is still generally seen as an illness, shame or curse despite the fact that both section 9 of the Constitution, Act No. 108 of 1996 and the Promotion of Equality and Prevention of Unfair Discrimination Act, No. 4 of 2000, prohibit unfair discrimination on the basis of disability.

2. Does your country, or any country you are familiar with, have any problem of prejudice or stigmatization against the persons with albinism? How serious is it?

   a. There are two perceptions in relation to people with albinism within society, especially within rural areas. On the one hand, there is the view that persons with albinism are regarded as a blessing and possess ‘magical’ powers or good

\(^1\) A/HRC/AC/12/L.7, 28 February 2014.
fortune. On the other hand, there is the view that persons with albinism are outcasts in society and are ‘cursed’ individuals.

b. Within South Africa, there is a general lack of understanding of persons with albinism and what the condition entails. Many persons with albinism are referred to as ‘inkawu’ which is translated to mean ‘ape’ or ‘monkey’. Often these misunderstood and stereotypical perceptions of albinism have resulted in the further marginalisation of persons with albinism.

c. In extreme situations, persons with albinism are abused, raped by people who believe that albinism can cure AIDS and killed for ‘muthi’ (traditional medicine).

3. What are the obstacles that impede the efforts to improve the human rights situation of persons living with albinism?

   a. People with disabilities, which include persons with albinism within the South African context, remain one of the most discriminated against groups in society. They often suffer unfair discrimination in silence due to societal stigma and stereotypes.

   b. Due to the fact that persons with albinism are grouped with persons with disabilities there are no specific measures in place to improve the human rights situation of persons with albinism. In addition, South Africa does not have a dedicated institution addressing the issues and rights of persons with albinism. There are also currently no projects or policies to sensitise persons and raise awareness on the rights of persons with albinism.

   c. It should be noted that in October 2013, the Department of Women, Children and People with Disabilities (DWCPD) held its first ever Conference on Albinism. During the conference, Minister for Women, Children and People with Disabilities, Lulu Xingwana, stressed that major challenge in South Africa is the non-recognition, discrimination, stigmatisation, prejudice and isolation of persons with albinism, including within government departments.²

4. What measures, if any, (legislative, administrative, institutional, or other policy/measures) have been put in place in your country to ensure the elimination of violence against persons with albinism and their protection from all other human rights violations?

   a. There are no specific measures addressed to persons with albinism. However, Section 9 of the Constitution Act 108 of 1996 provides:

   (1) Everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture,

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.

b. In addition, Section 10 of the Constitution enshrines that “everyone has inherent dignity and the right to have their dignity respected and protected”.

c. Further to this, the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000, is a core piece of enabling legislation aimed at facilitating the realisation of the rights of all people in South Africa, particularly minority groups which have been historically marginalized. This would therefore extend to persons with albinism.

d. Under the Employment Equity Act 55 of 1998, people with disabilities are regarded as a designated group. The purpose of the Act is to remove unfair discrimination and to promote equity in the workplace. The Act also protects people with disabilities and others against unfair discrimination and, as a previously disadvantaged group, persons with disabilities are regarded as eligible to benefit from affirmative action programmes. The Act places emphasis on the duty to “reasonably accommodate” people with disabilities in the workplace. Reasonable accommodation under the Act is defined as “any modification or adjustment that will enable a person from a designated group to have access to or participate or advance in employment.”

e. It should be noted that there is currently no coherent or comprehensive legislation pertaining to people with disabilities or persons with albinism, but the DWCPD is currently in the process of finalising the National Policy Framework to Uphold, Promote and Protect the Rights of Persons with Disabilities.

5. What improvements (if any) have to be made to such measures in order to make them more effective?

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Human Rights Council Advisory Committee

a. Vulnerable groups, such as children and refugees, have dedicated and consolidated pieces of legislation enacted to protect their rights. However, the rights of disabled persons are interspersed throughout the South African legal system. The possibility of enacting a comprehensive Disability Act, dedicated to the protection of the rights of people with disabilities, has been expressed as a priority, but remains forthcoming from government. It is preferable that should an Act of this sort be drafted, that it contains a specific section related to albinism. In the alternate, dedicated legislation for persons with albinism.

6. How, if at all, does your country rehabilitate victims of attacks against persons living with albinism?
   a. Currently there are no specific measures in place to rehabilitate victims of attacks against persons with albinism.

7. Do you have any information on allegations, complaints, investigations, prosecutions and their outcomes?
   a. The most infamous case in South Africa related to albinism is the matter of Sipho Lolwane, a person with albinism who died in 2002. Between 2010 and 2012, his grave was desecrated and robbed several times for remnants of his bones. Two suspects and a sangoma (witchdoctor) were arrested and charged with grave desecration.4

8. Do religious/spiritual institutions in your country play a role in helping persons with albinism? Are they effective in preventing attacks against these persons?
   a. It is unclear the extent of awareness-raising on persons with albinism within religious and spiritual institutions.

9. In what ways can the Human Rights Council and the other UN human rights bodies assist with improving the situation of persons living with albinism within your country or any country you are familiar with?
   a. Through greater awareness and specific campaigns education society on the condition of albinism.
   b. Encourage States to adopt specific measures to promote and protect the rights of persons with albinism.
   c. Through other UN human rights bodies, highlight the intersection of rights and how it pertains to persons with albinism.
   d. Mainstreaming the issue of persons with albinism within the daily activities of the different UN bodies.

Human Rights Council Advisory Committee

e. Monitoring the implementation of international instruments, including but not limited to the Convention on the Rights of Persons with Disabilities and ensuring the designation of an Article 33 monitoring body in terms of the Convention, which has yet to occur in South Africa.

10. What other institutional or practical measures should the Human Rights Council take to strengthen the efforts to improve the human rights situation of persons living with albinism?

a. Engage periodically with States to measure improvements on policies, laws etc related to persons with albinism.

b. Ensure that through the treaty body reporting mechanisms, and the UPR that specific questions are posed to government relating to their treatment of persons with albinism.

c. Ensure rapid response by UN and UN field offices when abuses or attacks on persons with albinism occur. Larger media focus on these issues.

d. To encourage States to prioritise the rights of persons with disabilities and albinism in the planning processes and budget allocation.

e. To encourage States to have specific legislation targeted at the rights of persons with albinism.

f. To liaise with pharmaceutical companies to arrange for cost-effective sunscreen and dermatological products for provision to persons with albinism, particularly to developing countries.

g. Encourage States that have ratified the CRPD to ensure that an Article 33(2) monitoring mechanism is established and capacitated.

h. To encourage the removal of barriers; investment in early development and education initiatives on albinism; and, participation of youth with albinism in decision-making processes.

**Deadline for submission of responses to the questionnaire:**

In order to give the Drafting Group the opportunity to take into account the different contributions, all parties are encouraged to submit their responses as soon as possible and at the latest by **11 April 2014**.

Answers can be submitted via email to the following address:

hradvisorcommittee@ohchr.org

OR
Thank you for your contribution.

For more information on the Advisory’s mandate:

http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/HRCACIndex.aspx
ANNEXURE B

EKURHULENI DECLARATION ON THE RIGHTS OF PERSONS WITH ALBINISM
NATIONAL ALBINISM CONFERENCE
25-27 October 2013

Noticed by many, but truly seen by few’

EKURHULENI DECLARATION
ON THE RIGHTS OF PERSONS WITH ALBINISM
EKURHULENI DECLARATION
ON THE RIGHTS OF PERSONS WITH ALBINISM
27 October 2013

We, the delegates at the first National Albinism Conference, constituting more than 300 persons with albinism and disability rights activists, gathered in Ekurhuleni, Gauteng, South Africa

Noting that

1. Persons with albinism are South Africans with equal rights and obligations as their fellow citizens;

2. Persons with albinism have the same dreams and aspirations to a decent standard of living, economic independence and social acceptance as any other South African;

3. Children and adults with albinism live in every community, and should therefore be visible in every crèche, school, playground, places of work, sports team and places of worship.
Furthermore noting that

4. Albinism is a rare, non-contagious, genetically inherited condition present at birth, resulting in lack of pigmentation (melanin) in the hair, skin and eyes, which causes vulnerability to sun exposure and bright light. As a result, almost all people with albinism are visually impaired and are at risk of developing skin cancer;

5. Erroneous beliefs and myths, heavily influenced by superstition, often threaten the life and physical integrity of persons with albinism. The majority of persons with albinism are subjected on daily basis to name-calling and exclusion, which impacts negatively on their rights to equality and dignity, access to equal opportunities, and which often leaves deep emotional scars.
Furthermore noting that


7. Article 8 of the CRPD requires of States Parties to adopt immediate, effective and appropriate measures that will, among others, raise awareness throughout society regarding persons with disabilities, foster respect for the rights and dignity of persons with disabilities, combat stereotypes, prejudices and harmful practices relating to persons
with disabilities in all areas of life, and promote awareness of the capabilities and contributions of persons with disabilities;

8. Persons with albinism in South Africa however continue to experience high levels of abuse and violence of their rights due to entrenched harmful societal attitudes and beliefs associated with albinism.

9. The South African Government, led by the Department of Women, Children and People with Disabilities, in partnership with the Albinism Society of South Africa, in response to the UN Human Rights Council’s Resolution 23/13, and the call made during the 2012 Presidential Siyahlola Disability Rights Event, convened this Conference as a platform to engage on strategies and actions that will accelerate the realisation of the right of
EKURHULENI DECLARATION
ON THE RIGHTS OF PERSONS WITH ALBINISM
27 October 2013

persons with albinism in South Africa to dignity and equality.

Believing that

10. Persons with albinism enjoy the same rights as all other South Africans under the Constitution of the Republic of South Africa as well as international law;

11. Persons with albinism should therefore enjoy equal protection against unfair discrimination and hate speech, and equal access to services and opportunities;

12. The right to self-representation by persons with albinism on matters affecting their lives, is enshrined in the Constitutional values of freedom of association as well as the CRPD;
EKURHULENI DECLARATION
ON THE RIGHTS OF PERSONS WITH ALBINISM
27 October 2013

13. International solidarity and action can eradicate
discrimination and violation of the human rights of
persons with disabilities;

Furthermore believing that

14. Urgent attention is required in the following areas to
achieve the above:

- Strengthening self-representation by persons
  with albinism through strong representative
  organisations of persons with albinism;

- Developing positive language and outlawing
  derogatory terminology and name-calling;

- Reducing the cost of living associated with
  albinism.

- Improving free and subsidized access to health
  care facilities and assistive devices;
EKURHULENI DECLARATION
ON THE RIGHTS OF PERSONS WITH ALBINISM
27 October 2013

- Accelerating equal access to life-long education, training, employment and recreation opportunities within the communities we live in;
- Strengthening South Africa’s condemnation in the international arena on the killings and torture of persons with albinism.

*Therefore resolve that*

On The Protection and Promotion of the Rights of Persons with Albinism

15. The SA Human Rights Commission should institute an investigation and research into the incidence of human rights violence against persons with albinism, including infanticide and human trafficking, in South Africa;
EKRULENI DECLARATION
ON THE RIGHTS OF PERSONS WITH ALBINISM
27 October 2013

16. A register to document incidents of human rights violations perpetrated against persons with albinism in South Africa, should be kept;

17. Legislation should be strengthened/developed to outlaw hate speech and enforce action against violation of rights of persons with albinism.

On The Right to Self Representation

18. The national, provincial and local structures of the Albinism Society of South Africa should be strengthened with organisers at all three spheres, with government support;

19. Marches at national, provincial and local level should be organised by ASSA to raise the visibility of persons with albinism and to demand that the rights of persons with albinism be recognised and protected;
20. The Department of Arts and Culture should ensure that the book “Understanding Albinism” is available in all public and school libraries of South Africa;

21. Persons with disabilities are encouraged to join civil society structures, including Disabled People South Africa, to empower themselves and as platform to bring about change.

On Reducing Personal Costs related to Albinism

22. Persons with albinism should be able to access subsidised/free services and products that will reduce the risk of secondary disabilities and disease;

23. A review of access criteria to care dependency and disability grants is required to determine why it is so difficult for persons with albinism to access grants;
On Equal Access to Health Care Services

24. Free access to health care services for persons with disabilities should be de-linked from disability grants and made available to all persons with disabilities, including persons with albinism;

25. The Department of Health and provincial health departments should provide free access to adequate and sufficient sunscreen protection;

26. The Department of Health should accelerate the roll-out of free eye tests and issuing of spectacles across all provinces;

27. The Department of Health should initiate negotiations in partnership with the Albinism Society of South Africa with the Council of Medical Aid Schemes for the inclusion of sunscreen and other essential assistive device benefits as prescribed minimum benefits;
28. The Department of Health should institutionalise training of all its medical and non-medical personnel to eradicate discrimination against persons with albinism, and to understand the different types of albinism and interventions required;

29. Access to discrimination-free health services in rural areas should be improved through, among others, roll-out of infrastructure.

On Equal Access to Lifelong Learning

30. Schools where learners with albinism are enrolled should be identified, with teacher empowerment and human rights programmes, as well as adequate support to these schools and learners, made available at the beginning of every school year;

31. FET colleges and universities should provide adequate and timeous support services to students with albinism.
On Equal Access to Skills and Economic Development

32. Barrier-free access to skills development programmes, entrepreneurship development and decent work programmes in rural areas should be accelerated;

33. We need to move beyond targets for employment equity, but focus on decent work and strengthen the fight against under-employment;

34. The focus on learnership programmes should not detract from the decent work agenda – persons with albinism want decent jobs and economic empowerment, and learnership programmes seldom lead to employment due to discrimination.
On the Development of Rights-based Language, and Strengthening Social Cohesion

35. Persons with disabilities should be recognised as a particular vulnerable group to social exclusion due to the harmful beliefs associated with albinism, and all social cohesion programmes should therefore address this exclusion;

36. The media should pay particular attention to the manner in which they portray persons with albinism in their reporting, and the current trend of providing a platform for persons with albinism on television should be encouraged and accelerated.

On International Cooperation

37. The South African government should champion an item on the rights of persons with albinism for consideration by the Heads of State of the African Union;
38. The South African government should support the convening of a Pan African Conference of Persons with Albinism by organisations of persons with albinism on the continent.

On Children with Albinism

39. Children with albinism should enjoy specific protection from discrimination and exclusion;

40. Conference adopts the resolutions tabled by the Children’s Conference as part of this Declaration.
FIRST CHILDREN WITH ALBINISM CONFERENCE
26-27 October 2013

Noticed by many, but truly seen by few'

EKURHULENI CHILDREN WITH ALBINISM CONFERENCE RESOLUTIONS
27 October 2013
RESOLUTIONS

We, the children who have participated in the Children’s Parallel Conference of the First National Conference on Albinism on 26-27 October 2013 at Ekurhuleni, Gauteng, have learnt that unity in action is a strength.

We have learnt that our cultural diversity makes us strong and special as a nation and that we should respect it at all times.

Therefore we should work towards unifying all our people on the issue of albinism so that we fulfil our constitutional rights as equal citizens of our country.

We have talked about many issues during this Conference. We have grown in creativity, knowledge and expressiveness and in our understanding of our roles as young people.

Therefore, resolved that
RESOLUTIONS

1. Better knowledge on albinism through awareness raising will lessen the discrimination we face in society;

2. Schools need to be better equipped, both in training of staff and the tools of teaching to fit the needs of learners;

3. We need to make social cohesion programmes in communities to encourage tolerance and respect for all;

4. By building on self-confidence, self-respect, self-image and self-representation we will become greater participants in our own lives and in the way we interact with society;

5. We encourage the establishment of a youth forum so that we can represent our views directly;

6. We should use media, especially social media to educate people and show them that we are as talented as anyone else in the world.
ANNEXURE C

REPORT OF THE HUMAN RIGHTS COUNCIL ADVISORY COMMITTEE ON THE STUDY ON THE SITUATION OF HUMAN RIGHTS OF PERSONS LIVING WITH ALBINISM
Human Rights Council
Twenty-eighth session
Agenda items 3 and 5
Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Human rights bodies and mechanisms

Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism
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I. Background

1. In three recent seminal resolutions, the Human Rights Council expressed its concern about the situation of the human rights of persons with albinism. In the first resolution, adopted in June 2013, it condemned attacks against persons with albinism and requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to submit, at its twenty-fourth session in September 2013, a preliminary report on the ongoing attacks and discrimination against persons with albinism.  

2. In the second resolution, adopted in September 2013, the Council requested the Advisory Committee to prepare a study on the situation of human rights of persons with albinism and submit a report thereon to the Human Rights Council at its twenty-eighth session.  

3. In its third resolution, adopted in June 2014, the Human Rights Council recommended that the General Assembly proclaim 13 June International Albinism Awareness Day. On 18 November 2014, the General Assembly took note of the Council’s recommendation and decided to proclaim 13 June as International Albinism Awareness Day, with effect from 2015.  

4. In accordance with its mandate pursuant to Council resolution 24/33, the Advisory Committee, at its twelfth session in February 2014, established a drafting group tasked with the drafting of the report and designated the following experts as members of the drafting group: Mohamed Al Faihani, Laurence Boisson de Chazournes (Rapporteur), Mario Luis Coriolano, Latif Hüseynov, Kaoru Obata and Obiora Chinedu Okafor (Chairperson).

