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‘Waiting to disappear’

**International and Regional Standards for
the Protection and Promotion of the Human
Rights of Persons with Albinism**

June 2017

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Foreword

By Ikponwosa Ero, United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism



As a young child growing up with albinism in Nigeria, I remember waking up each day with my heart pounding. How was I to handle another day of taunts from the public and verbal abuse from the streets? Being hypervisible in a context where the majority did not understand albinism but believed in negative

superstitions about it caused great anxiety in my mind. I hoped for the day when things would change for the better but, by all indications, it seemed like they would not. That said, never in my deepest fears did I imagine that things would become worse. That a near pan-African scale of violence would be meted out to persons with albinism.

In the last decade, over 600 persons with albinism across 28 countries in the region have been killed, or mutilated and traumatised after surviving attacks. These numbers are reported cases alone. It is believed that many cases go unreported for various reasons, including the involvement of family members, as well as a lack of formal monitoring mechanisms to accurately track and report cases. The situation is highly concerning.

Thankfully, efforts to end these attacks are now underway, including through my mandate by the United Nations (UN) Human Rights Council. Under this mandate, I have started to work with various stakeholders and other experts to develop effective responses. These include the development of specific protection and prevention measures, which could be easily implemented in the context of rural areas and developing countries – the setting of the majority of these attacks.

It is in this regard that I welcome this research paper on international standards relevant for the promotion and protection of human rights of persons with albinism, conducted by the International Bar Association's Human Rights Institute (IBAHRI). The paper provides a thorough overview of applicable international and regional laws, norms and interpretative frameworks with the goal of providing technical assistance for legal practitioners, human rights bodies and mechanisms.

With the IBA's expertise in the human rights of emerging groups, as well as in the area of multiple and intersecting forms of human rights violations, this paper provides a firm legal foundation for juridical action in favour of persons with albinism, particularly in countries with recorded attacks. Moreover, its presentation of technical detail in accessible language, along with practical recommendations, means that this paper will also be highly useful to a variety of stakeholders, including policy-makers, academics and civil society activists. In particular, it will equip advocacy groups and communities of persons with albinism, their family members and representatives with fundamental and effective tools to articulate their situation in human rights language. This will in turn remind governments of their legal duties and ultimately hold them to account.

On a day-to-day level, the use of the standards laid out in this paper, particularly the implementation of its recommendations, promises to contribute to the eradication of the real and palpable fear that has crippled persons with albinism and their families in the wake of attacks. It will also bring persons with albinism closer to remedies and treatments that will allow them to enjoy human rights on an equal basis with others. To that end, I hope that this report will be part of any formal human rights training, including on specific people groups, minority groups, persons with disabilities, topics of racial discrimination or discrimination based on colour, education and health. I look forward to its wide distribution and use.

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The IBAHRI expresses its gratitude to the members of the Task Force on the Enjoyment of Rights by Persons with Albinism, whose collective contribution played an important role in facilitating the production of this report.

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Executive summary

Albinism is a rare, non-contagious, genetically inherited condition. It affects people worldwide, regardless of race or ethnicity. It results in a lack of pigmentation (melanin) in any or all of the hair, skin and eyes, causing vulnerability to sun damage and bright light. Visual impairments of varying degrees are common and there is also an increased risk of developing skin cancer.

Persons with albinism are often victims of human rights violations, particularly in Africa. Since 2006, hundreds of persons with albinism, particularly women and children, have been killed or mutilated, and graves have been desecrated in order to obtain and sell fingers, limbs, hair, nails and other body parts to be used in witchcraft rituals. In the vast majority of cases, these violations have gone unpunished. Many survivors have been forced to flee their homes, communities and even countries to seek protection.

In addition, most persons with albinism in the region have faced prejudice and stigmatisation, as well as multiple and intersecting forms of discrimination on the basis of visual impairment, colour, gender or age, which prevents them from exercising their economic and social rights, condemns them to ostracism and poverty, and limits their life expectancy.

This report focuses on the international human rights laws and standards relevant for the promotion and protection of the rights of persons with albinism in the African region, particularly in Sub-Saharan countries, where extreme violations of human rights against persons with albinism have been reported.

The report shows that attacks and discrimination against persons with albinism are contrary to international and regional human rights standards, including the right to life, physical integrity, liberty and security, equality and non-discrimination; the right to the highest attainable standard of physical and mental health; the right to education; the right to an adequate standard of living; as well as the right to redress when those rights are violated by state or non-state actors.

The report reviews the work of international and regional human rights bodies and experts who have repeatedly expressed concerns at the violations against persons with albinism. These bodies and experts have called on states in

the region to guarantee the rights of persons with albinism and implement measures to put an end to the violations. However, so far, state responses have not been sufficient.

As the report shows, by voluntarily becoming parties to international and regional human rights treaties, states assume the duty to respect, protect and promote human rights. This duty extends to the rights of all persons, including persons with albinism, and cannot be considered a privilege or a favour bestowed by a state on individuals.