5. The Committee also decided to seek views and input from States and other stakeholders and, to that end, prepared a questionnaire requesting information on the status and treatment of persons with albinism around the world, which was disseminated in April 2014 to States, relevant special procedures, OHCHR field presences, national human rights institutions and non-governmental organizations. A total of 41 responses were received, including 15 from States: Azerbaijan, Burundi, Chile, Denmark, Georgia, Germany, Luxemburg, Mexico, Nicaragua, Paraguay, Senegal, Slovenia, Spain, Swaziland and Tunisia; 9 from national human rights institutions in the following countries: Bosnia and Herzegovina, Denmark, Malawi, Namibia, the Netherlands, Nicaragua, Romania, Rwanda and South Africa; 10 from the following non-governmental organizations: Amis des Etrangers au Togo; Bien-Être des Albinos de Côte d’Ivoire; the Elgon Foundation for Persons with Albinism (Uganda); the Uganda Albinos Association; the Albino Foundation (Nigeria); the Chinese Organization for Albinism; ALBA – Asociación española de ayuda a personas con albinismo (Spain); Genespoir (France); the Albinism Fellowship of Australia; and NOAH Albinismus Selbsthilfegruppe (Germany); and 7 from OHCHR, treaty monitoring bodies and special procedures: OHCHR in Occupied Palestinian Territory; OHCHR Regional Office for Southern Africa; OHCHR/United Nations Organization Stabilization Mission in the Democratic Republic of the Congo (MONUSCO);

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1 See Human Rights Council resolution 23/13 on attacks and discrimination against persons with albinism; Human Rights Council resolution 24/33 on technical cooperation for the prevention of attacks against persons with albinism; and Human Rights Council resolution 26/10 on International Albinism Awareness Day.


3 Human Rights Council resolution 24/33, para. 1.

OHCHR/Opération des Nations Unies en Côte d’Ivoire (ONUCI); OHCHR/United Nations Integrated Peace Building Office in the Central African Republic (BINUCA) (relating to Burundi); the Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment; and the Special Rapporteur on extrajudicial, summary or arbitrary executions.

6. Building on the facts and findings contained in the OHCHR report, the present study first provides an overview of the various obstacles faced by persons with albinism to the full enjoyment of their human rights, and includes the type and severity of the human rights violations involved. Second, it summarizes actions taken at the international level and by OHCHR in response to the issue. The third and final part recommends further initiatives for addressing some of the key problems identified in the first part.

7. On 24 September 2014, the Rapporteur of the Advisory Committee’s drafting group participated in an expert meeting on albinism organized by OHCHR in collaboration with the Organisation Internationale de la Francophonie. The meeting brought together experts from international and regional human rights mechanisms and participants from civil society. It was an opportunity to hear the testimonies of persons with albinism and to listen to their proposals on the way forward at the domestic, regional and international levels. The present study has benefited greatly from the expert meeting.

II. Albinism, special needs and human rights challenges

A. Albinism and special needs

8. Albinism is a rare, non-contagious, genetically inherited difference present at birth. In almost all types of albinism, both parents must carry the gene for it to be passed on, even if they do not have albinism themselves. The condition is found in both sexes regardless of ethnicity and in all countries of the world. Albinism results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, almost all people with albinism are visually impaired and are prone to developing skin cancer. There is no cure for the absence of melanin that is central to albinism.5

9. While numbers vary, it is estimated that in North America and Europe 1 in every 17,000 to 20,000 people have some form of albinism. The condition is much more prevalent in sub-Saharan Africa, with estimates of 1 in 1,400 people being affected in Tanzania6 and prevalence as high as 1 in 1,000 reported for select populations in Zimbabwe and for other specific ethnic groups in Southern Africa.7

10. Persons with albinism have special needs. An advocacy report of the International Federation of the Red Cross and Red Crescent Societies (IFRC) identified those needs as follows:

(a) Security;

5 The definition of albinism comes from A/HRC/24/57, para. 10.
(b) Help with reintegration into society after displacement or time spent in hiding;
(c) Health education on how to prevent skin cancer;
(d) Protective clothing;
(e) Optician services;
(f) Assistance in participating in mainstream primary and secondary education;
(g) Vocational training to maximize the chance of indoor work out of the sun.  

11. While the IFRC report focused on the Great Lakes region of east Africa, those needs, or at least some of them, may be considered to reflect the collective experience of persons with albinism.

B. Rights to life and security of person

12. With respect to security, grave concern has been expressed by the Human Rights Council about “attacks against persons with albinism, including against women and children, which are often committed with impunity.” Such attacks involve the violation of fundamental human rights.

13. As mentioned by six special procedure mandate-holders, persons with albinism face dehumanization because they “are regarded as ghosts and not human beings who can be wiped off the global map … [they are] the target of many false and harmful myths in several countries, especially in the African region.”

14. The OHCHR report states that “in some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at constant risk. These beliefs and myths are centuries old and are present in cultural attitudes and practices around the world.” The belief that the body parts of persons with albinism possess magical powers that can be used to gain wealth and prosperity and/or to gain power via winning elections are some of the reasons for the killing of, and attacks against, persons with albinism.

15. Violence against this vulnerable group takes various forms, including the killing of, and attacks against, persons with albinism with a view to using their body parts for ritual purposes. Arising from the attacks and the use of body parts is the trade of organs linked to trafficking in persons and the sale of children, infanticide and abandonment of children.

16. It is reported that, as of October 2014, over 340 attacks against persons with albinism, including 134 killings, have been recorded in 25 countries. Non-governmental organizations working in the field note that the number of ongoing attacks is higher than
that reported, but that data-gathering is difficult owing to the secretive nature of witchcraft, which serves as the context of most ritual attacks against persons with albinism.

17. On 15 May 2014, the former United Nations High Commissioner for Human Rights issued a press statement in which she called for increased protection for people with albinism after the murder of a 40-year-old woman with albinism in north-western Tanzania three days earlier. On 27 May 2014, the Working Group on the Rights of Older Persons and People with Disabilities in Africa also issued a press statement condemning that specific killing.

18. Since then, seven further attacks have been documented in Tanzania, between August 2014 and January 2015, including one murder, two cases of survivors with severe limb mutilation and the disappearance of a 4-year-old girl. The killing of a 25-year-old woman was reported in Malawi in November 2014 and another killing, of a 27-year old man, was reported in Burundi in December 2014. The circumstances in which the attacks took place reveal the severity of attacks against the group. The following are some examples:

(a) On 5 August 2014, Pendo Sengerema, a 15-year-old girl, was brutally attacked at her home in Kaliua District, in the Tabora Region of Tanzania. Three assailants with machetes hacked off her right arm just below the elbow. According to reports, her family could not scream for help as they were threatened with death by the attackers, who later disappeared with Pendo’s arm;

(b) On 16 August 2014, two unidentified men entered the home of Munghu Masaga, a 35-year-old woman with albinism and the mother of seven children, in Buhekela village, in Igunga District, also in Tabora region of Tanzania. Before chopping off her left arm and escaping, attackers killed Munghu’s husband as he tried to protect his wife. Two of their children sustained minor injuries;

(c) On 12 November 2014, a 25-year old woman with albinism by the name of Violet Kanyama was found dead in the garden of a school near her home in Gawani village, Mulanje district, Malawi. Her body was recovered with both arms and legs missing.

19. These latest attacks underscore the urgent need for States to adopt specific measures to protect and preserve the rights to life and security of person, and the right not to be subjected to torture or ill-treatment. Persons with albinism must be provided with safe and secure spaces where they are able to live dignified lives, free from the fear of being attacked.14

20. The Tanzanian police response to the attacks in August 2014 has been reported as adequate, with several arrests made, and a special task force has been set up by the Office of the Attorney General to investigate and prosecute the cases. Those welcome responses are ongoing and it is therefore premature to comment on their impact. Meanwhile, civil society groups have made a clarion call to the Tanzanian Government to enlarge the scope of investigation to unearth the black market in organs associated with the attacks and prosecute clients of the trade. Civil society actors also urged the relevant authorities to introduce effective regulation of the activities of traditional health practitioners. The practitioners, who reportedly practise witchcraft and are revered by many for their perceived supernatural powers and ability to carry out magic, have been mentioned as key players.15

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14 One of the recommendations of the Organisation Internationale de la Francophonie/OHCHR Expert Meeting on Persons with Albinism, held in Geneva on 24 September 2014.
C. Right to an adequate standard of living and other fundamental rights

21. The situation of persons with albinism who have gone into, or have remained in, hiding in the wake of attacks against them, is worrisome. For instance, according to information received by OHCHR, hundreds of children with albinism have been living in appalling conditions in 13 centres for displaced children and adults with albinism in Tanzania, after being abandoned by their families or fleeing their homes further to a spate of killings and attacks against them. Some of the centres are administered by the Government while others are owned by faith-based organizations.

22. Further, according to information received, the centres are overcrowded and the health and hygiene conditions are very poor. In addition, owing to very limited human and financial resources, teaching and learning materials are almost non-existent. Health-wise, there have been worrisome reports of skin cancer at various stages, which is visible on many of the children with albinism living in the centres, partly owing to the lack of awareness amongst staff as well as a lack of basic health information on self-care for the persons with albinism themselves. Sexual abuse has been reported in some of the centres.

23. In a press release of 15 May 2014, the former High Commissioner also expressed concern about the situation of children with albinism living in the centres. She called on the Tanzanian authorities to take urgent measures to assess and address the situation in the centres, including allegations of sexual harassment and abuse, and the poor living conditions. She added that staff working with people with albinism should be trained on their special needs, in particular with regard to basic preventive measures to avoid skin cancer. In August 2014, a United Nations mission visited two of the centres and expressed concern that the centres reinforce segregation of persons with albinism and separate children from their families. There is therefore an urgent need to look into long-term solutions to reintegrate the children into their communities, avoiding over-reliance on institutions as safe places for children.

24. Another example is Burundi, where, after a spate of killings and attacks registered from 2008 to 2012, persons with albinism were accommodated in police stations and houses nearby to guarantee their safety. An assessment of displaced persons with albinism in the Northern Province of Kayanza, in Musongati and in Gitega, recently conducted by the OHCHR field presence, shows the precarious security situation of some of them and the negative impact of the measure on the right to an adequate standard of living.

25. Those concerns were reiterated by the Human Rights Committee in its 2014 concluding observations, requesting Burundi to continue its efforts to protect persons with albinism and to find lasting solutions to their situation.

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16 The joint mission from OHCHR and the Resident Coordinator’s Office in Tanzania visited Buhangiya Primary School in Shynyanga District, which houses 174 children with albinism and Mitindo Primary School in Misungwi District, which houses 45 children with albinism.

17 The Committee on the Rights of the Child included a reference to those centres in the list of issues on Tanzania adopted on 27 June 2014 (CRC/C/TZA/Q/3–5), also mentioned in para. 53 of the present report. This is also a recommendation from the Expert Meeting: see outcome report of the Expert Meeting on Persons with Albinism, 24 September 2014 (see footnote 15), para. 73.

18 CCPR/C/BDI/CO/2; see also para. 55 of the present report.
D. Discrimination against persons with albinism

26. Security concerns and associated displacement of persons with albinism are linked to the overall issue of discrimination. The OHCHR report expressed “its grave concern at the severity of the human rights violations committed against persons with albinism in many countries, including the multiple and intersecting forms of discrimination they, particularly children and women, face.”

27. Those various forms of discrimination are evident from the “nasty, brutish and short” lives of persons with albinism: if they survive infanticide at birth, they face a constant threat of physical attacks. Should they survive those physical threats, they are unlikely to be educated, owing to the absence of reasonable accommodation for their poor eyesight. A lack of education leads to unemployment or employment outdoors in the sun, where they are vulnerable to developing skin cancer. Skin cancer remains a life-threatening condition for most persons with albinism under the age of 40.

28. All forms of discrimination affecting persons with albinism are interrelated, and there is an inextricable link between discrimination and poverty. “The right to education of persons with albinism, for instance, is adversely affected by the vision impairment they suffer from. A poor education, in turn, affects their right to an adequate standard of living, consigning many persons with albinism to poverty.” As a result, the economic and social rights of persons with albinism are disproportionately affected by various types of poverty.

E. Impunity

29. Discrimination encountered by persons with albinism also negatively impacts access to justice.

30. There are little data available on the legal treatment of cases of violence against persons with albinism. Where there is information, it is reported that persons with albinism are discriminated against throughout the whole judicial process. It is reported that law enforcement authorities and some members of the judiciary tend to share the same superstitious beliefs entrenched in the communities, including and not limited to, considering persons with albinism as subhuman beings. Procedural fairness including informing the victim of attack about the trial process, preparing him or her for trial and providing him or her with legal representation or access to the prosecutor are all reportedly impaired by subsisting prejudices against the victim as a person with albinism. In addition, erroneous beliefs about albinism, including inadequate knowledge about their condition, for instance knowledge of the visual levels of persons with albinism, has also been reported to negatively impact the weight ascribed to the testimony of victims of attack. Further, corruption and shortcomings in the resources of the justice system fail to translate initial police action into concrete results in the fight against impunity. Such factors effectively create significant obstacles in access to justice for persons with albinism.

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19 A/HRC/24/57, para. 84.
20 For example, one epidemiological study estimated that fewer than 10 per cent of persons with albinism in Tanzania survive to age 30, and only 2 per cent were expected to reach age 40. See Andres E. Cruz-Ingo et al., “Albinism in Africa: stigma, slaughter and awareness campaigns”, Dermatologic Clinics, vol. 29, No. 1, pp. 7981 (2011) (citing J. Luande et al., “The Tanzanian human albino skin”, Cancer, vol. 55, p. 1823 (1985)).
22 Ibid., para. 50.
31. The challenges persons with albinism face in having their cases brought to justice are grounded in the vulnerability of the population. They include

- the fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses owing to the ostracism they face within their community and, frequently, the involvement of family and community members in the attacks; the lack of awareness of legal rights; the lack of financial resources; the inadequate capacity of the judicial system to address such cases; the lack of legal aid and adequate legal representation; the lack of knowledge of or confidence in the law enforcement and justice systems.23

32. Without effective and affordable access to justice, persons with albinism are unable to adequately claim their rights and contest the human rights violations which they are subjected to.24 As a result, no type of redress is available to victims, even in the form of medical and psychological support.25 To date, it is reported that most assistance to victims in the form of medical and psychological support has been provided exclusively by non-governmental organizations.

33. The link between poverty and witchcraft is also a matter of concern and has been explained in the following terms:

As is the case with witchcraft accusations against women, the elderly and children, muti26 murders of persons with albinism appear to follow patterns of poverty, misfortune, tension and conflict in societies. Attacks may originate from tense social relations, where no effective or social alternative exists to release or explain such tension. Lack of access to basic resources, education and basic health services correlate with such human rights abuses. These spiritual explanations act as a way of justifying life’s misfortunes, hence, maintaining social order. It is, predominantly, the most vulnerable and marginalized groups in society who are accused of witchcraft, because they are either least able to defend themselves from attack and are, therefore, easy targets. Furthermore, as they are considered of little value to society, they consequently become a burden [sic] in times of hardship.27

34. States have an obligation to criminalize, investigate and prosecute perpetrators of crimes affecting persons with albinism. That is even more critical given the heightened vulnerability of persons with albinism. The strengthening of the legal response to killings of, and attacks against, persons with albinism will also serve as a deterrent.

F. Women and children

35. The OHCHR report mentions that “women and children with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination. In addition, children are particularly targeted for ritual killings and women with albinism are sometimes victims of sexual violence.”28 That is because there is the

23 Ibid., para. 53.
24 Ibid., para. 70.
25 Ibid., para. 55.
26 Muti is a word used in Southern Africa to refer to magic that enables people to gain power or wealth.
28 A/HRC/24/57, para. 74.
belief in some communities that having sex with a person with albinism can cure HIV/AIDS.  

Women who give birth to children with albinism are particularly exposed. They are often rejected by their husbands, accused of adultery and blamed for giving birth to children who are perceived as a curse, misfortune or a cause of shame for the family.

In her opening remarks at a press conference during her mission to Nigeria in March 2014, the former United Nations High Commissioner for Human Rights alluded to the specific discrimination faced by persons with albinism and the extra vulnerability faced by children with the condition. She stated “One group at particular risk are the some 800,000 children among the 2 million people living with albinism in Nigeria. Many of them are not in school because of visual impairment, discrimination from other children, and social exclusion as a result of their skin colour.”

The 2014 annual report of the Special Representative of the Secretary-General on Violence against Children identified children with albinism as particularly vulnerable. The report explains that children with albinism are at high risk of abandonment, stigmatization, and marginalization as a result of their appearance, and due to disability factors associated with their condition, such as impaired eyesight and sensitive skin (…). Social and structural discrimination condemns these children to a position of extreme vulnerability. Children with albinism are exposed to severe incidents of violence, mutilation and murder. At times they become the target of witchcraft accusations, leading to the use of their body parts for ritual purposes. Children who survive such attacks are left with serious and long-lasting health and psychological consequences, and the development of their full potential is compromised for life. Driven by fear and superstition, incidences of violence are largely met with silence and indifference. They are rarely reported or followed by investigation or prosecution. Overall, there is a pervasive culture of impunity.

G. Violence and discrimination against persons with albinism: a global phenomenon?

While it has been reported that persons with albinism globally face discrimination and stigma, information on cases of physical attacks against persons with albinism is mainly available from countries in Africa. It is important to reiterate the point made in the OHCHR report that any real or apparent focus on Africa—whether in the present report or the issue generally—is explained by the fact that, to date, all reported cases of ritual attacks have come from that region.