States' approaches to albinism have thus far been insufficient. In some instances, the rights of persons with albinism have been considered purely within a disability framework. In other cases, in countries where the incidence of violent attacks against persons with albinism has been high, the focus has been on criminal prosecutions to the exclusion of other concerns impeding the enjoyment of human rights by persons with albinism. This report outlines and proposes a holistic approach to ensuring the rights of persons with albinism. As the report shows, concerns related to the rights of persons with albinism have been raised by UN human rights experts covering issues such as child rights, gender, racial discrimination, minority issues and torture, as well as disability. Therefore, a state viewing albinism purely within the disability framework or within its criminal law is failing in its obligation to protect the rights of persons with albinism.

Chapter 1 sets out the context of the report. It briefly explains albinism and provides an overview of the human rights violations experienced by persons with albinism. It further sets out the purpose and scope of the report.

Chapters 2 and 3 focus on attacks against persons with albinism. The chapters set out the duty of states to take measures to prevent such attacks and protect persons with albinism, as well as their duty to ensure redress for such attacks. In this regard, redress not only requires that all perpetrators are held accountable, but also that the state ensures adequate reparations to victims, including compensation, rehabilitation and guarantees of non-repetition.

Chapter 4 moves the focus away from attacks against persons with albinism and looks at the violation of the right to equality and non-discrimination. It shows how persons with albinism are often the victims of multiple and intersecting forms of discrimination which lead to further violations of

economic, social and cultural rights. It further shows how the failure of a state to ensure equal and adequate access to education for children with albinism may impact the child's ability to access work later in life and have a knock-on effect on the right to health.

Chapter 5 sets out recommendations to states and the international community for the effective promotion and protection of the rights of persons with albinism. In this regard, it is essential that efforts are made to address a lack of data. This includes disaggregated data on the number of persons with albinism, both regionally and nationally, as well as their situation and needs. This data would enable states to adopt effective policies and programmes to respond to those needs; make appropriate budgetary provisions or, where necessary, seek international cooperation and assistance; and set up mechanisms to evaluate their progress.

In addition, to ensure comprehensive protection and promotion of the human rights of persons with albinism, it is key to have a meaningful consultation with both them and their organisations on the selection, design and implementation of such policies and plans. Particular attention should be given to consultation and participation when defining policies and plans to address the multiple and intersecting forms of discrimination they face, in order to ensure that they reflect their experiences and respect their identity.

At both international and regional levels, there is a continued need to closely monitor individual situations. The implementation of recommendations at a national level should also be followed up, with international assistance being offered when needed.

Attention should also be given to strengthening international protection for persons with albinism in the African region through the Draft Protocol on the Rights of Persons with Disabilities in Africa, and internationally, through the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, by ensuring it applies to all forms of exploitation affecting persons with albinism, such as the sale of body parts.

The report and the recommendations contained herein set out a comprehensive analysis of the obligations of states with regard to persons with albinism. It highlights the provisions of existing international treaties and the current gap between these agreements and current state practices.

List of acronyms and abbreviations

NB: Some treaty bodies have the same official abbreviation as their relevant treaty. For the purposes of this report, to avoid confusion between the two, an unofficial abbreviation is being used for the treaty bodies which consists of the letter 'o' after the 'C'.

ACERWC	African Committee of Experts on the Rights and Welfare of the Child
ACHPR	African Commission on Human and Peoples' Rights
ACRWC	African Charter on the Rights and Welfare of the Child
African Charter	African Charter on Human and Peoples' Rights
African Court	African Court on Human and Peoples' Rights
CAT	Convention against Torture
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CESCR	Committee on Economic, Social and Cultural Rights
CoAT	Committee against Torture
CoEDAW	Committee on the Elimination of Discrimination against Women
CoRC	Committee on the Rights of the Child
CoRPD	Committee on the Rights of Persons with Disabilities
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities

Draft Protocol	Draft Protocol on the Rights of Persons with Disabilities in Africa
Fair Trial Guidelines	Principles and Guidelines on the Rights to a Fair Trial and Legal Assistance in Africa
HR Committee	Human Rights Committee
IBA	International Bar Association
IBAHRI	International Bar Association's Human Rights Institute
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
Maputo Protocol	Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa
NGO	non-governmental organisation
OCA	Oculocutaneous albinism
OHCHR	Office of the United Nations High Commissioner for Human Rights
SDGs	Sustainable Development Goals
UDHR	Universal Declaration of Human Rights
UN	United Nations
UPR	Universal Periodic Review
WHO	World Health Organization

Chapter 1: Introduction and scope

‘When I was young, I was told that I would not die. They said I would disappear because people like me – people with albinism – are not like other people and do not die. I spent my childhood waiting to disappear...’

Peter Ogik, Source of the Nile Union of People with Albinism, Uganda

1.1 Introduction

Albinism is a rare, non-contagious, genetically inherited condition. It affects people worldwide, regardless of race or ethnicity. It results in a lack of pigmentation (melanin) in any or all of the hair, skin and eyes, causing vulnerability to sun damage and bright light.¹ Visual impairments of varying degrees are common in persons with albinism. There is also an increased risk of developing skin cancer.