The manner in which discrimination faced by persons with albinism manifests itself, and its severity, vary from region to region. In the western world, including North America, Europe and Australia, discrimination often consists of name-calling, persistent teasing and bullying of children with albinism. In those regions, the substance of discrimination is

29 This phenomenon has been exposed by various NGOs working in Burundi, Côte d’Ivoire, Kenya, Namibia, Tanzania and Zimbabwe.
30 Outcome report of the Expert Meeting on Persons with Albinism; Violence, Discrimination and Way Forward, 24 September 2014 (see footnote 15), para. 15.
31 A/69/264, paras. 34–37.
32 A/HRC/24/57, paras. 2 and 65.
33 See Under the Same Sun (UTSS), www.underthesamesun.com/; see also Asociación de Ayuda a
entrenched misconceptions and misunderstanding about albinism, notably perpetuated by the media and popular culture, which consistently portray persons with albinism in a negative light.\textsuperscript{34} Given the rarity of albinism in those regions (an estimated 1 in 17,000 to 20,000) the media and popular culture are major sources of information on the condition for the majority. Therefore, unless specific albinism awareness-raising is conducted by support groups and civil society, such discrimination is unlikely to be brought to light.

41. Persons with albinism face more severe forms of discrimination and violence in those regions where the majority of the general population are relatively dark-skinned. The degree of contrast in pigmentation between the majority and the person with albinism in a community tends to correlate positively with the severity and intensity of discrimination faced by persons with albinism. In other words, a greater degree of contrast in pigmentation often gives rise to a greater degree of discrimination. That appears to be the case in some sub-Saharan African countries where albinism is shrouded in myth and dangerous and erroneous beliefs.

42. Little information is available from other regions such as Asia, South America and the Pacific etc. However, some reports indicate that in China and other Asian countries, children with albinism face abandonment and rejection by their families. A recent epidemiological study of persons with albinism from a specific tribe in Pakistan explains the multi-layered human rights problems faced by persons with albinism, including lack of understanding of albinism, social rejection, medical and psychological problems, as well as confinement to poverty.\textsuperscript{35} Reliable testimonies received from Mumbai, India, also indicate that persons with albinism tend to be viewed as cursed on account of their appearance. That perceived curse is considered contagious by some, such that persons with albinism are effectively ostracized and isolated from and by mainstream society. Such isolation has been reported to occur even when persons with albinism are moved into special schools such as schools for the blind owing to their visual impairment. Such treatment even within the community of persons with disabilities shows the pervasiveness of discrimination against persons with albinism.

43. Given the fact that evidence such as the above has only come to the fore in the last year, the absence of information on other regions should not be interpreted to mean that there is no problem of discrimination, stigmatization and violence in those regions. Rather, there should be a general presumption that there are human rights issues facing persons with albinism in each region. That presumption can be rebutted by targeted studies in the near future. Lack of sufficient knowledge remains a significant barrier to tackling discrimination, stigma and violence.

III. Responses: successes and subsisting challenges

A. Advocacy

44. The documented reports of ritual killings of, and attacks against, persons with albinism, and the many more undocumented acts of violence and discrimination they face,
undoubtedly call for a more active promotion of, and advocacy for, the rights of persons with albinism. Without strong advocacy it will be difficult to achieve concrete results at the international and regional levels.

45. One example of such advocacy is the initiatives recently taken by OHCHR to raise awareness and promote the protection of the rights of persons with albinism, thus increasing the visibility of violations against the group, which until then had received little attention from the international community. The High Commissioner’s voice, through press statements; side-events on the margins of Human Rights Council sessions; expert meetings such as that mentioned in paragraph 7 of the present report; and online public information campaigns; are all tools that can be used to increase understanding and raise awareness of albinism, all of which OHCHR has been successfully using with the aim of achieving a consensus among States on the importance of promoting and protecting the rights of persons with albinism and combating impunity for attacks against them.

46. Another advocacy tool that can be used to raise awareness of the human rights situation of persons with albinism is through engaging artists in the endeavour, as they can reach out to a greater number of people through their voices and work. In that regard, it is noteworthy that, on 5 December 2013, Salif Keita, musician and advocate for the rights of persons with albinism, performed at the Palais des Nations in Geneva.

47. In addition to advocacy at the international level, it is equally important to engage in advocacy at the regional level. Here the role of civil society organizations becomes very important and their engagement with human rights mechanisms at regional level needs to be enhanced with a view to stimulating regional responses to key human rights concerns. Representatives of civil society organizations conducting advocacy on behalf of persons with albinism in African countries for instance, can be supported to participate in platforms such as the Non-govermental organization (NGO) Forum in Banjul or in discussions on cooperation with the African Union organs, as was done by OHCHR in 2013.

48. At the national level, there are only very few instances of such advocacy that can be referred to. For instance, the Human Rights Component of the United Nations Operation in Côte d’Ivoire (ONUCI) has strengthened the operational and institutional capacities of one of the albinism groups in the country, Bien-Etre des Albinos de Côte d’Ivoire (BEDACI), through a quick impact project, and has conducted training on documentation techniques of human rights violations. The Human Rights Component of the United Nations Office in Burundi (BNUB) has for its part been monitoring the situation of people with albinism in the country. Human rights advisers can also be another good option for advocacy as they can be instrumental in promoting a more active role of key stakeholders in the protection of persons with albinism, including the United Nations Country Team, the national human rights institution and the relevant authorities.

B. Assistance to victims

49. The United Nations Voluntary Fund for Victims of Torture, managed by OHCHR, is a concrete way to care for the survivors of attacks and their family members. It provides direct assistance to victims of torture and their family members through grants awarded to non-governmental channels of assistance, including NGOs, rehabilitation centres, associations of victims and family members. In 2014, the Fund awarded a grant, through its

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36 See ONUCI replies to the Advisory Committee questionnaire, available from www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx.
intersessional emergency procedure, to the non-governmental organization Under The Same Sun in Tanzania, for the provision of medical rehabilitation (prosthetic work) and psychological assistance to several identified victims, both men and women, mutilated during attacks. The financial support to that victim-focused project has been renewed by the Fund for 2015 so as to extend the specialized assistance provided by the project to an additional number of victims and their families.

C. International human rights mechanisms

50. Various human rights mechanisms, notably the Human Rights Council, including the universal periodic review and treaty monitoring bodies have addressed the situation of persons with albinism. Some examples of the recommendations made in 2014 are listed below.

51. In April 2014, during the review of Côte d’Ivoire under the universal periodic review (UPR), Spain expressed concern regarding discrimination against persons with albinism and made the following recommendation which enjoyed the support of the country: “To take concrete measures to protect the rights of people with albinism, in accordance with the recommendations made by the Office of the High Commissioner, and raise awareness among society about their situation.”

52. Also in April 2014, during the UPR of the Democratic Republic of the Congo, Guatemala shared the concern of the Committee on Economic, Social and Cultural Rights about the killing of persons with albinism and the use of their organs for witchcraft ceremonies. The following recommendation, which enjoyed the support of the country, was made: “To combat all forms of discrimination against persons with albinism”.

53. In June 2014, the Committee on the Rights of the Child, in its list of issues for Tanzania, requested the State Party to:

indicate whether a comprehensive strategy has been put in place to stop the gross violations of the right to life, survival and development of children with albinism in the State party. In particular, please provide precise and detailed information on: (a) The educational and awareness-raising measures undertaken and currently being conducted by the State party to overcome traditional beliefs causing stigma and discrimination against children with albinism leading to killings and a wide range of violence against them; (b) The measures adopted to prevent, investigate and punish crimes against children with albinism, including the use of their body parts for witchcraft and to provide redress to victims; (c) The measures taken to improve the living and safety conditions in the centres where these children are placed, to ensure that they are not subject to degrading treatment or abuse in these centres, to adequately train staff and hold them accountable for any professional misconduct, and to ensure regular supervision and control of these centres; (d) Any pilot initiative aimed at preventing the placement of these children and/ or to encourage the reunification of children with albinism with their families, when possible.

54. In its concluding observations on the periodic report of Swaziland of July 2014, the Committee on the Elimination of Discrimination against Women expressed concern

37 A/HRC/27/6, recommendation 127.103.
39 A/HRC/27/5, recommendation 134.47.
40 CRC/C/TZA/Q/3-5, para. 8.
at the gruesome murders of women and girls with albinism, whose body parts are harvested for rituals. The Committee is particularly concerned at reports that, in the past, perpetrators of such murders were prosecuted for less-serious crimes, such as causing grievous bodily harm, and therefore received lenient sentences upon conviction. The Committee recommends that the State party urgently establish a national register of persons with albinism and provide protection to women and girls with albinism. The State party should ensure that all complaints relating to violence against women and girls with albinism are effectively investigated and perpetrators prosecuted and punished with appropriate sanctions upon conviction.\footnote{CEDAW/C/SWZ/CO/1-2, paras. 22–23.}

55. In October 2014, in its concluding observations on the periodic report of Burundi, the Human Rights Committee requested the State Party to continue its efforts to protect persons with albinism against any form of discrimination, including physical attacks, and to find sustainable solutions guaranteeing their access to health care, social services, employment and education.\footnote{CCPR/C/BDI/CO/2.}

56. The Human Rights Council, in June 2014, adopted resolution 26/10 without a vote, recommending that the General Assembly proclaim 13 June as International Albinism Awareness Day. The date is symbolic, as the first global resolution on attacks and discrimination against persons with albinism was adopted by the Human Rights Council on that date in 2013. The initiative provides a platform through which stakeholders can raise public awareness on this pressing human rights issue. The resolution recognizes the importance of increasing awareness and understanding of albinism in the fight against global discrimination against, and stigmatization of, persons with albinism. The day was called for by some NGOs serving persons with albinism, particularly those based in countries were there have been records of attacks. It has also been welcomed by an overwhelming majority of a cross-regional listing of NGOs serving persons with albinism worldwide. Following the recommendation made by the Council, on 18 November 2014, the General Assembly proclaimed 13 June as International Albinism Awareness Day.

D. Regional human rights mechanisms

57. As a very significant step at the African regional level, on 5 November 2013, the African Commission of Human and People’s Rights adopted resolution 263 on the prevention of attacks and discrimination against persons with albinism. Among other things, the resolution requires member States to include in their reports to the African Commission information on the situation of persons with albinism, including good practices in protecting and promoting their rights.

58. Also in November 2013, at its twenty-second ordinary session held in Addis Ababa, the African Committee on the Rights and Welfare of the Child considered the issue of albinism and adopted a Declaration on Ending Discrimination and Violence against Girls in Africa, in which the situation of children with albinism was addressed.

E. Challenges

59. Despite the above strides, there remain a number of challenges to a more active engagement with human rights mechanisms. They are detailed below, amongst other challenges to ensuring an adequate response to the issue:
(a) Limited knowledge of the issue and its impact on the enjoyment of human rights by persons with albinism;

(b) Limited knowledge and capacity of associations of persons with albinism around the world to engage with human rights mechanisms;

(c) Little information, scarce data and incomplete reports on cases of discrimination on specific grounds;

(d) Scarcity of reliable data on cases of killings of and attacks against persons with albinism in countries other than Burundi, Côte d’Ivoire or Tanzania, where there is a higher prevalence of albinism, but also a more active and better skilled civil society. The lack of information makes it difficult for potentially relevant special procedures mandate-holders to give attention to the issue within their respective mandates, including the Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment, on racism and related intolerance, education, disability, health, violence against women and violence against children. Similarly, the secrecy surrounding witchcraft and the underground nature of the market associated with the trafficking of persons and organs make it difficult to find evidence relevant to the mandate of the Special Rapporteur on the sale of children and the Special Rapporteur on trafficking in persons;

(e) Further, the scope of certain special procedures mandates prevents the mandate-holders from addressing the issue. For example, persons with albinism do not fall under the internationally accepted definition of minorities, which is limited to national, ethnic, religious or linguistic minorities, and do not fall therefore within the scope of the mandate of the Special Rapporteur on minority issues. While the definition of “minority” is currently under review, it is unclear at this point whether the new definition will accommodate persons with albinism;

(f) Human rights challenges associated with albinism are multi-layered and are not currently being addressed in a comprehensive and sustainable manner by any human rights mechanism. In addition to the fact that they do not fall within the scope of the current definition of minorities, persons with albinism often suffer from poor eyesight and are prone to developing skin cancer, but cannot or would not want to be classified as persons with disabilities, as that would mean adding another layer of labelling and discrimination to which they may be subjected. They are attacked and tortured, and their body parts and organs are trafficked and sold owing to the myths and misconceptions surrounding albinism. Yet the protection afforded to persons with albinism by international human rights treaties does not cater for their special needs or the complexities they face, while existing special procedures can only partly address the situation of persons with albinism from a particular and limited angle to the extent that the scope of their mandates allows.

IV. Findings and recommendations

60. Persons with albinism have special needs. In addition to issues pertaining to the rights to life and security of person, it is necessary to address their special needs in terms of education due to their poor eyesight as well as their special health needs, particularly in the area of skin cancer prevention. The situation of human rights of persons with albinism should therefore be addressed in a holistic manner.

43 It should be noted that ritual killings and attacks remain undocumented and unreported, owing to the code of silence surrounding such crimes and the vulnerability of the targeted population.

The severity of the violations of the human rights of persons with albinism and the particular vulnerability of that segment of the population requires States not only to take a more active role to protect them, but also to take effective measures to eradicate poverty and improve enjoyment by persons with albinism of all their rights.

61. There is increased engagement of international and regional mechanisms with the issue of persons with albinism. Efforts however continue to be fragmented and only partially address the complexity of the human rights challenges that persons with albinism face. A more sustainable response, to bridge protection gaps and to ensure accountability for human rights violations committed against persons with albinism, is required.

A. States

62. States are the prime guardians of the human rights of all persons within their jurisdictions. States should have protection measures against practices such as attacks against persons with albinism and should comply with their international obligations concerning human rights, which are enshrined in both local laws and international human rights legal instruments. With regard to the latter, special mention should be made of the Convention on the Rights of the Child (see in particular articles 19 to 23), the Convention against Torture, the African Charter on the Rights and Welfare of the Child, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The existing body of international human rights law in terms of general human rights, standards on non-discrimination, equality and human dignity require effective implementation so as to protect and preserve the rights to life and to security of persons with albinism, as well as their right not to be subjected to discrimination, torture and ill-treatment.45

63. Clear laws criminalizing and punishing acts of violence against persons with albinism should be enacted. States need to clarify ambiguities where they exist in laws relating to witchcraft and traditional health practice, including through the effective regulation of the licenses of traditional healers and witchdoctor and a clear ban on the use of harmful practices. Attacks against persons with albinism should also be considered as an aggravated form of the crime, incurring a more severe punishment so that additional deterrence may be achieved.46

64. It should be stressed that simply promulgating laws is not enough to prevent violence. They should be implemented. Current laws against assault and murder tend to provide persons with albinism with minimum protection of their rights to life and security of person. Without effective implementation of those laws, States may become complicit in such attacks by enabling a reign of impunity and perpetuating fear of attack in the lives of persons with albinism. Hence, laws should be accompanied by concrete measures that would facilitate their implementation, such as advocacy and the training of law enforcement personnel and judicial authorities.

65. In order to respond to violence and discrimination against persons with albinism and address their root causes, a multipronged and holistic approach is necessary, involving protection and accountability measures in addition to broad public education campaigns.47

45 Outcome report of the Expert Meeting on Persons with Albinism; Violence, Discrimination and Way Forward, 24 September 2014, para. 54.
46 Ibid., para. 70.
47 Outcome report of the Expert Meeting on Persons with Albinism; Violence, Discrimination and Way Forward, 24 September 2014 (see footnote 15), para. 52.
Accountability measures should include successful prosecution and the guarantee of redress in the form of compensation and rehabilitation.

66. States should fight impunity and ensure that cases of violence and attacks are prosecuted successfully. Publicizing the verdicts of prosecutions will serve as deterrence and, in effect, protect persons with albinism while granting them legal redress and justice for the attacks. Ensuring registration of birth is also an important measure in the fight against impunity, as it will remove the invisibility of children with albinism. It is equally indispensable to evaluate the needs of persons with albinism and plan for the basic social services to which they are entitled.48

67. The protective role of the family should be supported. Parents and caregivers, as well as members of the extended family, play a central role in the protection of children with albinism. They need to be sensitized and engaged. There is also a need to empower children to prevent and address incidents of violence against them.49

68. Active public education and awareness-raising campaigns must be launched and sustained. Given the powerful potential of such campaigns for dispelling superstition and misinformation about albinism, they remain indispensable tools for curbing violations of the human rights of persons with albinism. They should aim at combating prejudice, superstition, misconception and stigma, with a view to diminishing the multiple and intersecting forms of discrimination affecting persons with albinism. States bear the ultimate responsibility for such attitudes and practices. A gradual approach may be adopted, by which States would first target specific key groups such as law enforcement officers, members of the judiciary, educators, social workers, medical service providers, and the families and communities of persons with albinism. Further, it is important that States include in their educational curricula, in a standardized manner, courses to instruct people on the rights of persons with albinism.50

69. In raising awareness of the problems through the mass media, both traditional and social media will be crucial in highlighting the issues faced by persons with albinism, including marginalization, stigmatization and discrimination, and could also contribute positively to protecting their rights by directing public opinion to the core of the problem, sensitizing the population and collectively searching for a solution to help protect persons with albinism. Television campaigns to demystify perceptions about persons with albinism and promote positive stories about them are one of the tools that could be used.

70. Greater attention will need to be given to supporting community level public campaigns through a wider use of community radio. When planning and implementing community level responses, there is a need to take into consideration the prominent community role played by traditional health practitioners involved in witchcraft.51

71. Resources, both financial and otherwise, are important for the success of any effort to improve the lives of persons with albinism. Taking into consideration that persons with albinism are disproportionately affected by poverty, owing to the discrimination and marginalization they face, there is a need for resources to develop activities designed to decrease and eliminate prejudice and create an environment conducive to respect for their rights and dignity.

72. There is a need for a comprehensive strategy to guarantee the protection of persons with albinism, notably in those countries where attacks have been reported. Such a strategy

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48 Ibid., para. 63.
49 Ibid., paras. 66–67.
50 Ibid., para. 57.
51 Ibid., para. 60.
should be developed and implemented in coordination with, and with the support of, State authorities, various sectors of society, key stakeholders and civil society, as well as persons with albinism. Key non-governmental organizations such as Under The Same Sun and the World Albinism Alliance are important actors in that endeavour.

73. The commitment of all stakeholders to combat violence and discrimination against persons with albinism is critical. It is important to involve religious leaders who are well respected and influential in their communities and are in a position to provide followers with guidance on the issue of respect for the human rights and dignity of persons with albinism.52

B. International community

74. International and regional mechanisms should continue to give the necessary attention to the issue. Some of its facets can be integrated across existing human rights mechanisms, but credible data on cases of attacks and discrimination in several countries are few and far between or not entirely reliable.53 Action should be taken to gather such information in order to put in place effective preventive and remedial action. Gathering information should be an independent process and ought not to be expected of existing special procedures mandate holders, as it is beyond their current scope and capacity.

75. Therefore it is necessary to consider setting up a specific dedicated mechanism to work on ending violence against persons with albinism and the structural and multi-layered discrimination they face. A large number of the answers to the questionnaire of the Advisory Committee called for the establishment of such a mechanism. A call for a specific and dedicated special procedure was also made by the participants at the expert meeting.

76. The special procedure would initiate and foster a holistic approach to the issue. Further, the mandate-holder would have better access to information, improved understanding of albinism both regionally and globally, and could initiate as well as follow up on concrete measures taken on the ground, through regular field visits and cooperation with authorities, civil society and other key stakeholders.

77. In conclusion, a dedicated special procedure mandate would be a first step towards ensuring an effective, comprehensive and more sustainable response to the human rights violations faced by persons with albinism.

52 Ibid., para. 58.
POLICY: GUIDELINES FOR PEOPLE WITH DISABILITIES

RESOLVED:

1. That the contents of the report on Policy Guidelines for People with Disabilities BE NOTED.

2. That the policy guidelines in respect of People with Disabilities, with amendments to its introduction, BE APPROVED as the Ekurhuleni Metropolitan Municipality’s Policy, subject to the deletion of section 12.2, the first bullet of section 13.1 and the third bullet of section 13.3.

3. That a further report on the Programme of Action for the implementation of the policy in 2 supra BE SUBMITTED.
THE EKURHULENI METROPOLITAN COUNCIL

DISABILITY POLICY GUIDELINES
1. INTRODUCTION

The fact that people with Disabilities are marginalized and discriminated against has created an environment with a range of factors such as physical, and psychological contributing to the high prevalence of disability.\footnote{Amended in terms of resolution 2 of item B-I (6-2005) of the Mayoral Committee Meeting of 21 April 2005 read with the Comments under Municipal Infrastructure in the report.} It is exacerbated by other obstacles that prevented people with disabilities from taking part in family life and the community on the same footing as every one else. It is a diverse phenomenon with a variety of needs experienced not only by people with disabilities but also their families and broader community.

Majority of people with disabilities have been excluded from the mainstream of society and prevented from accessing fundamental social, political and economic rights. To address this anomaly, the Ekurhuleni Municipality together with people with disabilities must take full responsibility.

The Ekurhuleni Metropolitan Council's approach to disability is informed and guided by the Integrated National Disability Strategy [INDS], Gauteng Provincial Government Disability Policy Framework and other relevant legislation and regulations.

The approach taken seeks to operationalise the objectives of existing legislative and policy frameworks and builds on the other programmes that are initiated by the Metropolitan Council and the Disability Forum.

2. VISION

The Smart, Creative and Developmental City.

3. MISSION

To sustain non-discriminatory attitudes and to ensure inclusivity is fostered throughout the Metropolitan Council, Community, and Business sector in line with the 'Batho Pele' principles.

4. PURPOSE

The purpose of this policy is to set out guidelines for the Ekurhuleni Metropolitan Municipality to ensure that:

4.1 The interests and needs of people with disabilities are taken into account by provision of accessible and equitable services.

4.2 People with disabilities are protected and empowered to enable them to live an independent sustainable life.

4.3 Through education and awareness campaigns, myths and wrong perceptions about people with disabilities are curbed.

5. SCOPE OF APPLICATION
The policy guidelines shall be applicable to all the regions in the Ekurhuleni Metropolitan Municipality. All Non-Governmental, Community Based Organizations, Religious Based Organisations and families dealing directly with people with disabilities shall be co-ordinated, as to ensure coherence and comprehensiveness in the delivery of services.

6. **PRINCIPLES**

The following principles should underpin the Council’s approach to the management of disability in Ekurhuleni:

6.1. We are committed to respect human dignity of people with disabilities

6.2. To ensure that people with disabilities are afforded accessible transport

6.3. We are committed to ensure access to rehabilitation, medication and assistive devices.

6.4. Committed to ensure that there is networking amongst all departments, directorates and the disability forums

6.5. To ensure the provision of widest possible economic and social opportunities to people with disabilities.

6.6. Committed to ensure access to education and training in the mainstream.

6.7. Committed to the provision of resources needed to realize the highest potential.

6.8. Committed to the eradication of discrimination in communities and place of employment.

6.9. Committed to barrier-free public and private sector buildings.

6.10. Committed to fighting poverty and HIV/AIDS pan
7. **LEGAL FRAMEWORK**

7.1. **The South African Constitution**

Chapter 2 of the 1996 constitution guarantees fundamental rights to all citizens. It includes section 9, the equality clause and the right to freedom from discrimination based on a number of social criteria.

Discrimination based on disability is especially mentioned and disabled people are thus guaranteed the right to be treated equally and to enjoy the same rights as all other citizens. Provision is also made of affirmative action.

7.2. **The Reconstruction and Development Programme**

The Reconstruction and Development Programme commit itself to the following:

- The Government will design in consultation with people with disabilities a comprehensive programme for the disabled, which will enhance their engagement in society and remove discriminatory practices against them.


Emphasizes the shift from viewing disabled people from the medical perspective to the human rights and developmental approach.

7.4. **Code of good practice on employment of people with disabilities (2002)**

7.5. **Employment Equity Act (Act 55 of 1998).**


7.7. **Labour Relations Act (Act 66 of 1995).**


7.11. **South African Schools Act**


7.13. **Development Facilitation Act (Land and Integrated Development Plans).**

7.10 National Building Regulations and SABS 0400 Code of Practice.

7.11 National Land Transport Transition Act as well as the Moving SA: A Transport Strategy for 2020 and Model Integration in Gauteng policy documents


8 DEFINITION, TERMINOLOGY, CATEGORIES AND SITUATIONAL ANALYSIS OF DISABILITY

8.1 Definition of People With Disabilities

"People with Disabilities" (PWD) refer to People who have physical and or mental impairment, long-term or recurring, which substantially limits their prospects of entry into, or advancement in employment, health care, leisure and education.

A disability is a long-term or permanent impairment or recurring condition, which needs to be reasonably accommodated in the workplace, in family life and the community and calls for the elimination of barriers for optimal functioning. The impairment may be of physical, mental, sensory, learning or psychiatric nature, which is medically certified.

8.2 Disability Terminology

8.2.1. The words and terms used in this policy are defined in appendix A below.

8.2.2. Impairment

In order to qualify for protection as a person with a disability, all the criteria of the definition must be satisfied. This refers to: "long term", "recurring impairment", "physical or mental impairment" and "substantially limit".

8.2.3. Long-term impairment

The impairment has lasted or is likely to persist for at least 12 months. A short term or temporary illness or injury is not an impairment which gives rise to a disability.

8.2.4. Recurring impairment

Is likely to recur and be substantially limiting regardless of whether the effect on a person fluctuates. Progressive conditions are deemed a disability once impairment starts to be substantially limiting. Progressive or recurring conditions, which have no overt symptoms or do not substantially limit individuals, are not considered disabilities.

8.2.5. Physical impairment

This refers to the partial or total loss of a bodily function or part of the body. It includes sensory impairments such as being deaf, hearing or visually impaired and any combination of physical or mental impairments.

8.2.6. Mental impairment

This refers to clinically recognized conditions or illnesses that affects a person's thought processes, judgment or emotion.
9. CATEGORIES OF DISABILITY

9.1. Physical Disability

Refers to damage to muscles, nerves, skin or bones that leads to difficulties in moving around and performing activities in daily living.

Physical disabilities include:

- Paraplegia: a substantial loss of function in the lower part of the body.
- Quadriplegia: substantial loss of function in all four limbs.
- Hemiplegia: substantial loss of function on one side of the body, often due to a stroke
- Cerebral palsy: damage to the brain that causes muscular incoordination.
- Post-polio paralysis: weakness in some muscles, and underdevelopment of some limbs.

9.2. Visual Disability

Refers to the loss of sight that may be total or partial. Visual disabilities include:

- Blind: refers to total loss of sight. A person might experience difficulty in moving around and knowing where things are.
- Low vision: a limited range of sight and focus that can easily be corrected with spectacles.

9.3. Hearing Disability

Refers to hearing loss that may be mild, severe or total. Hearing disabilities include:

- Deaf: hearing loss that usually results in difficulties in learning a spoken language.

9.4. Mental Disability

Mental disabilities include cognitive, psychiatric and learning disabilities as well as physical head trauma.

- Intellectual disability: people with intellectual disabilities find it difficult to learn and retain new information, and often struggle to adapt to new situations.
- Psychiatric disability: people living with a psychiatric or mental illness often experience difficulties in perceiving or interpreting reality and coping with some aspects of daily life.
9.5. Multiple Disabilities

Multiple disabilities means having more than two of the disabilities, for example - people who have a hearing and visual disability.

9.6. Epilepsy

Epilepsy is a recurrence of seizures, and a seizure is an episode caused by a sudden disturbance in the brain. Epilepsy is a chronic condition which can be controlled with medication but if not can become a disability.

9.7. Albinism

Albinism is not a disability per-se, is an inherited condition where a person has absence of pigmentation of the skin and hair and is partially sighted. Most people with albinism identify with other people with disabilities due to the nature of discrimination they experience.

10. SITUATIONAL ANALYSIS

People with disabilities in Ekurhuleni are continually faced with different barriers that prevent them from enjoying their full civil, political, economic, social, cultural and developmental rights.

This is due to the lack of policies that ensure the protection of human rights and empowerment of people with disabilities by the Metropolitan Council, when implementing their programmes and projects with regard to people with disabilities.

10.1. Challenges

The key issues that face people with disabilities in-order for them to achieve equality, inclusion and empowerment are the following:

- **Employment**: there is serious lack of employment opportunities for people with disabilities and high level of discrimination

- **Transport**: there is lack of accessible public transport for physical and visual and hearing people with disability and hence make it extremely difficult to travel to places of employment and health facilities.

- **Housing**: houses are often not accessible to people with disabilities which means that they have to be institutionalized.

- **Accessibility**: public and private buildings are not designed to cater for the needs of people with disabilities.
Public schools: are often not designed in ways which can be accessible for people with disabilities.

Children whose parents have some form of a disability are often excluded from education opportunities due to financial constraints.

-Social security: there is still a problem in people accessing disability grants.

-Assistive devices: inadequately access to other devices, e.g. spectacles, white canes, Braille machines, etc.

-Advocacy: there is lack of awareness programmes to curb attitude against people with disabilities and enhance the concept of self representative.

10.2. Arising from the situational analysis, the Ekurhuleni Metropolitan Municipality recognizes and commit itself to the following:

-The International Day of people with disabilities that was proclaimed in 1981 by the United Nations.

-Disabled people have rights and equal opportunities to participate fully in the country’s economy and general life like everyone else.

-Society has a duty to adapt its standards to the specific needs of people with disabilities in order to ensure that they can lead independent lives.

-Creation of awareness in our communities about disabilities is needed.

-Disability is not regarded as a health and welfare issue but should be seen from a human rights and development perspective.

10.3. IMPLEMENTATION

In the implementation of this policy, the Ekurhuleni Metropolitan Municipality with its stakeholders must ensure that:

-The interest and needs of people with disabilities are promoted through the provision of services that will enhance self-independence.

-There is genuine active participation by people with disabilities in the community and organisations of their own.

-That all Ekurhuleni Metropolitan Municipality buildings and facilities are accessible to people with disabilities.

-The Ekurhuleni Metropolitan Municipality policies and programmes are developed and operationalised with the full participation of people with disabilities.
11. STRATEGIC AREAS / PRIORITIES

Arising from the situation analysis and challenges, the Metropolitan Council will give priority to the following key interventions:

11.1. Preventable measures both genetic and medical by providing affordable and accessible health care.

11.2. Forge partnership with the Education Department to provide educational opportunities and with Department of Sports for recreational programmes relevant to the development of people with disabilities.

11.3. Reinforce home care services and assisting by accessing resources in the community and state grants.

11.4. Providing training services and allowing people with disabilities to obtain employment by implementing the employment equity principles. With regard to the most severe people with disabilities, to ensure that they are employed in co-operatives and sheltered workshops.

11.5. Link people with disabilities with all services within the Ekurhuleni Metropolitan Municipality Departments.

11.6. Support and improve awareness of disability through workshops and awareness campaigns at ward level.

11.7. Ensure that a comprehensive policy is fully and coherently applied as proposed in the Integrated National Disability Strategy.

11.8. Set up a planning, implementation, evaluation and monitoring system to obtain statistics, information on disability and assess impact.

12. PROGRAMME CONTENT

The Ekurhuleni Metropolitan Council and the Disability forum will establish and support formation of the Forums at Metro, Regional and Sub-regional level and encourage participation of organizations.

12.1. Co-ordinate services in existing NGO's and CBO's of people with disabilities at Ward level.

12.2. *(Deleted in terms of resolution 2 of Item B-H(6-2005) Mayoral Committee Meeting of 21 April 2005).*

12.3. Promote, encourage and capacitate the organizations to be part of poverty alleviation programmes.

12.4. Support initiatives by NGO's/CBO's and link them to relevant resources.

12.5. The severely disabled to be encouraged to be part of sheltered employment.

12.6. Promote and encourage participation in recreational activities.

12.7. Promote integrated approach with other departments e.g. Sports
Recreation, Arts and Culture to establish recreational facilities that are user friendly to people with disabilities.

12.8 Promote and facilitate awareness campaigns on human rights i.e. National and International events.

12.9 Promote skills development and occupational trainings.

12.10 Encourage participation in the Integrated Development Plans (IDP) meetings by people with disabilities.

12.11 Establish a link with the department of Social Services to ensure smooth and fair grant approvals.

13. INSTITUTIONAL ARRANGEMENTS

To ensure that disability issues are raised and taken seriously by the Metropolitan Council and that the policy is implemented, Council need to have the following structures in place for accountability:

13.1. Executive Mayor’s office

-(Deleted in terms of resolution 2 of Item B-H (6-2005) Mayoral Committee Meeting of 21 April 2005).

- To develop progress reports on disability in the metropolitan area
- To monitor and evaluate programmes implemented by departments and directorates
- Network and liaise with the disability forum

13.2. Interdepartmental Task Team

The Ekurhuleni Interdepartmental Task Team to:

- Ensure that disability is on the agenda of departmental meetings
- Develop a programme of action on disability to be implemented by all departments
- Ensure that the chairperson of the forum attends the task team meetings [optional] and ensures that representatives from the forum also attends departmental meetings

13.3. Disability forum

The Ekurhuleni Metropolitan Forum of people with disabilities with other stakeholders shall:

- Develop mechanisms to monitor progress and impact of disability issues
- Ensure participation by people with disabilities in decision making through a forum and other structures.

-(Deleted in terms of resolution 2 of Item B-H (6-2005) Mayoral Committee Meeting of 21 April 2005).
Committee Meeting of 21 April 2005.

• Visit the NGO's and CBO's to establish and promote optimal utilization of resources and give assistance where possible.

• Develop a progress report with recommendations every six-month and submit to Council.
Appendix A

1. DISABILITY RELATED DEFINITIONS
The words and terms used in this policy are defined below:

1.1. Disability Discrimination
- The systematic societal and individual discrimination against people with or perceived to have, disabilities that hinder or preclude their ability to conduct their activities, undermines their sense of human dignity and self-worth and prevents their full integration into the greater society.
- The defining, perceiving of or limiting of people with disabilities by their disability rather than examining societal and individual biases and stereotypes that continue to disadvantage and discriminate against people with disabilities.
- Contravening the South African Bureau of Standards Code of Practice or Regulations that govern environmental accessibility.
- Disqualifying a suitably qualified person from employment because of her/his disability.

1.2. Reasonable Accommodation
Refers to the modification or adjustment to a job or working environment that will enable persons with disabilities to have access to participate or advance in employment on the same levels with other people.

1.3. Rehabilitation
Refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and social functional levels, thus providing them with the tools and training to change their lives towards higher levels of independence.

1.4. Assistive Devices
These are devices and ergonomic solutions capable of reducing the limitations and difficulties experienced by people with disabilities.