Persons with albinism² are often victims of prejudice, stigmatisation and discrimination. It appears that there is a correlation between discrimination and the relative contrast in skin pigmentation of persons with albinism to that of the general community.³ That is, the bigger the difference between the majority of the community’s skintone with the person with albinism, the greater the prejudice. This seems to be the case in most Sub-Saharan African countries, where albinism is shrouded in myth, as well as dangerous and erroneous beliefs.

1 For a complete definition of albinism, see p 28.

2 Persons with albinism are sometimes referred to as ‘albinos’. This term is viewed by some as offensive, as it places the emphasis on the disability rather than the person. For the purposes of this report, we will use ‘persons with albinism’.

3 See Human Rights Council, ‘Report of the Human Rights Council’s Advisory Committee on the study on the situation of human rights of persons living with albinism’ A/HRC/28/75 (10 February 2015), para 41; Muthee Thuku, ‘Myths, discrimination and the call for special rights for persons with albinism in Sub-Saharan Africa’ (February 2011), p 2; Daniel Ikuomola Adediran, “‘We thought we will be safe here’: Narratives of Tanzanian Albinos in Kenya and South-Africa’ Vol 9(4) *African Research Review* 2015, S/ NO 39, pp 43 and 48.



1.2 Human rights violations against persons with albinism in Sub-Saharan Africa

Persons with albinism in Sub-Saharan Africa are often victims of human rights violations. Since 2006, hundreds of persons with albinism, particularly women and children, have been killed or mutilated, and graves have been desecrated in order to obtain and sell fingers, limbs, hair, nails and other body parts to be used in so-called witchcraft rituals. In the vast majority of cases, these violations have gone unpunished. Many survivors have been forced to flee their homes, communities and even countries to seek protection.

In addition, most persons with albinism in the region have faced multiple and intersecting forms of discrimination on the basis of visual impairment, colour, gender or age, which prevents them from exercising their economic and social rights, condemns them to ostracism and poverty, and limits their life expectancy.

Case of discrimination

On 22 October 2016, an 18-year-old man with albinism from Nchilamwela Village, Traditional Authority Nchilamwela in Thyolo District, Malawi, was sentenced to a penalty ten times higher than usual for being drunk. The justification for this increased penalty was that, given the risks persons with albinism face, the court expected him to be more cautious.

In taking into account the appellant's albinism as an aggravating factor, the court noted that 'due to the killings and attacks [against persons with albinism] in the country... it's pathetic that the same people who are the targets of attacks are too casual with their lives... the police officers cannot accompany these people to the bars and wait for them until 11pm and carry them home. They also have the responsibility over their lives, and that includes protection by their parents and relatives'.ⁱ

On appeal, on 8 February 2017, the review court reduced the custodial sentence to a fine. However, it reinforced the discriminatory position in a judgment that further victimises persons with albinism and violates their right to dignity, fair trial and equality.

ⁱ See www.southernafricalitigationcentre.org/1/wp-content/uploads/2017/01/Precious-Michael-Review-skeletal-arguments.pdf accessed 21 April 2017.

Physical attacks

Physical attacks against persons with albinism in Sub-Saharan countries include 'ritual attacks',⁴ which have led to death or mutilation, as well as trafficking and the sale of body parts on the black market, abandonment of children, infanticide and sexual violence against women and girls.

4 The Office of the UN High Commissioner for Human Rights (OHCHR) defines ritual attacks as those that reportedly aim to use the body parts of persons with albinism for the purposes of witchcraft. See 'Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights', A/HRC/24/57 (12 September 2013), para 19, www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Pages/ListReports.aspx accessed 21 April 2017. There is not a unique definition of 'witchcraft'. For the purpose of this report, witchcraft used to harm persons with albinism is understood as the set of beliefs, structured and shared by a given population, that addresses the origin of misfortune, illness and death, and the set of practices for detection, treatment and punishment that corresponds to these beliefs, including both the belief that a person has supernatural powers and operates in secret in order to harm victims and the belief that certain plants and substances can be used to cause harm.

These attacks are motivated by prevailing myths, such as the misbelief that the body parts of persons with albinism – when used in witchcraft rituals, traditional medicine and potions or amulets – will induce various benefits, most commonly wealth, good luck and political success. Other myths that facilitate the perpetration of attacks are those linked to perceptions of their appearance, including misbeliefs and myths that persons with albinism are not human beings but ghosts, that they are subhuman, and that they do not die but disappear.⁵

Children with albinism are often particular targets of attacks due to the witchcraft-based belief that the innocence of a victim from whom body parts are taken increases the potency of the potion for which the body parts are used.⁶ Cases reported by civil society indicate that children constitute a noticeable proportion of victims of actual and attempted human rights violations, including ritual attacks.⁷ Women with albinism are also reportedly victims of targeted acts of sexual violence spurred by the myth that sexual intercourse with a woman with albinism can cure HIV or AIDS.⁸

In the past ten years, civil society has reported more than 500 attacks against persons with albinism, in 25 African countries.⁹ These statistics include 187 killings and more than 250 cases of other physical attacks, including mutilations, sexual violence and attempted abductions. It also includes cases of persons with albinism who have been reported missing among concerns that they might have been victims of a violent attack or kidnapped to be sold.¹⁰

5 See 'Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, A/ HRC/31/63 (18 January 2016) para 16, www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session31/Documents/A.HRC.31.63_EN.docx accessed 21 April 2017.