1.5. Barrier Free Environment
An environment, which is accessible to all people and services are equally available to all, including people with disabilities.

1.6. NGO
Refers to a non-profit making organization, which receive part subsidy from government in implementing their programmes.

1.7. CBO
Refers to a non-profit making organization, which is community based, no subsidy from the government - implement programmes in the community.

1.8. Independence
Is a state of being, whereby available and adequate support services, assistive devices and personal assistance to people with disabilities at all levels. It enables people with disabilities to exercise choice, bear responsibility and participate fully in society.
ANNEXURE E

SOUTH AFRICAN BILL OF RIGHTS: TABLE OF NON-DEROGABLE RIGHTS
Table of Non-Derogable Rights

<table>
<thead>
<tr>
<th>Section number</th>
<th>Section title</th>
<th>Extent to which the right is protected</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Equality</td>
<td>With respect to unfair discrimination solely on the grounds of race, colour, ethnic or social origin, sex, religion or language.</td>
</tr>
<tr>
<td>10</td>
<td>Human Dignity</td>
<td>Entirely</td>
</tr>
<tr>
<td>11</td>
<td>Life</td>
<td>Entirely</td>
</tr>
<tr>
<td>12</td>
<td>Freedom and Security of the person</td>
<td>With respect to subsections (1)(d) and (e) and (2)(c).</td>
</tr>
<tr>
<td>13</td>
<td>Slavery, servitude and forced labour</td>
<td>With respect to slavery and servitude</td>
</tr>
<tr>
<td>28</td>
<td>Children</td>
<td>With respect to:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- subsection (1)(d) and (e);</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- the rights in subparagraphs (i) and (ii) of subsection (1)(g); and</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- subsection 1(i) in respect of children of 15 years and younger.</td>
</tr>
<tr>
<td>35</td>
<td>Arrested, detained and accused persons</td>
<td>With respect to:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- subsections (1)(a), (b) and (c) and (2)(d);</td>
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<tr>
<td></td>
<td></td>
<td>- the rights in paragraphs (a) to (o) of subsection (3), excluding paragraph (d)</td>
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<tr>
<td></td>
<td></td>
<td>- subsection (4); and</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- subsection (5) with respect to the exclusion of evidence if the admission of that evidence would render the trial unfair.</td>
</tr>
</tbody>
</table>

(6) Whenever anyone is detained without trial in consequence of a derogation of rights resulting from a declaration of a state of emergency, the following conditions must be observed:
ANNEXURE F

REPORTED ATTACKS OF PEOPLE WITH ALBINISM
Reported Attacks of Persons with Albinism – Most Recent Attacks Included
By Under The Same Sun (UTSS) Canada & Tanzania http://www.underthesamesun.com/
DATE OF REPORT: November 6, 2015

PWA = Person(s) with Albinism
PFI = Press Freedom Index for 2015 (180 countries surveyed)
http://index.rsf.org/#/index-details
(PFI for Canada = 8 of 180 & USA = 49 of 180)

Killings: 162
Attacks: 262 *Attacks include survivors of mutilations, violence, rape, attempted abductions, missing, grave violations, asylum (permanent residency) cases*
Total: 424
Total Countries: 25

NOTE 1: Many attacks & killings of PWA in Africa are not documented or reported. UTSS is certain that crimes of colour against PWA are common in various parts of almost all African countries. LEGENDS & MYTHS ABOUND, AND UTSS HAS YET TO HEAR OF ONE THAT IS HUMANIZING. Most myths reduce PWA to ghosts, magical beings or curses, etc. On rare occasion the discrimination is reversed and the PWA are “deified” into “gods”. Either way, they rarely get to enjoy their status as normal human beings. Many countries have stories about the mysterious disappearance of PWA. There is a growing, documented truth to these rumors. We know that many PWA have “disappeared” due to abduction, then mutilated and killed by fellow citizens (sometimes family members “friends” or neighbours) for the purpose of witchcraft related rituals. Muti murders or “medicine” killings have a deep, longstanding history, and are a familiar concept to most Africans.

NOTE 2: Countries known to be involved in the cross-border trade of PWA and their body parts: Tanzania, Burundi, Kenya, DRC, Mozambique, South Africa, Swaziland,

**Benin, 2 reports:** (PFI 84 of 180) 2 killings
In 2012, a 20 year old woman with albinism was found dead in a bush at Togba, in the town of Abomey-Calavi, Benin with her genitals removed. In their statements to the Criminal Investigation Department, the criminals declared they sell them to make money. (Source: Cotonou, December 01, 2013 @ Koaci.com; Posted by Sekodo, http://koaci.com/articles-87884; media's contact in Abidjan: www.koaci.com Tel: +225 08 85 52 93)

In 2012 a male with albinism was sent from Dogbo, Benin to Nigeria by his own siblings for the purpose of selling him. In their statements to the Criminal Investigation Department, the criminals declared they sell them to make money. (Source: Cotonou, December 01, 2013 @ Koaci.com; Posted by Sekodo, http://koaci.com/articles-87884; media's contact in Abidjan: www.koaci.com Tel: +225 08 85 52 93)

**Botswana, 3 reports:** (PFI 42 of 180) 3 survivors
Survivor account: In September of 1998, a 27 year old woman with albinism by the name of Ofentse Serurubele narrowly escaped a second plot against her life. The incident took place at Kanye, her native village in Southern Botswana. Although Serurubele was a primary school teacher in the city of Jwaneng, Botswana, she was pregnant and staying in her native village at the time. On this near fateful day, her young brother encountered three guys in the village night club who knew Serurubele. They offered him some beer to get him drunk, hoping to manipulate him into joining their murder plot against his sister.
Fortunately he sensed something was wrong and secretly managed to replace the beer with water while pretending to be drunk. The guys asked him: “Where is your sister, the albino teacher?” “Your sister could actually make the deal: She is albino and pregnant!” “We want her flesh…!” Seururubele’s brother lied, telling them she was teaching in Jwaneng City but would be home for the weekend and that they could find her then. When he got home from the club that evening, Seururubele’s brother told her everything and warned her to leave immediately to Jwaneng city for her safety. After that incident, Serrurubele stayed in the city for a long time. (Source: Personal interview by UTSS on January 22, 2014 with Mrs. Ofentse Serurubele, founder & chair of PWA Tshimologo Association Botswana, mobile number +267-72-962-779; Botswana Gazette, January 16, 2014, Understanding Albinism by Kago Komane, http://www.gazettebw.com/?p=6718)

**Burkina Faso, 9 reports:** (PFI 46 of 180) 2 killing / 6 survivors / 1 asylum

**Most recent killing:** On August 14, 2012 a 12 year old boy with albinism was killed in Gaoua, Burkina Faso. Witnesses report that the body was found with his head and genitals removed. (source: “L’Express du Faso” on Wednesday, August 15, 2012)

**Other killing account (date unknown):** A 16 year old person with albinism (PWA) was allegedly murdered by François Compaore, brother of Burkina Faso’s president at that time. It is believed that the killing was related to human sacrifice. In the newspaper “L’Indépendant”, a former soldier by the name of Delma Daogo, who was in active service to Compaore at that time, gave an interview where he explained: François Compaaoré (the president’s brother) sent David Ouedraogo (his driver) to Ouagadougou Central Mosque, a place where PWA congregate to appeal for money, in order to bring one of them to him so that he could make a sacrifice. David brought a 16 year old PWA for the alleged purpose of making prayers in the compound of François Compaaoré. The driver was then given 50.000F (about 100 US dollars) and asked to go home. Once at his home, David realized he had forgotten his wallet and returned to pick it up. When he arrived, he saw that they had killed the PWA and cut him into pieces. (Source: l’Indépendant - link to article no longer active - This newspaper was founded by the late journalist, Mr. Norbert Zongo who was allegedly assassinated by President Blaise Compaore's regime due, in part, to the publication of this article about a PWA murder.)

**Most recent abduction:** On April 18th, 2012, Dr. Pius Kamau, an American physician originally from Kenya, was an eye witness at the Nairobi airport to three aggressive African men being allowed to transport a young boy with albinism out of the country without a passport. He said the men had come from Tanzania and were headed to Ouagadougou, in Burkina Faso and that they used loud, offensive language as the airline attendant asked for the missing passport -- they had three passports and none for the child. Dr. Kamau is now convinced that the three-year-old boy with albinism is no longer a baby headed to a loving family, but a sacrifice at some altar of a cruel witchcraft ceremony. (Source: HUFF POST: IMPACT - The BLOG; Three Year Old Albino – Victim of Witchcraft Sacrifice by Pius Kamau, Posted: 05/01/2012 at 4:00 pm)

**Burundi, 35 reports:** (PFI 145 of 180) 18 killings, 13 survivors, 4 grave robbery.

**Most recent killing:** On Friday, December 12, 2014, a 27 year old man with albinism by the name of Cyriaque Minani was ritually murdered in the province of Makamba, in the town of Kayogoro on the hilltop of Rutenderi area of Gatabo, in Burundi. On the day of his attack Cyriaque had no particular worries and everything seemed normal as he spent time with others. While heading for home at around 7 PM, Cyriaque encountered a gang of criminals who suffocated him, chopped off his left leg and ran away with it. His lifeless body was left lying at the edge of the path and found by passers-by the next morning. Cyriaque was married and had 3 children including a newborn. One person has been arrested for further investigation. The albinism association in Burundi (OPA) says: “For now, we are inclined to link this murder to false beliefs surrounding albinism (muti / juj purposes) as elections are underway.” (Source: Moise Nkengurutse, legal representative of the Organization for People with Albinism of Burundi;
**Most recent survivor:** On October 6, 2015, a 10 year old girl with albinism by the name of Alice Girukwishaka miraculously survived a brutal attack at her home in Busoni town, in the province of Kirundo, in MUyange-Gisozi, Northern Burundi. Men armed with machetes attacked the family of Gerard NKUNZIMANA & NIZIGIYIMANA who were accommodating Alice. Fortunately neighbours managed to intervene and help bring a premature end to the attack. Little Alice sustained injuries to the head and shoulder and underwent intensive treatment at Kanyinya Hospital in Kirundo. The criminals escaped before being identified. (Source: Moise Nkengurutse, Legal Representative of the of Burundi albinism association – OPAB; Address: Q. Mushasha, Sous Q. Nyabisindu, Transversal IV, No 18, Gitega_Burundi, BP: 179, Gitega; Tel: +257-79323225 / +257-75401739; E mail: opa.burundi@yahoo.com)

**Second most recent survivor:** On March 20, 2015, a 28 year old man with albinism by the name of Ndagijimana Debok was attacked with a machete and his left leg severely injured, in the town of Gihanga, North western province of Bubanza in Burundi. As presidential elections approach in Burundi, the safety of PWA remains a matter of concern. The victim received treatment in a local hospital. Ndagijimana’s neighbour is suspected to be the perpetrator of this attack and investigations are underway. (Source: Account provided on March 28, 2015, by Mr Pascal Matabishi, member of Burundi’s PWA association - ASF – email: pascaloni@icloud.com; tel: +257-75 97 14 98)

**Graver robbery:** In August of 2012, the grave of a woman with albinism by the name of Tabu was violated by unidentified criminals and her head was stolen. Eight months earlier, Tabu had succumbed to an extended and tragic battle with skin cancer and was buried in the cemetery of the Bugarama area, in the town of Muramvya in the province of Muramvya. Her son Venuste, also a PWA, was informed of his mother’s exhumed body and immediately reported it to the leaders of the Burundian PWA Association called “Albinos Sans Frontieres”. (Source: ASF – Burundi PWA Association)

**Cameroon, 10 report:** (PFI 133 of 180) 2 killings, 2 survivor, 5 asylum, 1 grave robbery

**Most recent killing account:** In August of 2009, the foot of a young girl with albinism whose identity remains undisclosed was found in a garbage can in Douala, the capital of the region of Littoral, Cameroon. She reportedly worked in a Snack Bar in that area. Her foot was kept in the morgue of the Laquintane Hospital in Douala. (Source: Information provided to UTSS on July 03, 2013 by Kakmeni Wembou Raphael, the leader of Cameron Association for the Promotion of Albino CAPA)

**Most recent survivor account:** In 2013 a mother and her infant with albinism began the process of seeking asylum in France because she feared for the life of her child in Cameroon where members of her community attempted to kill the baby for ritual purposes during local elections. (Source: Interview on June 12, 2014, between UTSS and Genespoir, France’s major PWA group who were strongly involved in this case.)

**Most recent asylum account:** On June 7, 2014, a 34 year old man with albinism from Cameroon was granted asylum in France. (Source: Interviews with UTSS on June 9, 2014)

**Democratic Republic of Congo (DRC), 61 reports:** (PFI 150 of 180) 14 killings / 31 survivors / 1 missing / 9 grave robberies / 6 asylums

**Most recent killing:** On August 5, 2014, a girl with albinism by the name of Namukyungu Byaombe was abducted and killed by unidentified criminals. Her body was found by a Police Unit of PNC. Investigation is underway and the Police report was submitted to the Public Prosecutor's Department. (Source: Mr. JEAN DE DIEU KWIBONERA, Police Commander at the PNC of BARAKA; Phone: +243-811-374-759 and a PWA group called FFERAD; fferadrdc@gmail.com)

**Most recent survivor:** On April 27, 2015, around midnight, a 2 year old girl with albinism...
narrowly escaped abduction in the town of Kampene, a mining city located about 150 km away from Kindu in Maniema Province of DRC. After noticing her daughter had disappeared, the mother screamed for help and her daughter was released by the kidnapper. Sources from civil society in the territory of Mpangi declared having identified the man who attempted to kidnap the girl and indicated that the kidnapper sought shelter in the forest. (Source: Article published on May 05, 2015, on Radio Okapi Website: http://radiookapi.net/actualite/2015/05/05/maniema-deux-enfants-albinos-echappent-aux-tentatives-denlevement-kampene/)

**Most recent missing:** On February 16, 2015, a two year boy with albinism was abducted in Nyannte, in the territory of Kabare, province of South Kivu, DRC. A journalist for the Congolese Press Agency reported that early in second week of September, 2015, a trafficker of children with albinism was arrested for this crime by the police in Kamanyola in the territory of Walungu. The child's father and paternal uncle explained that the criminal, along with his accomplice and their neighbours, broke into their house while the parents were away, enticing the boy with sweets and wrapping him in a bag. The victim's older brother, age 7, said the kidnappers bought him cookies to gain his favour in order to commit their heinous crime. They have since vanished with the boy. One of the arrested suspects declared that it was his accomplice who wrapped the boy in the bag. The latter is now in the hands of police. (Source: Congolese Press Agency - ACP [Agence Congolaise de Presse]; An albino child trafficker arrested in Kamanyola; September 10, 2015, http://acpcongo.com/acp/un-trafiquant-denfants-albinos-arrete-a-kamanyola/)

**Most recent grave desecration:** On February 4, 2015, the grave of a young man with albinism by the name of Mr. Augustin Kerekwa was robbed. He previously died at age 40 and was buried in the community of Nyangezi, within the province of South Kivu, DRC. This case was corrupted. (Source: Mr. Lushole Jonena, chairperson of DRC's ASSOCIATION FOR COMPLETE PROMOTION OF PEOPLE WITH ALBINISM (APIA), SOUTH – KIVU, DRC; Tel: +243-0853-155-093 / +243-081-467-3706. The information was collected from APIA and sent to UTSS in July of 2015 by BBC Journalist Byobe Malenga; https://www.linkedin.com/pub/byobe-malenga/9a/50b/105; https://www.facebook.com/permalink.php?id=1391123401155312&story_fbid=1594200034180980.)

**Most recent asylum:** During the first week of June, 2015, legal history was made in Ireland when a man with albinism from DRC who wishes to remain anonymous was granted secured permanent residency through a non-asylum process. He suffered severe persecution and untreated skin cancer in his native country. (Source: UTSS was informed via a personal contact from his sister who is now a resident of Canada.)

**Egypt, 1 report:** (PFI 158 of 180) 1 asylum – September 16, 2011

On Friday, September 16, 2011, Hazem Abd Elkade, a 28 year old man with albinism from Egypt told journalist Sophie Bond about his life in Egypt and his new found asylum in New Zealand. He contrasted the profound discrimination facing people with albinism in Egypt with the amazing and equal opportunities he has found in New Zealand. Hazem’s lawyer says: “He was seriously maltreated at multiple levels including such things as deliberate cigarette burns from supposed educators.... The hostility toward him was serious at best because of his Albinism. He has now been able to both marry and continue his studies. He is one of the nicest and most considerate people I have met in a long time and doing very well.” Hazem says; “I want to be a professor in the university. The first time I ever got a salary was here in New Zealand. I can support myself and my research. I don't want to go back to Egypt, not even for a visit.” (SOURCE: The Aucklander (online) - New home for Hazem, By Sophie Bond, Friday 16 September 2011, http://m.nzherald.co.nz/aucklander/news/article.cfm?c_id=1503378&objectid=11040952 ; Hazem’s lawyer Allen Little QSM,JP)

**Ghana, 3 report:** (PFI 22 of 180) 1 killing / 2 survivors

**Most recent killing:** On February 17, 2015, the lifeless body of a 35 year old man with
albinism by the name of Kofi Yeboah aka Agbleyevu was found at the entrance of Pastor Emmanuel Agbeze’s residence in Owoakra, Boketey, under Amanase in the eastern region of Ghana. According to the pastor’s wife, Gifty Asare, her husband ran off shortly after the death of Kofi and she has not heard from him since. Unfortunately the police have not been responsive to crimes committed in this area and allowed Pastor Agbeze to escape without questioning. Since that time however, police commander Spt. Yahaya of Suhum police station announced that because of the public interest whipped up by media related to the death of Kofi Yeboah, the homicide unit at police headquarters in Accra had taken over the investigation. (Source: Newton Kwamla Katseku, Executive Director of the Ghana Association of Persons with Albinism – GAPA, June 6 & July 24, 2015; info@gapaghana.org / gapa4all@gmail.com / www.gapaghana.org and Suhum police report number 112967)

Most recent survivor: On February 27, 2010, a man with albinism by the name of Newton Kwamla Katseku, who is also the Executive Director of the Ghana Association of Persons with Albinism (GAPA), narrowly escaped death. This event took place while attending a funeral in the town of Akwamufie, a community along the Volta Lake near the Adomi bridge on Atimpoku Ho road in the eastern region of Ghana. Early on during the funeral ceremonies Newton was approached by 4 different parties urgently warning him to leave or go into hiding. When he asked why, they informed him that it is against local tradition to tolerate or accept people with albinism in the vicinity. Newton spent close to nine hours hiding in a car as the funeral and other rites were performed before he was able to leave. He later reported the incident to several authorities but has never received a reply. (Source: Newton Kwamla Katseku, Executive Director of the Ghana Association of Persons with Albinism – GAPA, June 6 & July 24, 2015; info@gapaghana.org / gapa4all@gmail.com / www.gapaghana.org)

2nd most recent survivor: On July 16, 2009, in the country of Ghana, a 2 year old boy with albinism (unnamed) was kidnapped by an 18 year old woman named Akua Linda. A week later on July 22, 2009 Linda was apprehended and confessed that a man named Biyanka sent her to feign playing with the boy so that she could steal him. Linda continued that Biyanka took the boy to Asuoyeboah, another Kumasi suburb, after which he was taken to an unknown destination. Akua Linda, according to the Police Capo, noted further that Biyanka returned the boy to her yesterday morning, explaining that what he intended to use the boy for could not work out as expected. Linda was therefore on her way to return the child to his mother when someone saw them at the Kejetia Bus Terminal in Kumasi, Ghana, and raised the alarm leading to her apprehension. Investigations continue. (Source: Daily Guide posted by Ghana Pundit; Thursday, July 23, 2009, “Girl Arrested for Stealing Albino” http://ghanapundit.blogspot.ca/2009/07/girl-arrested-for-stealing-albino.html)

**Guinea, 14 reports:** (PFI 81 of 180) 5 killings / 5 survivors / 3 asylum / 1 permanent residency

2 Most recent killings: 1st Killing: On a Sunday in September of 2010, at the area of La Carrière, in the town of Matam, district of Conakry, the body of a PWA was found with the eyes missing— very likely removed with a knife. According to our source, the unnamed PWA used to wander daily in that area with some friends, looking for their daily bread. Their life is made up of begging at the big market of Matam’s main station and on the streets of the Capital City. One morning his lifeless body was found laying on the sidewalk. 2nd Killing: At very much the same time in 2010, at the Matoto Market, in the town of Matoto, another PWA was killed in some unexplained circumstances. His body was found completely dismembered; the attackers having made off with many of the body parts. These two PWA lifeless bodies have made the headlines of all local media including the National Broadcaster RTG. Many Websites and Private Radios have used these murders in their headlines. But unfortunately, no investigation has been considered as if PWAs have no rights. This silence and impunity make fragile the life of PWA in the republic of Guinea and everywhere in Africa.

Most recent survivor account: On Saturday, June 18, 2011, a 12-year old boy with albinism by the name of Abdoulaye Sylla managed to escape from his kidnappers near the Sous-Prefecture of Kouria located at the exit of Coyah, in the country of Guinea. The boy Abdoulaye explained that he had been
abducted the day before just after leaving his father’s rice field. He had been sitting under a big tree when he saw two men rapidly approaching but doesn’t remember anything after that. The next morning he woke up in a strange house in another village but is unable to remember where it is. His feet and hands were tied and he was scared so he started to cry. Shortly after a woman appeared, untied the ropes and showed him where the main road was. As he was walking away he heard voices asking: “Where’s the little boy?” He began running and two men gave chase until they reached the main road and saw a taxi parked there at which time they vanished into the bush. This took place at around 8 PM when Mohamed Camara, a taxi driver on his way to the city of Kindia, rescued the boy. The taxi driver was Abdoulaye’s maternal uncle whose sister had called him the day before in tears saying her son had not come home. Mohamed says; “I was on my way to Kindia to report the boy missing when I saw him being chased by two strangers. I immediately parked at the side of the road and instead of pursuing the boy, the kidnappers ran away. My nephew was lucky. Last year my neighbours son with albinism went missing at Coyah, and to date he has not been found.” (Source: Le Nimba, Friday, July 8, 2011; http://kaloumpresse.com/economie/936-kouria-un-albinos-echappe-a-ses-ravisseurs and Bangoura, founder of Guinean albinism association - CNAB)

Another survivor account: In October of 1994, Amadou Diallo, a 19 year old teenage boy with albinism was assaulted in the Capital City of Conakry in his native country of Guinea. One day while walking to his home Amadou was approached by two unfamiliar men who stepped out of a military vehicle and surrounded him. He remembers them saying; “This is the meat we were looking for. We’ve now got it.” Amadou was knocked unconscious with a sharp cutting object. His next memory is of regaining consciousness two weeks later in a local hospital with a severe wound to the back of his head and a piece of skin missing. Several years later he realized the attackers intended to get his body parts. The injury to his head still troubles him to this day.

Permanent Residency: On June 4, 2013 Amadou Diallo, a man with albinism from the country of Guinea was granted Permanent Residency status in Canada. Originally, Amadou fled Guinea to Norway and from 2008 to 2012 urgently sought asylum there. He was held in a refugee camp for 3 of these years during which time his asylum request was denied 4 times even though 2 persons with albinism had been murdered in his home country. UTSS worked extensively with Amadou’s case during this time, providing written testimony on the plight of PWA in Guinea. We also worked with the Canadian government and on July 16, 2012 he was granted a work permit and moved to Canada. On Tuesday, June 04, 2013, the country of Canada received Amadou with open arms by offering him permanent residency status.

Most recent asylum: On July 27, 2015, Mrs. Konate and her 6 year old son with albinism by the name of Aboubacar from Guinea were granted asylum in Belgium. (Source: Ms. Annie Mokto and her association ASBL Ecran Total, Belgium, email: contact@ecran-total.org , Ph: 485 103 145 or 497 550 634)
at Yopougon Police Station "Commissariat du 16e Arrondissement de Yopougon". Mr. Coulibaly’s contacts are: ongbedaci@yahoo.fr or ongbedaci@gmail.com, Cell: +225-05 42 07 39

**Most recent survivor:** On the night of March 6, 2014, Brou Yao Serge, a 25-year old man with albinism living in Port-Bouët (Gonzakville), in the district of Abidjan, Ivory Coast narrowly escaped abduction and possibly death. At around 9:30 that evening, Serge was stopped by two young men as he was walking from his Brother’s home. When he asked why they had stopped him, a quarrel ensued. As Serge tried to push his way past the attackers, they grabbed him by the neck saying they wanted his head. Fortunately Serge was able to defend himself and managed to escape. This incident has been reported to the police by Ivory Coast’s albinism society, BEDACI. (Source: PWA Group - Bien-Etre Des Albinos de COTE D’IVOIRE (BEDACI); Adresse: 10 BP 1989 Abidjan 10; Tel: 24 00 31 20 /21 24 28 34/ 07 67 43 26; Email: ongbedaci@gmail.com)

**Another survivor account:** On August 9, 2012, a 28 year old woman with albinism by the name of Julienne managed to escape a second attack in her homeland of Ivory Coast. This date is branded in her memory. It was pouring rain on her way home from the marketplace in Abidjan when man offered to give her a ride. Julienne hesitated but finally decided to accept the offer. After a few miles the driver bluntly told Julienne he was sick and to get healed, his witchdoctor told him to have sex with a woman with albinism. The car was heading to the forest of Banco at the edge of the city of Abidjan to a place where mystical practices often take place. Fortunately Julienne was able to open the car door and jump out. On August 13, 2012, just 4 days after this second attempted attack, she fled her native Côte d'Ivoire to Tunisia. (Source: French Daily Paper “Le Monde” published on May 20, 2013; http://emilien nemalfatto.blog.lemonde.fr/2013/05/20/julienne-29-ans-refugiee-dermatologique/)

**Asylum account:** Julienne is a 29-year old woman with albinism and a mother of a 13-year old daughter and an 8-year old son who, just four days after narrowly escaping a second attack due to her albinism, fled her native Côte d'Ivoire on August 13, 2012 to Tunisia. She was hoping to find a better life in another African country. Shortly after her arrival in Tunisia she obtained refugee status from the UNHCR. Despite her refugee status in Tunisia, Julienne’s life has not improved as much as she had hoped, summarizing her experience by saying: “Here, people slap me, insult me and mock me. I don’t have a job and I am unable to become integrated”. (Source: French Daily Paper “Le Monde” published on May 20, 2013; http://emilien nemalfatto.blog.lemonde.fr/2013/05/20/julienne-29-ans-refugiee-dermatologique/)

**Kenya, 13 reports:** (PFI 100 of 180) 5 killings / 8 survivors

**Most recent killing:** On September 20, 2015, a 56 year old man with albinism by the name of Enock Jamenya succumbed to injuries from a brutal machete attack and died. Ten days earlier on September 10, 2015, it was reported that Enock survived a ritual attack by three men armed with pangas at his home in Gavudunyi village, Hamisi Subcounty, Vihiga county, Kenya. “When I told them I did not have any money, they asked for my ear or hand to sell to Tanzania,” he said. A struggle ensued and the attackers sliced his left ear, arm, neck and fingers and left him unconscious. His brother Nickson Lugadiri, also with albinism, said Enock was found in that state by his son, who called for help. Lugadiri took his brother to Hamisi Subcounty Hospital, where he was referred to Vihiga. Enock was operated on for three hours after which medics said he was out of danger. The attack has rekindled concerns over the security of people with albinism ahead of Tanzania’s October elections. “The attackers wanted my brother’s body parts to sell to Tanzania,” said Lugadiri who is one of four PWA in their family. The national coordinator of Kenya’s Albinism Empowerment Network, Martin Wanyonyi, visited Enock at the hospital, condemned the attack and said if the criminals are not apprehended within 48 hours, his network would take to the streets in protest. (Source: theSTAR; Hamisi albino attacked for his body parts; by JOSEPH JAMENYA; September 14, 2015; http://www.the-star.co.ke/news/hamisi-albino-attacked-for-his-body-parts) / The Telegraph; Kenya's albinos moved away from Tanzania border amid witch doctor threat; By Aislinn Laing; September 24, 2015; http://www.telegraph.co.uk/news/worldnews/africaandindianocean/kenya/11885641/Kenyans-albinos-moved-away-from-Tanzania-border-amid-witchdoctor-threat.html)
Most recent survivor: On Friday, March 15, 2013, a 7 year old boy with albinism in Embu, Kenya managed to escape relatives who tried to sell him for ritual purposes. He was kidnapped by his uncle together with other relatives who attempted to take off to an unknown destination where they were to meet the buyers. The boy said that the kidnappers threw him out of the window of a moving vehicle when he screamed. (Source: "7 Year Old Escapes Deathly Ritual," Citizen News, March 15, 2013, accessed June 26, 2013, http://www.citizennews.co.ke/news/2012/local/item/8667-7-year-old-escapes-deathly-ritual)

**Malawi, 18 reports:** (PFI 59 of 180) 5 killings, 10 survivors, 2 missing, 1 grave robbery

Most recent killing: On September 4, 2015, Nyasa Times of Malawi reported that in Mchinji, Malawi, police spokesman for the district officer, sub inspector Moses Kajawa Nyirenda, said they have found the body parts of a person with albinism in the Dagrasi Mwale’s garden. Nyirenda said Police are investigating the matter. (Source: All Africa – Nyasa Times: Malawi: Albino Attacks Resurfaces - Body Parts Found in Mchinji As Abducted Karonga Boy Throat Cut; September 4, 2015; By Tiwonge Kumwenda; http://allafrica.com/stories/201509041222.html)

Second most recent killing: During the night of January 21, 2015, a 9 year old girl with albinism by the name of Ida Thomas was attacked in Chalela Village, Chikhwawa district, Malawi. The intruders broke in while Ida was sleeping at her Aunt’s house and kidnapped her. She is believed to have been killed as her blankets were found outside the home covered with blood. The incident was reported to the police though no one has yet been arrested. (Source: an email to UTSS on March 1, 2015, by UN Human Rights Office, Malawi)

Third most recent killing: On January 18, 2015, a 68 year old woman with albinism by the name of Malita Makolija went missing from Masali village, traditional authority Mwambo in Zomba District, Malawi. Her dismembered body was found the following day near to her home, buried next to an ant hill with head, arms and legs missing. (Source: Communication between UTSS and Bonface Ophiyah Massah, Executive Director of THE ALBINO ASSOCIATION OF MALAWI –TAAM; email: albinismassociationmw@gmail.com; mobile: (265) 0881006474 & (265) 0 999399337)

Most recent survivor: NAME UNKNOWN: On September 30, 2015, Malawi police announced that a 4 year old boy with albinism narrowly escaped abduction when his mother, Maria Mtengo (25), lodged a complaint with them in Mzimba, Malawi. Maria’s husband Christopher Kumwenda (38) wanted to sell his stepson to Lusungu Sere (31) for K20 million and the two men had been trying to force her to cooperate. National police spokesperson Rhoda Manjolo confirmed the arrest of both men in a statement made available to Malawi News. Sere comes from Mkoko Village and Kumwenda comes from Jamu village, both in the area of Traditional Authority Chindi in Mzimba. The two have since been charged with conspiracy to commit a felony which is contrary to section 404 of the Penal Code. (Source: allAfrica; Malawi: Two in Custody for Conspiring to Sell Albino Child; by Bernard Chisoni; September 30, 2015; http://allafrica.com/stories/201510010992.html)

Second most recent survivor: On September 13, 2015, a 17 year old girl with albinism by the name of Netani Mphepo was abducted and narrowly escaped death in the village of Symon Mphepo, Traditional Authority (T/A) Kampingosibande, Mzimba district, northern Malawi. A teacher, 21 year old Phillip Ngulube, had reportedly approached a Tanzanian National (name withheld) to buy the girl for the price of K 6,000,000 or $10,000.00 USD. The Tanzanian notified police and an ambush was made, leading to the teacher’s arrest. Phillip is now in custody awaiting trial and subsequently admitted to Police that he had indeed approached the Tanzanian to buy Netani. Prior to this incident, Phillip Ngulube, originally from Mtambo village in the area of T/A Timbiri in Nkhatabay, went to the victim’s village to see his relatives. While there he started working as a volunteer teacher at Mongo primary school. During that time he says that he fell in love with Netani who was a Form 1 student at Mzimba Secondary School. Incidentally she had dropped out of school since January and was living at home due to fears related to the drastic increase in attacks against PWA in Malawi. On September 12, 2015, the teacher went to Chibanja Township in Mzuzu City where he approached the Tanzanian National. (Sources: THE ASSOCIATION OF PERSONS WITH ALBINISM OF MALAWI (APAM); September 16, 2015, by Mr. Bonface Ophiyah Massah,
Third most recent survivor: On September 4, 2015, Nyasa Times of Malawi reported that an 11-year-old boy with albinism whose name is not mentioned was battling for his life at Karonga District hospital after two men kidnapped him and tried to cut his throat and right arm in Ipyana, Malawi. Karonga police spokesperson Enock Livason told Nyasa Times that they have 2 suspects, Fiskani Mtambo (35) from Mukwavi Village, Traditional Authority (T/A) Mwenewenya in Chitipa and Sam Wamisi Kaumba (32) from Cheyama Village, T/A Kyungu in Karonga. He also said that on the day of the incident the two suspects deceived the boy into accompanying them to a nearby market to collect a chicken which his mother had bought. When they got to the Ipyana, they dragged the boy to a nearby forest and started cutting his throat and arm. Fortunately the boy’s cries for help were heard and he was rescued, but the two suspects managed to escape. They were arrested later on the same day. Livason said the boy situation is "improving." (Source: All Africa – Nyasa Times: Malawi: Albino Attacks Resurfaces - Body Parts Found in Mchinji As Abducted Karonga Boy Throat Cut; September 4, 2015; By Tiwonge Kumwenda; http://allafrica.com/stories/201509041222.html)

Fourth most recent survivor: On August 6, 2015, a 6-year-old boy with albinism by the name of Esime Zulu was abducted by 4 men in the Dedza district of Malawi. According to Machinga police publicist, Assistant commissioner Nahumu, the Police have arrested four men, three from Mozambique plus a Malawian, Collins Zulu (27), who is also Esime’s biological father. Police say the father had agreed with his wife to go to the commercial city of Blantyre where he had just secured a job so the family was staying in a rest house at the Nselema Trading Centre in Machinga. Early Wednesday morning the father took Esime out saying he was taking him to a nearby hospital. Esime’s mother waited in agony until noon when she was told that the child had been abducted. She reported the matter to police and an investigation was launched. On Friday, August 7, the father was caught along with the three other abductors. The men were trying to leave the country for Mozambique where they intended to sell the boy. They are scheduled to appear in court and answer abduction charges, police say. (Source: Malawi24 – All the latest in Malawi news; “Malawian father arrested for selling his albino baby”; By Archangel Nzangaya; August 8, 2015; http://malawi24.com/2015/08/08/malawian-father-arrested-for-selling-his-albino-baby/)