6 *Ibid*, para 42; Under The Same Sun, 'Children with Albinism in Africa: Murder, Mutilation and Violence' (19 June 2012), p 27, www.underthesamesun.com/sites/default/files/UTSS%20report%20to%20UN%20-%20REPORT.pdf accessed 21 April 2017.

7 See n 5 above.

8 See n 5 above, para 44.

9 Benin, Botswana, Burkina Faso, Burundi, Cameroon, Côte d'Ivoire, Democratic Republic of the Congo (DRC), Ghana, Guinea, Kenya, Lesotho, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, South Africa, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe. See 'Reported Attacks of Persons with Albinism' (11 April 2017), www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20201%20page.pdf accessed 21 April 2017. There have been no reports of physical attacks from outside the African region.

10 *Ibid*.

In addition, in at least 44 reported cases, the graves of persons with albinism have been reportedly desecrated, with the intent of selling the body parts of the deceased.¹¹

The cases are likely to represent only a small proportion of the actual number of attacks and violations. In most cases, attacks go undocumented and unreported due to the limited capacity of most civil society organisations monitoring the situation, as well as the secrecy that often surrounds ritual attacks, the complicity of family and community members in certain cases, and the difficulty in accessing data due to the fact that most attacks occur in rural environments.

The trade of organs has also reportedly led to human trafficking across African countries. According to reports, the body parts of persons with albinism have been sold both locally and across borders, at prices ranging from US\$2,000 for a limb to US\$75,000 for a ‘complete set’ or a whole corpse.¹² Civil society reports indicate that, motivated by those prices, family members and communities have sold, or attempted to sell, persons with albinism.¹³ There have been reports of the cross-border trade of persons with albinism and their body parts in Burundi, the Democratic Republic of the Congo, Kenya, Malawi, Mozambique, South Africa, Swaziland and Tanzania.¹⁴

All cases of physical attacks and violations documented to date have been reported from Sub-Saharan Africa, which is why this report focuses its analysis on that region.

11 *Ibid.*

12 See ‘Through albino eyes: The plight of albino people in Africa’s Great Lakes region and a Red Cross response – Advocacy report’, International Federation of Red Cross and Red Crescent Societies (IRFC, 2009), p 5, www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf accessed 21 April 2017.

13 See n 5 above, para 24; ‘Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on her mission to Malawi’, A/HRC/34/59/Add.1 (14 December 2016), paras 55–57.

14 See www.underthesamesun.com accessed 21 April 2017.

Impunity and lack of protection for victims

Attacks against persons with albinism are seldom investigated and alleged perpetrators often evade justice. The low response to attacks and significant impunity serve as hindrances to the reporting and visibility of attacks.

Across Sub-Saharan Africa, legal responses to the killings and mutilation of persons with albinism has been slow or, in some cases, non-existent. In Tanzania, for example, arrests have been made and special task forces have been set up since 2008 to investigate and prosecute such cases. However, civil society organisations have raised concerns regarding the number of cases not prosecuted or dismissed in court, due to lack of evidence as a result of security forces' failure to carry out proper investigations.¹⁵

In Burundi, over the past decade, there have been reports of 38 attacks against persons with albinism, including 21 murders. According to civil society, 11 suspects have been arrested in connection with a few attacks and, of those charged, only five are serving prison sentences.¹⁶

In Malawi, none of the alleged perpetrators of the 19 killings of persons with albinism documented by Amnesty International between 2014 and 2017 had been convicted at the time of writing this report.¹⁷

15 Tanzania Mid-term Implementation Assessment, page 21, www.upr-info.org/followup/assessments/session25/tanzania/MIA-Tanzania.pdf accessed 26 May 2017; Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism, A/HRC/28/75, para 20; Under The Same Sun, 'Children with Albinism in Africa: Murder, Mutilation and Violence' (19 June 2012), p 35, www.underthesamesun.com/sites/default/files/UTSS%20report%20to%20UN%20-%20REPORT.pdf accessed 21 April 2017; Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism, paras 20 and 38.

16 Under the Same Sun, 'The Torture of People With Albinism in Burundi' (4 July 2016), p 2 and 6, http://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/BDI/INT_CAT_NGO_BDI_24556_E.pdf accessed 21 April 2017.

17 Amnesty International, 'Malawi: We are not animals to be hunted or sold – Violence and discrimination against people with albinism in Malawi' (7 June 2016), www.amnesty.org/en/documents/afr36/4126/2016/en accessed 21 April 2017.

Cases of physical attack

On 24 May 2016, a 38-year-old man with albinism, Fletcher Masina, was attacked and killed by unknown persons while working in his garden in Zintambira Village under Traditional Authority Chakhumbira in Ntcheu District, Central Region, Malawi. That morning, Masina and his wife had gone to their vegetable garden, which is some distance from their village. Masina's wife said that at lunchtime he told her to go home while he continued working in the garden. At about 1900, she told her brother that Masina had not returned home. A search party was sent to the garden to look for him. When they arrived, they saw blood all over the garden and signs of a struggle. They tried to follow the blood trail but it was too dark to see anything. The following day, police and relatives continued the search and found Masina's body a few hundred metres from the garden with both hands and legs cut off. Nearly two years after the attack, no arrest had been made, according to Amnesty International, which documented the killing.ⁱⁱ

The killing of Masina is not an isolated incident. Amnesty International has reported at least 18 cases of persons with albinism killed and at least five abducted, who remain missing. According to the Malawi Police Service, at least 69 cases involving crimes related to persons with albinism have been reported since November 2014.ⁱⁱⁱ

The killing of persons with albinism continues unabated. On 25 February 2017, 31-year-old Zainabu Mercy Banda was reportedly killed for ritual purposes. She had left her home in area 36 of Lilongwe, Malawi, on 23 February, having informed her mother and friends that she was going to town and would be back later. Her body was found lying in a maize field at Chadza Village in the area of Kaphiri within the city. The police confirmed that Banda had been murdered. Her left arm and breast were missing and her hair had been shaved off. Ropes were found around her neck and on her right hand. At the time of writing this report, no arrest has been made and the police are still investigating the case.^{iv}

ii *Ibid* 23.

iii *Ibid* 5.

iv Under The Same Sun, 'Reported Attacks of Persons with Albinism – Most Recent Attacks Included' (11 April 2017), www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf accessed 21 April 2017.

The barriers to guaranteeing the right of access to justice for persons with albinism who have been victims of human rights violations include the lack of political will to enforce existing legislation, as well as a lack of resources for police forces to deal with cases, including tools for forensic and DNA analysis, especially in rural areas. In some cases, police officers, prosecutors and judges also hold the same prejudice against persons with albinism and fail to properly investigate, prosecute or convict. According to reports, on occasions, prosecutors and judges do not consider the discrimination against the victim as an aggravating factor in the attack, and court sentences handed down to convicted criminals do not reflect the gravity of crimes against persons with albinism.¹⁸

In some cases, victims, relatives and members of the community are reportedly unaware of how to file a complaint with the relevant authorities. Often, they fail to come forward for fear of reprisals. The need to strengthen protection measures has been stressed by many supporting persons with albinism. Although there have been efforts by some states to protect victims, in some cases, these have been inadequate or have further violated the rights of the victims. For instance, following a series of attacks against persons with albinism in the Lake Zone region in Tanzania, the authorities placed children with albinism in ‘safe’ houses, often referred to as temporary holding shelters. Concerns have been raised that the shelters are unhygienic, overcrowded and have limited human and financial resources, and that children with albinism have been subjected to threats, as well as to physical and sexual assault.¹⁹

The African Committee of Experts on the Rights and Welfare of the Child (ACERWC) carried out an investigative mission on the situation of children with albinism in these temporary shelters. ACERWC concluded that the procedures that were followed to take children to the centres were contrary to the provision of the African Children’s Charter and other international instruments. ACERWC also reached the same conclusion regarding the children with albinism’s situation in the shelters – it documented that the conditions in the shelters violated the children’s rights to health, education,

18 See n 13 above, para 22.

19 See Under The Same Sun, ‘Children with Albinism: Violence & Displacement’ (16 April 2013), pp 3–5, http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/TZA/INT_CRC_NGO_TZA_18032_E.pdf accessed 21 April 2017.

adequate food, nutrition, accommodation, water and sanitation, as well as their right to enjoy parental care and protection.²⁰

Displacement

As a result of ostracism by communities or fear for their lives, persons with albinism and their families have been forced to restrict their freedom of movement, leave their communities and even flee their countries to seek refuge abroad. Cases of persons with albinism who have been granted asylum have been documented in Belgium, Canada, France, Ireland, Israel, New Zealand, Spain, Tunisia, the UK and the United States.

In some cases, fleeing a country to seek refuge in other African states has not improved living conditions or stopped the abuse. There have been reports of persons with albinism who have been forced to flee Tanzania and Côte d'Ivoire to South Africa, Kenya and Tunisia. They have continued to suffer discrimination, been subjected to attacks and denied access to social services, education and healthcare in their new residences.²¹

Discrimination

Discrimination against persons with albinism is reportedly a worldwide issue. While the degree, scope and severity varies from country to country, there is a common thread of bullying of school-aged children. There have also been reports of family ostracism, as well as access to employment discrimination – based on appearance and how it would impact customer service – reported in Spain and India.²²

In most Sub-Saharan Africa countries, persons with albinism and their families routinely face prejudice, stigmatisation, and multiple and interrelated forms of discrimination based on colour, visual impairment, gender and age. Such discrimination is based on myths and misconceptions about the causes of

20 ACERWC, 'Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania' (27 October 2016), www.refworld.org/docid/5811f7234.html accessed 21 April 2017.