Fifth most recent survivor: On March 5, 2015, a 2-year-old girl with albinism by the name of Chakupatsa Stenala was rescued from 3 kidnappers in Murukhu Village, Machinga Region, Malawi. After being abducted from her home the girl’s mother, Lonely Stenala, screamed for help. A prompt response from the villagers caused the assailants to flee. One of them, 19-year-old Joseph Andiwochi, hid in the bushes with little Chakupatsa where he was discovered and arrested for kidnapping. His 2 brothers & accomplices, Kamanga Likhutu, and Sinoya Likhutu, fled into a maze field and are still at large. Police in Machinga said instigations are ongoing to arrest all involved. Since his arrest, Joseph Andiwochi committed suicide by jumping from a moving police vehicle on his way to Zomba on Tuesday morning, March 10, where he was expected to appear in court to answer abduction charges. Two year old Chakupatsa is one of the three girls with albinism born to Lonely Stenala, a mother of four, and has now been reunited with her family. (Sources: UTSS interview with Bonface Massah, director of the local albinism group in Malawi; bonmassah@gmail.com; also see The Maravi Post http://www.maravipost.com/national/malawi-news/law-and-order/8366-malawi-police-claim-accused-albino-abductor-has-died-when-he-jumped-from-their-moving-car.html and http://www.maravipost.com/national/malawi-news/society/8361-malawi-police-in-machinga-district-nabs-albino-kidnapper.html; and UNHR http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15673&LangID=E)

Sixth most recent survivor: On March 4, 2015, a 12-year-old girl with albinism (name
withheld) narrowly escaped her abductors in Kalambo village in the area of Kawinga, in the Eastern part of Malawi. According to Eastern region police spokesperson, Thomeck Nyaude, a group of unknown criminals broke into the house of Mrs Chiissy Amidu (mother - age 37). After hearing footsteps, the mother went to her daughter’s bedroom, but she was missing. The criminals had taken her child as she slept. The mother started shouting for help, mobilizing people from the village who started chasing the abductors. Nyaude added that the kidnappers dumped the girl after a long chase by the villagers. (Source: allAfrica; Malawi: Albino Rescued From Kidnappers in Machinga, Malawi Police Say; March 5, 2015; http://allafrica.com/stories/201503060469.html)

Seventh most recent survivor: On January 5, 2015, an 11 year old girl with albinism by the name of Mina Jeffrey was kidnapped by 3 men, one of whom was her uncle, in Machinga district, Saiti village, Malawi, in an isolated area close to Mozambique. She managed to escape the men and was found. The case was reported to Machinga police. The area that Mina comes from has a lot of persons with albinism and they are living in fear. As a consequence of this incident eleven school children with albinism have dropped out of different schools in the area, due to fears for their safety. (Source: Communication between UTSS and Bonface Ophiyah Massah, Executive Director of THE ALBINO ASSOCIATION OF MALAWI –TAAM; email: albinismassociationmw@gmail.com; mobile: (265) 0881006474 & (265) 0 999399337)

Most recent missing: On January 16th, 2015, a two years old girl with albinism by the name of Ibrah Pillo was kidnapped from her parent’s home around 10pm in Matindira - Chindambo Village, traditional authority Kawinga Machinga district, Malawi. Ibra’s father is Pillo Imlani and her mother is Magret Chikopa. (Source: Communication between UTSS and Bonface Ophiyah Massah, Executive Director of THE ALBINO ASSOCIATION OF MALAWI –TAAM; email: albinismassociationmw@gmail.com; mobile: (265) 0881006474 & (265) 0 999399337)

Grave robbery: On August 6, 2015, the grave of a man with albinism by the name of Thomson Mwakanema was desecration in Malawi’s Northern district of Karonga. According to police, his bones were found exhumed and that a shovel, hoe and some bones were also found at the grave. Samson Mwakanema, a brother to Thomas, confirmed that he had albinism and died in 2009 at the age of 58. Police investigations are underway to capture the perpetrators. Assertions are being made in Malawi that the bones and body part of PWA are being used in rituals by people who are hoping to get rich. (Source: Malawi24 – All the latest in Malawi news; “Unknown people in Karonga exhume albino bones”; By Luke Bisani: August 8, 2015; http://malawi24.com/2015/08/08/unknown-people-in-karonga-exhume-albino-bones/)

Mali, 14 reports: (PFI 118 of 180) 3 killings / 2 survivors / 2 missing / 7 asylums

Most recent killing: In 2008, in the region of Segou, a seventy-year-old man, by the name of DEMBELE killed a six-year-old boy with albinism, chopped off his hand and disposed his body in an abandoned well. The young boy regarded the old man as his Grand-father. The reason for this - local belief is that a dried hand of a PWA has some therapeutic virtues against impotence. (Source: S.O.S. Albino Report)

Most recent survivor: In 2011, an ashamed young mother attempted to throw her 7yr old daughter with albinism into a well. Fortunately, she was stopped by a neighbor who threatened to call the police. The girl was safely placed with authorities. A few weeks later the girl was united with her biological father after proving his paternity and commitment to protect his daughter. Since that time the mother and her daughter were reunited and relocated to Burkina Faso.

Most recent missing: In 2006, the abduction of a baby boy with albinism occurred in Mali. On that fatal night the mother had decided to sleep outside in their yard so that her infant son could enjoy the fresh air. Upon waking the next morning she found that her baby was gone. (Source: An interview of Tierno Diallo on Radio France International on May 20, 2009 called “Invité Afrique” presented by Journalist Christophe Boisbouvier. Tierno is a man with albinism who founded the Malian albinism
Asylum: On July 29, 2011, Ms. Rokia Kone, a woman with albinism from Mali received asylum in France.

Mozambique, 6 reports: (PFI 85 of 180) 2 murders, 2 survivors, 1 grave robbery, 1 unknown status

First murder account: On September 17, 2015, at approximately 4:00 PM, a man with albinism by the name of Alfane António was abducted and brutally dismembered in the woods near where he worked in Larde district, Nampula province, Mozambique. Alfane was a health professional at Health Center Topuito. The *Verdade* newspaper reported that he was apparently surprised by the criminals while waiting for some equipment that was to be delivered to a patient. On the morning after his abduction, Alfane’s mutilated corpse was found in scattered pieces, his arms in one place, the legs elsewhere along with his belongings and mobile phone. His head and torso were found in an abandoned bag in a forest. Police also discovered that some body parts were missing and assumed they had been taken for ritual purposes. Sérgio Mourinho, Provincial Command spokesman for the Police of the Republic of Mozambique (PRM) in Nampula, confirmed the incident. Three individuals are being held in connection with this case. The victim left a widow and two young children. (Source: An investigation conducted by journalist Leonardo Gasolina was translated and sent as page 5 & 6 of a report to the UN about Mozambique by Margarida Ferreira Carneiro of Kanimambo Mission (albinism association), Lisbon, September 23rd, 2015, mmsrfc@gmail.com; kanimambpt@gmail.com; https://www.facebook.com/Mkanimambo)

Second murder account: On August 19, 2015, the body of a 22 year old man with albinism by the name of Avelino Rumualdo was discovered by the Mozambican police in an abandoned house in the northern port city of Nacala in the neighbourhood of Mocone, Mozambique. The corpse was in an advanced state of decomposition, and was missing unspecified body parts. Rumualdo had gone missing three weeks earlier and his mutilated body was only discovered when a young man, who wanted to rent the house, visited it. Nacala residents wondered how it was that the owner of the house knew nothing about it. The association “Amor a Vida” (Love for Life), which defends the rights of persons with albinism (PWA), protested that the police were taking little or no action to protect them. Its spokesperson, Milton Mujovo, told the paper “the police are doing little” and that when they went to complain the police simply ignored them. (Source: allAfrica.com, “Mozambique: Body of Murdered Albino Found”, August 24, 2015; http://allafrica.com/stories/201508210147.html)

Most recent survivor: In mid-July of 2015 a male with albinism by the name of Domiciano Rosario (also Rosario Rodrigues) was abducted from his home in the district of Nipepe, Niassa province, Mozambique. This incident had a happy ending in that the police secured the release of Rosario and arrested three of the kidnappers. (Source: allAfrica.com, “Mozambique: Body of Murdered Albino Found”, August 24, 2015; http://allafrica.com/stories/201508210147.html) On September 10, 2015, allAfrica.com news and STV reported that a man with albinism by the name of Rosario Rodrigues (33) survived a kidnapping attempt and that, after an anonymous tip, 3 men have been arrested in the northern province of Nampula, Mozambique. A fourth kidnapper escaped and police are searching for him. The men admitted to police that they enticed Rodrigues with promises of employment and took him to a place ten kilometers outside Nampula city. Their true intention was to cut off his hair and sell it to a Tanzanian witch-doctor for 450,000 meticais (about 112 US dollars). Rodrigues told reporters “They enticed me and when we got to the place they said they were waiting for a boss who wanted to buy my hair. I was surprised, because I didn't know that hair could be sold, and I was afraid I was going to be killed”. The kidnappers claimed that Rodrigues family was involved in the deal with the Tanzanian. “His mother told us to sell Rosario's hair”, one of them claimed. “The mother said that when the money arrived, we would divide it. Rosario's brother rang me up later, and told me to charge 450,000 meticais. My share would be 50,000 meticais”. The family strongly denied their involvement and that when they noticed Rodrigues was missing they went to the

**Grave Robbery: On Monday November 2, 2015,** three arrested criminals admitted to police in Massinga district, in the southern province of Inhambane, Mozambique, that they had desecrated the grave of a person with albinism and removed his bones for the purpose of selling them. According to a report in Monday's issue of the independent daily “O Pais”, the grave robbers also told police that they came from the northern province of Cabo Delgado, where they worked as informal miners. Having been promised four million meticais (about 100,000 US dollars) for the bones of an albino, their plan was to take them back to Cabo Delgado to a man named Geraldo. They claimed he was just a middleman, working for a Tanzanian businessman whose name they did not know. An official in the Massinga district police command said “We received a phone call from an anonymous source last Wednesday night. He told us of three individuals who were hunting albinos, and that they intended to take the bones and sell them in Cabo Delgado”. (Source: allafrica.com; Mozambique: Three Arrested for Desecrating Grave of an Albino; November 2, 2015; http://allafrica.com/stories/201511030092.html and starafrica.com; Three nabbed for desecrating albino grave; November 3, 2015; http://en.starafrica.com/news/mozambique-three-nabbed-for-desecrating-albino-grave.html)

**Unknown status account:** In 2009 a family in the Northern Province of Cabo Delgado, Mozambique, sold their son to foreigners because he had albinism. A year later, on September 24, 2010, this incident was told to Mozambican President Armando Guebuza by Ana Gabriela, chairperson of a local PWA association. This report was made to express her deep concern for the dire conditions faced by her fellow citizens with albinism. (Source: allAfrica, Mozambique: Guebuza Receives Albino Association - http://allafrica.com/stories/201009250010.html)

**Namibia, 3 reports:** (PFI 17 of 180) 1 survivor / 2 killings

**Most recent killing:** In June of 2010 Ananias Shifotoka, a young man with albinism from Uukwiyuwushona Village in Oshikoto Region was found brutally murdered days after he went missing. His decomposing body was found in a bush cut into pieces with his head removed as well as his genitals, tongue, hands and toes missing. (Source: NEW ERA News Paper for a New Namibia, 29-June-2010)

**Most recent survivor:** On Saturday, May 12, 2012 a 16 year old girl with albinism claims to have been raped by 44 year old man. Prior to the rape he had been visiting the victim and enticed her with money and promises of a shiny car, cattle and marriage. They went for a ride that day and on their return to the village, the accused forced his victim into one of his abandoned buildings, where he is alleged to have raped her. This was confirmed by the victim herself. On Monday, May 21 2012 the suspected rapist was denied bail in Oshakati Magistrate Court. The accused, Jonas Mathias, known as lingumu Netsali (44), was from a village near Ongwediva where he was arrested by the police. The case of Mathias was postponed by Magistrate Mika Namweya to 27 June 2012 for further investigation. (Source: Informante’, May 23, 2012)

**Niger, 1 report:** (PFI 47 of 180) 1 missing

**Missing & Presumed Dead - On the 17th day of the 2012 Islamic month of Ramadan in Niger (likely August 6, 2012),** a young man born with albinism in 1986 by the name of Seyni Hama went missing in the ward of Dar es Salam in the capital city of Niamey, Niger. He has not been seen since. On September 13 & 20, 2014, Ms. Kadidjatou Mounouni, leader and founder of the PWA association in Niger interviewed the victims’ family and neighbours to confirm Seyni’s disappearance. Both parties told her that the abduction did in fact take place. At the time Seyni went missing, his family reported the case to the Police who did their investigation, but sadly were not able to find him. Two of Seyni’s brothers also have albinism. (Source: On September 20, 2014, UTSS interviewed Ms. Kadidjatou Mounouni, leader and founder of the PWA group in Niger; ANAN Niger - anan2013.niger@yahoo.com)
Nigeria, 10 reports: (PFI 111 of 180) 4 killings / 1 missing / 3 asylum / 1 kidnapping / 1 attempted kidnapping

Most recent killing: In April of 2013 a woman with albinism was found dead with some of her body organs missing at Okuta, a border town at Baruten Local Government Area of Kwara State, Nigeria. (Source: The Guardian Nigeria, Friday, April 19, 2013, 19:32; From Abiodun Fagbemi, Ilorin)

Missing report: In April of 2013 a woman with albinism went missing according to her relatives. She was a resident around Saw Mill area in the city of Ilorin, Kwara State, Nigeria. (Source: The Guardian Nigeria, Friday, April 19, 2013, 19:32; From Abiodun Fagbemi, Ilorin)


Rwanda, 1 report: (PFI 161 of 180) 1 grave robbery

On July 2, 2013, authorities of the Macuba sector in Nyamasheke district in Rwanda were notified that the grave of Nyirahakuzimana Consolee, a woman with albinism buried eight months earlier, had been found desecrated and empty. Nyamasheke district mayor, Habyarimana Jean Baptiste, confirmed the grave tampering. He noted that it was difficult to determine who was behind the incidence, but that the coffin and cloths of the deceased were found scattered about 700 meters from the grave. (Source: Online media: Œil d'Afrique – Article published on July 03, 2013 http://oeildafrique.com/le-cadavre-dun-albinos-vole-au-rwanda/; IGIHE.com Published on 3-07-2013 http://en.igihe.com/news/body-of-albino-stolen-from-grave.html)

Senegal, 9 reports: (PFI 71 of 180) 3 alleged killings / 4 survivors / 2 asylum

3 alleged killings: Three unproven murders of people with albinism are alleged to be linked to the March, 2012 elections in Senegal. Several different sources have purported 1 killing in 2012 and 2 killings in 2010. These charges were actually made by President Abdoulaye Wade but apparently not at the same time:


- In July of 2010 Abdoulaye Wade accused the regime of his predecessor Abdou DIOUF and his political party, the Socialist Party (PS), “of the mysterious deaths of two young female albinos whose disappearance was never clarified”. (Source - WikiLeaks, December 17, 2010)

Most recent survivor: On September 8, 2014, an 8 year old boy with albinism by the name of Mohamed Diop was fortunately released by his kidnappers in Thies, a city located about 70 km East of Dakar, the capital city of Senegal. Mohamed was on his way home when accosted by occupants in a black 4×4 who forced him into the vehicle and drove away. Providentially a local-taxi driver witnessed the scene and gave chase while raising the alarm. This alerted people near the vehicle and the assailants ending up stopping and throwing the boy out. Mohamed was then taken to his mother by the taxi driver. (Source: Report received by UTSS on Friday, January 16, 2015 from Mr. Mouhamedou Bamba Diop, Chairperson of the Senegal PWA Group - association nationale des albinos du Sénégal – ANAS)

Asylum: On June 17, 2015, legal history was made yet again in the USA when a man with albinism from Senegal (he wishes to remain anonymous) who underwent severe persecution due to his albinism was granted asylum in New York City, New York. (Source: His lawyer at Fried, Frank, Harris, Shriver & Jacobson LLP, One New York Plaza, New York, NY 10004; friedfrank.com)
**South Africa, 5 reports:** (PFI 39 of 180) 2 killings / 1 missing / 1 survivor / 1 grave robbery  
**Most recent killing:** On August 5, 2015, Ms. Thandazile Spongwa Mnpunzi, a 20 year old woman with albinism who was also a Grade 6 student at Sibongiseni Primary School, went missing in Phelandaba in Kwa-Zulu Natal, South Africa. On August 16, 2015, her remains were found in a shallow grave with most of the body parts and her skin missing. On the day of Thandazile’s disappearance, she had received a call from one of the suspects to meet at Phelandaba, and by that evening she was not reachable on her cell phone. The family reported her missing on two occasions to the local police but they were ignored both times. Thandazile’s mother then reported the matter to the local chief and ward council and a search was launched. They worked closely with the community and the police forum and were taken to a house where the community thought the murder might have taken place. A woman who lived there indicated that she had slaughtered a goat and not killed anyone, but with further interrogation the community found some clothing which was identified by the victim’s mother. Several young men also present at the house then revealed a shallow grave where they had buried Thandazile’s remains. Four suspects have been arrested but one name is being withheld since he is a minor. Their names are Mr. Khumalo 19, Mr. Mabuza 19 and Mr. T Zwane 65 (a traditional healer and pastor). They have appeared twice at the Manguzi Magistrate’s Court and bail has been denied on both occasions. The case has been remanded to 13th October 2015. (Sources: Nomasonto G. Mazibuko, National Director of the Albinism Society of South Africa, 187 Lara’s Place, Bree Street, Johannesburg, 2000, Tel: +2711 838-6529, Mobile: +2782 755-3884, Email: mazibukong@gmail.com, www.albinism.org.za; News24, Albino victim's family lives in fear, by Amanda Khoza, August 26, 2015; http://m.news24.com/news24/SouthAfrica/News/Albino-victims-family-lives-in-fear-20150826)