21 See n 3 above, Daniel Ikuomola Adediran, for information of human rights violations against migrant persons with albinism from Tanzania in South Africa and Kenya; n 21 above, p 8, for information about a report of a refugee woman with albinism who fled from Cote d'Ivoire to Tunisia.

22 See n 5 above, paras 31 and 44.

albinism. These myths include that they are ghosts, that albinism is the result of conception during menstruation or that it is a curse.

Persons with albinism are often referred to using demeaning and derogatory names that suggest they are lesser beings because of their appearance.²³

Women who give birth to a child with albinism may face ostracism and discrimination. They are also exposed to rejection by their husband or partner, accused of adultery or infidelity and blamed for giving birth to a child who is generally seen as a curse or bad omen. The rejection and ostracism of mothers and sometimes entire families of children with albinism exposes them to poverty and isolation, increases their vulnerability to attacks, and also contributes to infanticide and abandonment of children with albinism.²⁴

Discrimination, lack of information about albinism and the absence of adequate provisions from the state in response to their particular needs has acted as a barrier preventing persons with albinism from accessing education, health, work and an overall adequate standard of living.²⁵

In some regions, children with albinism are prevented from going to school or drop out because of safety fears for reasons linked to stigma or because no reasonable accommodation is made for their visual impairment. Lack of information or understanding about albinism among teachers has led to a lack of accommodation for the visual impairment associated with the condition. Poor vision may cause students with albinism to learn with difficulty. They may be unable to clearly see a chalkboard or markerboard, or may not be able to read books or other learning materials. These conditions have led to poor academic performances and low education levels for persons with albinism.²⁶

These low education levels, combined with an absence of healthcare information about the condition, often leads to persons with albinism taking jobs outdoors, without sun protection. This exposes them to a high risk of skin cancer. Due to the lack of protective melanin pigment in the skin of persons with albinism, they are at lifelong risk of sun-induced damage. This can range

23 See, eg, n 3 above, Muthee Thuku, pp 6–8, and Daniel Ikuomola Adediran; n 14 above; n 16 above, *Under The Same Sun*, p 4; n 17 above, pp 18–20.

24 See n 5 above, para 44.

25 See n 3 above, Human Rights Council, paras 27–28; n 4 above, para 71.

26 See n 4 above, para 68; see n 3 above, Muthee Thuku, p 12; Albinism Foundation of East Africa et al, 'The human rights of persons with albinism in Kenya' (30 June 2014), paras 19–21.

from severe sunburn, which can become infected, to pre-cancerous lesions that can develop into life-limiting skin cancer if not identified and treated early. To lessen the effects of the sun, persons with albinism need to apply sunscreen, and wear wide-brimmed hats and sunglasses, which can be costly or unavailable, especially in rural areas. The lack of provision by the state, together with the lack of self-care knowledge, has had severe consequences for the right to health and life of persons with albinism.

In Africa, especially in equatorial regions, albinism is a life-limiting condition due to early death from skin cancer. The introduction of sun protection programmes may result in a longer life expectancy for those receiving this support from a young age. However, the availability of such programmes generally remains limited in the region.

‘I had no knowledge of my skin condition’

I was born in Nigeria. Both of my parents were black and I was the only child with albinism in a family of 11. I have suffered a great deal of maltreatment from family members, at school and in social circles.

At school, my challenges were multifaceted. They stemmed from visual impairment resulting in my inability to see the board, as well as disrespect and mockery by teachers and pupils alike.

Growing up, I was told that I could only see well at night and not during the day; that persons with albinism had very limited longevity and may die young; that albinism is contagious and will affect pregnant women and, as such, I was not allowed to go into some relatives’ and friends’ homes.

My parents weren’t educated, so were uninformed about albinism and the challenges thereof. Growing up, I had no knowledge of my skin condition and no one to advise me on what to do. Because of this, I unduly exposed my skin in the sun so now I have freckles and other skin irritations.

There is no documented statistical data on the number of persons with albinism in Nigeria and those affected by skin cancer in Nigeria. However, NGO The Albino Foundation has estimated that there could be as many as 27,000 persons with albinism who have skin cancer.

Nigeria runs a healthcare project to treat persons with albinism who show signs of skin cancer. The project was set up in 2007 by the then president. It is run by the Federal Ministry of Health, the Federal Ministry of Finance and the National Hospital in Abuja, with the collaboration of The Albino Foundation, which provides referral letters for persons with albinism who need treatment. To date, The Albino Foundation has referred 3,140 persons with albinism affected with skin cancer to the National Hospital.

However, in recent years, the National Hospital has reported a lack of resources to provide comprehensive treatment for persons with albinism who have skin cancer. The hospital currently provides free testing, chemotherapy, dermatological and surgical services, while patients sometimes provide drugs when they are not available in the hospital pharmacy.

* Jake Epelle, Founder of The Albino Foundation, Nigeria

1.3 Definition of albinism and the percentage of people affected

In the first report to the Human Rights Council, the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism refers to the definition by the US National Organization for Albinism and Hypopigmentation. According to the organisation, albinism is a rare, non-contagious, genetically inherited condition that affects people worldwide. It results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light.²⁷ As a result, almost all persons with albinism have visual impairments and can develop skin cancer if they do not take sun protection measures. There is no cure for the condition as there is no way to replace melanin at present.

There are different types of albinism. The most common and visible type is OCA, which affects the skin, hair and eyes. Within this type, there are subtypes, which reflect varying degrees of melanin pigment deficiency in an individual. The main subtypes are OCA1 and OCA2. In OCA1, there is little or no production of melanin and it is often characterised by white hair and

27 See n 5 above, para 12; 'Information Bulletin – What is Albinism?' National Organization for Albinism and Hypopigmentation, www.albinism.org/site/c.flKYIdOUlhJ4H/b.9253761/k.24EE/Information_Bulletin__What_is_Albinism.htm accessed 21 April 2017.

opaque or transparent irises. OCA2 is the more prevalent type, particularly in African countries; some melanin is produced and it is characterised by yellow-blond or sandy-coloured hair and grey to light-brown irises.²⁸

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.²⁹ There is a 25 per cent chance that a child will be born with albinism if both parents are carriers.³⁰

The proportion of persons affected by albinism in the world differs from region to region. Reports suggest that in North America and Europe an estimated one in every 20,000 people have some form of albinism.³¹ A public survey in African countries, published by the World Health Organization (WHO) in 2006, mentions that:

‘Epidemiologic data on albinism, such as prevalence, were available for South Africa, Zimbabwe, Tanzania and Nigeria. Prevalence as high as 1 in 1,000 were reported for selected populations in Zimbabwe and other specific ethnic groups in Southern Africa. An overall estimate of albinism prevalence ranges from 1/5,000 – 1/15,000.’³²

According to the WHO, the estimated prevalence of albinism suggests the existence of tens of thousands of persons with albinism in Africa. However, it is important to note that accurate data on prevalence remains lacking as available information – including from the WHO study – is often affected by certain bias in methodology.

A demographic survey carried out in Tanzania indicated that there were 16,127 persons with albinism in the country in 2012.³³ A disability survey in Namibia based on demographic data collected in 2011 stated that there were 1,153 persons with albinism in the country.³⁴

28 See n 5 above, para 13.

29 The exception is one type of ocular albinism, which is passed on from mother to son.

30 See n 4 above, para 10.

31 See n 27 above.

32 Esther S Hong, Hajo Zeeb and Michael H Repacholi, ‘Albinism in Africa as a public health issue’ (17 August 2006), <https://bmcpublihealth.biomedcentral.com/articles/10.1186/1471-2458-6-212#Sec21> accessed 21 April 2017.

33 ‘Basic Demographic and Socio-Economic Profile – Statistical Tables: Tanzania Mainland’ (April 2014), p 122, www.tanzania.go.tz/egov_uploads/documents/Descriptive_tables_Tanzania_Mainland_sw.pdf accessed 21 April 2017.

34 Namibia Statistics Agency, ‘Namibia 2011 Census: Disability Report’ (2016), http://cms.my.na/assets/documents/Namibia_2011_Disability_Report.pdf accessed 21 April 2017.

1.4 Purpose, scope and methodology

This report focuses on the international standards relevant for the promotion and protection of the rights of persons with albinism in the African region, particularly in Sub-Saharan Africa countries, where extreme violations of human rights against persons with albinism have been reported. Much of the information contained in this report is from Sub-Saharan Africa countries such as Malawi and Tanzania, where there have been a large number of well-documented cases of killings and mutilations of persons with albinism. The availability of these cases in Malawi and Tanzania is partly explained by the attention the issue has garnered from local civil society organisations and the relative greater freedom of the countries' press.³⁵ But the cases have often been the focus of regional and international attention and criticism. However, information from other states in the region, even if scarce, clearly indicates that violations against persons with albinism is a regional problem and that persons with albinism in many parts of Africa are often victims of stigmatisation, discrimination and attacks.

The purpose of this report is to provide a comprehensive compilation of all international and African human rights standards and jurisprudence relevant to persons with albinism, with a view to ascertain the scope and content of the obligations of African states to protect, promote and fulfil their human rights. The report aims to provide a useful advocacy tool for the advancement of the rights of persons with albinism.

35 Malawi and Tanzania ranked 66 and 71 respectively in the 2016 World Press Freedom Index: <https://rsf.org/en/ranking> accessed 21 April 2017.

In doing so, the report reviews international human rights treaties,³⁶ as well as the work of selected UN Human Rights Council Special Procedures³⁷ and human rights treaty monitoring bodies³⁸ relating to the obligation of states to promote and protect the human rights of persons with albinism.

Treaty bodies are committees of independent experts that monitor the implementation of the core international human rights treaties.³⁹ Special procedures, on the other hand, do not monitor any specific treaty. They are ‘prominent, independent experts working on a voluntary basis, appointed by the [UN]’ to ‘address either specific country situations or thematic issues in all parts of the world’.⁴⁰ They include special rapporteurs, independent experts and working groups.