**Most recent survivor:** On February 22, 2013, a 6 year old girl with albinism by the name of Ntandane Kgomotso went missing at Sandy River near Hazyview in Mpumalanga, South Africa. She was abducted while playing in the yard on Friday afternoon. The community pulled together and combed the bushes and after hours of searching, found Ntandane unhurt in the bushes. She was tired and hungry and her mother fears the kidnapper may try again. The incident was reported to the police (Source: NewsBites, November 5, 2013 http://www.zimkasi.com/index-id-news-zk-14983.html)

**Swaziland, 10 reports:** (PFI 155 of 180) 3 killings / 7 survivors  
**Most recent killings:** On September 26, 2015, a man with albinism by the name of Magidi Mlambo was brutally killed and dismembered on a mountain of Mambane, Swaziland, where he was said to have been lured to collect herbs with the accused. Two traditional healers, Tikhali Majozi Mango (65) and Mbongeni Sibusiso Buthelezi (35), have been arrested for the murder and subsequently confessed to killing him, saying they actually wanted an albino. The Mambane area witch doctors made the confession before Magistrate Joseph Dlamini on Tuesday. According to the charge sheet the accused were acting in furtherance of a common purpose, wrongfully, unlawfully and intentionally killing Magidi by hitting him with an axe on the head, resulting in his death. They further confessed intentions to sell the body parts to third traditional healer who also doubles as a Zion prophet at Hlutse. The accused said the healer, who is popularly known as umthantazi, placed a very specific order for the hand of a man with albinism genes. The murderers charged the umthantazi an amount of E2 000 for the hand which has since been recovered by police. The two “butchers” also confessed to cutting off a leg of the deceased and selling it to a fourth traditional healer. The remaining parts of the body were recovered from a forest after they led police to the scene of crime on Monday. During their appearance in court, the accused rights to legal representation were explained and they both elected to engage the services of an attorney. The Crown, represented by Prosecutor Philisiwe Msibi, filed an application to have the accused remanded into police custody pending further investigations. The application was granted and they were ordered to return to court the following day. (Source: SwaziOBSERVER; “TINYANGA CONFESSIONS; WE WANTED AN ALBINO”; October 15, 2015; By Wonderboy Dlamini; http://www.observer.org.sz/news/76626-tinyanga-confess-we-wanted-an-albino.html)

**Most recent survivors:** 4 SURVIVORS OF THE SAME ATTACK: On September 02, 2013,
4 men with albinism were attacked and seriously injured in the town of Mankayane next to Manzini, in Swaziland. Mr. Vilakati received this information from the victims’ families and reported it to UTSS. He was able to visit 2 of the 4 victims in hospital; one called Thulane (19) and the other Ndzinisa (24); the other 2 remain unidentified. (Source: Mr. Dalton Vilakati, a PWA and recently appointed Member of Parliament in Swaziland - Phone number: +268-763-604-80)

**World Press Freedom Index Trend for Tanzania:**

2008 – 70 of 173  
2009 – 62 of 175  
2010 – 41 of 178  
2011 & 12 – 34 of 179  
2013 – 70 of 179  
2014 – 69 of 180  
2015 – 75 of 180

*Tanzania, 159 reports: (PFI 75 of 180)* All Tanzanian information on killings and attacks are gathered by UTSS through its field work and research; reports from victim's families and police reports in Tanzania.

- **76 killings**  
- **64 survivors; all are deeply traumatized and most are severely mutilated**  
- **1 abduction**  
- **16 grave robberies**  
- **2 failed grave robbery attempt**

**Most recent killing:** On Tuesday, February 17, 2015, the mutilated remains of a 1 year old baby boy with albinism by the name of Yohana Bahati were discovered by police in Shilabela Mapinduzi Sub-Village, a few kilometers from his home in Isabilo Sub-Vilage of Ilelema Village, Iparamasa Ward of Chato District, Geita Region, Tanzania. Both of Yohana’s arms and legs were hacked off. Two days earlier five unidentified men armed with machetes attacked the homestead. Three of them seized Misalaba (father) while two of them forced their way into the house where Ester (mother) was preparing the evening meal. Misalaba managed to fight off the attackers and ran away leaving his wife behind with two children with albinism, one year old Yohana and his 3 year old sister Tabu. One of the assailants slashed Ester’s face and body rendering her unconscious while the second grabbed little Yohana and ran away. Ester remained in serious condition in Bugando Referral Hospital in Mwanza City even after doctors operated on the machete lacerations sustained while trying in vain to protect her baby boy. A police search is underway and Yohana’s father is being held in remand prison. No other arrests have been made at the time of this report. (SOURCE: UTSS interviews with Deputy Director of Public Prosecution Ms. Neema Ringo in Dar es Salaam and Iparamasa Ward Executive Officer (WEO), Christopher Mabuba who confirmed the attack.)

**Most recent survivor:** On October 21, 2015, a 35 year old man with albinism by the name of Mohammed Saidi who served as the Tanzania Albinism Society’s (TAS) District Secretary was attacked at his home in Mkuranga town, about 42km from Dar es Salaam City Centre, Tanzania. He sustained serious injuries to the right side of his head and ear. In conversation with UTSS First Response Team from his sick bed, Mohamed recounts that “Three men wearing balaclava broke into my home and attacked me with machete’s. I put up a fight but was overpowered. They tied a piece of cloth around my neck and put another one into my mouth to stop me from raising an alarm. Then they tried to hold my legs wide apart and were talking of mutilating my genitals." At this point he heard the voice of a third man from outside, who the two criminals referred to as “Boss”, saying; “If you can’t get the genitals, get flesh from any part of the body!” Then the so called “Boss” entered the room and used a machete to chop off some flesh from the right side of his head and ear. The attackers then ran into the darkness leaving him bleeding profusely. Mohammed managed to remove the gag and cry for help. Neighbours, including his landlord,
Athuman Suleiman (44) rushed to his rescue. The District Medical Officer, Dr. Paulina Mbezi, said that Mohammed had been received at the Mkuranga District Hospital with serious head wounds on Wednesday night. She went on to say that “When he was brought here his condition was critical and he had lost a lot of blood”. According to Dr. Mbezi, Mohammed was treated immediately and given a blood transfusion. She was satisfied with his condition saying “He is stable and improving”. The OCD of Mkuranga Police Station, Mayenga T. Mapalala, confirmed the incident and said the police force has begun investigations into the incident. (Source: On October 22, 2015, Under The Same Sun’s First Response Team visited all relevant parties including the victim in Mkuranga District Hospital.)

Second most recent survivor: On June 16, 2015, a 6 year old girl with albinism by the name of Margaret Khamis was rescued from abduction after she went missing several days earlier in Kona Nne Village, Ugembe Ward of Nzega District in the Tabora Region of western Tanzania. Margaret lives with her three siblings and her mother Joyce Mwandu, who also has albinism. After she went missing, Margaret’s mother raised the alarm and villagers started a search. Acting Tabora Regional Police Commander ACP John Bwire told the media that good Samaritans informed them of a man who was looking for a buyer willing to purchase Margaret. The police set a trap, rescued the little girl, re-united her with the family and arrested her 44-year old uncle, Masanja Mwanamila, who is now in custody. (Source: ITV News at 20:00 hrs, Tuesday, June 16, 2015; UTSS Phone Conversation with IPP Media Reporter, Kabendara Simon, in Tabora)

Third most recent survivor: On May 14, 2015, a 30 year old woman with albinism and mother of 4 by the name of Limi Luchoma was rescued from abduction after she went missing in Kabunde Village, Mamba Ward, Mawiti ‘A’ suburb, Melele District in the Katavi Region of Tanzania where she lives with her father. Limi was asleep with her children when the attack occurred at around midnight. The assailants locked her father’s door from the outside to prevent him from helping. Limi is recovering in Mpanda District Hospital in Katavi while her father cares for the children. To help identify suspects, a secret ballot of the villagers was held and then reported to police. Several suspects are now in custody including family members of a witchdoctor (Mayigu Sadima - now missing) who lives 1 kilometer from Limi’s home and another witchdoctor (Goga Silanga) who lives 1.5 kilometers from her house. One of Limi’s brothers may also be involved. (Source: On May 16 – 18, 2015, a UTSS team inspected the scene of the attack, visited Limi in hospital and interviewed her, her family, neighbours, Village Executive Officer, Police & Government officials.)

Fourth most recent survivor: On March 07, 2015, a six year old boy with albinism by the name of Baraka Cosmas Rusambo lost his right hand in a witchcraft-related machete attack by 2 unidentified men. The incident occurred in Kipeta Village, Kipeta Ward of Sumbawanga Rural District in Rukwa Region, western Tanzania. His mother, Ms. Prisca Shaaban, also sustained serious machete injuries to her head. Both mother and child were sent for extensive treatment at Mbeya Referral Hospital in south-western Tanzania. The youngest child with albinism, Lucia (3), was also sent to the hospital. Police moved Baraka’s elder sibling with albinism (8) from the village to a safer place. According to Rukwa police, 17 suspects were arrested in connection with the mutilation including Cosmas Rusambo (Baraka's father) and his younger brother. (Source: UTSS interviews on March 9 &10, 2015, with Police, Community Development Officer, Social Welfare Officer, Office of the Director of Public Prosecution, Kipeta Ward Executive Officer, Baraka’s mother, family and neighbours.)

Most recent survivor of rape: In February of 2014 a 17 year old woman with albinism by the name of Masalu Masanja was gang-raped by five men on her family farm in Gasuma Village, Bariadi District of Simiyu, Region, in north-western Tanzania. She contracted 2 STDs and became pregnant from the rape. Government officials brought Masalu and her three brothers with albinism to Buhangija Center for displaced PWA in Shinyanga where she was treated for the STD’s and in November of 2014 gave birth to a baby girl without albinism. She does not know who the father of her child is and suffers from deep physical and psychological trauma as a result of the attack. Her ordeal was made worse by the fact that Masalu is also speech impaired, with minimum ability to make audible sounds, rendering her unable to cry for help. (Source: On June 6, 2014, UTSS staff first met and conducted a personal interview with Masalu
during a routine visit to Buhangija, a key government center housing displaced persons with albinism in Shinyanga Town, Shinyanga Region, Northwest Tanzania.)

**Most recent abduction:** On December 27, 2014, a 4 year old girl with albinism by the name of Pendo Emmanuel was abducted in Ndamhi Village of Fukalo Ward, Kwimba District, Mwanza Region, Tanzania. The police have arrested 15 suspects in connection with the kidnapping. Three of the arrestees are relatives: Pendo’s paternal grandfather, maternal grandfather and her mother. Due to the fact that her mother had just given birth to a baby girl with albinism and prison would not be appropriate for the baby, the Mwanza Regional Commissioner has ordered them to be sent to an alternative secured environment. The police have also set up a search party to look for Pendo. (Source: UTSS interview with Tanzanian police and Ndamhi Village Executive Officer as well as newspapers reports including: http://www.dailymail.co.uk/wires/afp/article-2903078/UN-demands-investigation-albino-girl-abduction.html; http://allafrica.com/stories/201501080704.html; http://dailynews.co.tz/index.php/dailynews/39960-proven-albino-killers-must-be-severely-punhed; http://www.dailynews.co.tz/index.php/local-news/40153-rc-gives-mwanza-village-five-days-to-find-msing-albino-girl; http://www.ippmedia.com/frontend/index.php?id=76048)

**NOTE:** The first actual police documented murder of PWA in Tanzania was that of Arif in 2006.

**Uganda, 4 reports:** (PFI 97 of 180) 4 survivors

On Thursday, May 29, 2014, the Daily Monitor reported that a father of nine children by the name of Godfrey Ndahabwerize has been accused by his wife of attempting to kill four of their children in Kabale District, Kinyamari Butanda Sub-county, Uganda. Their crime – they were born with albinism. The mother, Ms Medius Kyarisima age 50 says; “Last month, my husband threatened to kill our four Albino children, saying they were a disgrace to his family. When I tried to reason with him, he picked a panga and cut me on the right side of my nose. I packed my belongings and those of my albino children and we went to my mother’s place for refuge.” Ms Kyarisima complained to the authorities and they were still looking for Mr Ndahabwerize explaining that her husband may have a mental disturbance. (Sources: Daily Monitor, May 29, 2014, by Robert Muhereza; http://www.monitor.co.ug/News/National/Father-attempts-to-kill-his-four-children-for-being-albinos/-/688334/2329758/-/g56m7sz/-/index.html and Michael Sabiiti, Founder and Director of SITE FOR COMMUNITY SERVICES PROGRAM (SCOSP), Plot 110 Kabale – Mbarara Road– P.O.Box 312,Kabale - Uganda ~ Mobile: +256 781524064/ +256790877802 ~E-mail: Michael@scosp.org | michaelsabiiti@gmail.com, Website: www.scosp.org)

**Zambia, 5 reports:** (PFI 113 of 180) 4 killings / 1 survivor

**Most recent killing:** On May 26, 2015, a 37 year old woman with albinism by the name of Charity Zulu was killed during a ritual attack at her home in Kalumbu Village, Chief Magodi's area, Lundazi District, Zambia. The couple had just settled down to sleep when they heard a knock at the door. When Charity’s 42-year-old husband Robin Nyirongo opened the door, four men pushed their way in and stabbed him before going for his wife while he lay unconscious. Grabbing Charity, they cut off both of her hands and forcibly extracted several teeth from her mouth before fleeing. Her bother-in-law rushed to the house after hearing shouts for help; arriving just in time for her to narrate the ordeal before passing away. Eastern Province Police chief Eugene Sibote said they have launched investigations. Charity’s body was brought to Lundazi District Hospital mortuary while her husband was brought to the same hospital for recovery. District Foundation coordinator, Dylan Chifita, of the Lundazi District Albino Foundation has appealed to police to ensure that those behind the murder are arrested and prosecuted. (Source: allAfrica; Zambia: Albino Murdered; by Julius Phiri; May 29, 2015; http://allafrica.com/stories/201506011441.html; Also: https://www.daily-mail.co.zm/?p=31345 And response by the NHRI: http://www.lusakatimes.com/2015/06/03/hrc-condemns-albino-murder/ ;
2nd most recent killing: On December 18, 2014 a 17 year old boy with albinism by the name of Naftali Banda died after injuries he sustained during a kidnapping attempt the previous day on his way home from the market in Chipata, Eastern Province, Zambia. Although he was seriously injured during the abduction, Naftali managed to escape with the help of some people near him. They also helped him return to his home in Lundazi where he died the following day of the injuries. (Source: Dickson Konkola, founder & president of National Albinism Initiative Networking of Zambia in conversation with UTSS and his report titled: “REPORT ON THE INVESTIGATION OF THE RITUAL MATTERS OF PEOPLE LIVING WITH ALBINISM IN CHIPATA”; email: dicksonkonkola@gmail.com ; mobile: +260-97-380-4324)

Survivor: On June 3, 2013, a twenty year-old man with albinism by the name of Yohane Kamwendo from Machinjiri, Blantyre, Malawi, escaped his traffickers in Chipata, Zambia. He was tricked through Facebook saying “I come from Malawi and went to Zambia after a friend (Mr. Banda), who I met two weeks ago on Facebook, told me that there was a job opportunity in Zambia with good pay. Yohane fell for the trap after telling Mr. Bamda about the struggle to raise fees for education because his family members showed no interest in helping due to his albinism. Yohane learned that he was being trafficked from a guard at the place in Zambia where Mr. Banda had told him to wait outside as he went in to meet the boss. While waiting, the guard informed Yohane that there was no job and that “when albinos arrive at that place” they are sold or some fishy business happens to them because when they enter the house they never come back”. The guard then gave Yohane some travel money and told him to use routes where he couldn’t be traced because they would come looking for him. Yohane explained his horrific ordeal to the Police and spent a night at Mchinji Police Victim Support Unit. A private organization then provided transport back to Blantyre where he will be staying. (Source: TAAM MALAWI - albinismassociationmw@gmail.com; & Mwana Mission Project, Inc., P.O. Box E571, Post Dot Net, Blantyre, Malawi - http://www.mwanamissionproject.com/#/the-gift-project-albino-care--refuge/c1uf8)

Zimbabwe, 2 report: (PFI 131 of 180) 1 killing / 1 asylum

In 2011 the severely mutilated body of a 26 year old woman with albinism was discovered. Professor John Makumbe was contacted by Zimbabwe police and taken to the morgue to assist in identifying the body. He noted that she had albinism and that her breasts and genitals had been removed. (Source: Professor John Makumbe, a professor of political science at the University of Zimbabwe and president of the Zimbabwe Albino Association (Zimas))

On November 29, 2012, a woman with albinism from Zimbabwe was granted asylum in Atlanta, Georgia. (Source: UTSS served as expert witness in this case)