In this regard, it is worth noting that special procedures and treaty bodies have provided guidelines, responses and information based on information provided to them by states and civil society organisations. Most of this information has come out of Southern and East Africa. However, as already stated, violations of the rights of persons with albinism happen in countries all over Africa, and internationally.

36 The International Covenant on Civil and Political Rights (ICCPR); the International Covenant on Economic, Social and Cultural Rights (ICESCR); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT); the Convention on the Rights of the Child (CRC); The Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW); the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD); and the Convention on the Rights of Persons with Disabilities (CRPD).

37 Special Rapporteur on Torture, Special Rapporteur on the Right to Health, Special Rapporteur on the Right to Education, Special Rapporteur on the Rights of Minorities and Special Rapporteur on Extrajudicial Executions, as well as the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism.

38 The Human Rights Committee, which monitors the implementation of the International Covenant on Civil and Political Rights; the Committee on Economic, Social and Cultural Rights (CESCR); the Committee against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (officially CAT, but CoAT for the purposes of this report to avoid confusion), the Committee on the Rights of the Child (officially CRC, but CoRC for the purposes of this report to avoid confusion); the Committee on the Elimination of all forms of Discrimination against Women (officially CEDAW, but CoEDAW for the purposes of this report); Committee on the Elimination of Racial Discrimination (CERD); and the Committee on the Rights of Persons with Disabilities (officially CERD, but CoERD for the purposes of this report).

39 The exception is the Subcommittee on Prevention of Torture, established under the Optional Protocol to the CAT, which monitors places of detention in States Parties to the Optional Protocol. See ‘Human Rights Bodies’, OHCHR: www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx accessed 21 April 2017.

40 *Ibid.*

In addition, it reviews African human rights treaties and interpretative work of the African Commission on Human and Peoples' Rights (ACHPR); the African Court on Human and Peoples' Rights (the 'African Court'); ACERWC; the Working Group on Death Penalty and Extra-Judicial, Summary or Arbitrary Killings in Africa; and the Working Group on Rights of Older Persons and People with Disabilities.

Based on the documents reviewed, the report proposes a list of key recommendations to African states and the international community aimed at strengthening or clarifying the legal protection to which persons with albinism are entitled, providing decision and policy-makers with the necessary information to guarantee protection to persons with albinism and, ultimately, improving the adequate protection of the rights of persons with albinism.

Chapter 2: Violence against persons with albinism

By becoming parties to international and regional human rights treaties, states assume the duty, among others, to protect individual human rights and to prevent human rights violations from taking place. They bear the primary responsibility for this and must ensure that rights are not violated, either by themselves or non-state actors.

The duty to prevent human rights violations is both direct and indirect. It includes states' obligations to take measures to prevent human rights violations directly. This means that they must mitigate or eliminate risk factors and establish a legal, administrative and policy framework that seeks to prevent violations. States are required to take indirect measures to protect human rights, and to prevent the recurrence of violations by identifying and addressing the causes of these violations.

States are responsible for human rights violations by action (when state actors commit human rights violations) or by omission (when they fail to act to prevent violations from non-state actors).

2.1 International obligation of states to prevent human rights violations and protect persons with albinism against attacks

Relevant rights in international law

Physical attacks against persons with albinism constitute a violation of a number of human rights, including the right to life and security of person. In some cases, attacks may also violate the right to be free from trafficking and exploitation, as persons with albinism are sometimes trafficked to other areas

where their body parts are used for ritual practices.⁴¹ International human rights law also stipulates that states must protect women and children from all forms of trafficking and exploitation.⁴²

These rights are guaranteed to all persons and are enshrined in various international human rights treaties, including:

- Universal Declaration of Human Rights (UDHR);
- International Covenant on Civil and Political Rights (ICCPR);
- Convention on the Rights of the Child (CRC);
- Convention on the Rights of Persons with Disabilities (CRPD);
- International Convention on the Elimination of All Forms of Racial Discrimination (ICERD);
- Convention Against Torture (CAT);⁴³ and
- Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children.

Response by international human rights bodies

International human rights bodies have repeatedly raised concerns about human rights violations against persons with albinism and have demanded that states prevent such abuses and protect persons with albinism from human rights violations.

41 The Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children defines trafficking in persons as ‘the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation’. It also states that ‘exploitation’ should include the removal of organs.

42 Art 6 of the CEDAW; Art 36 of the CRC; and Art 16 of the CRPD.

43 Art 6(1) of the ICCPR, Art 6(1) of the CRC and Art 10 of the CRPD consecrate the right to life; Art 3 of the UDHR, Art 9 of the ICCPR, Art 14 of the CRPD and Art 5 of the ICERD provide for the right to security of person; Art 5 of the UDHR, Art 7 of the ICCPR, Arts 2 and 16 of the CAT, Art 37(a) of the CRC, Art 15 of CRPD and Art 5 of the ICERD prohibit torture and other cruel, inhuman or degrading treatment or punishment.

For example, on 13 June 2013, the Human Rights Council expressed concern regarding physical attacks against persons with albinism and the widespread discrimination, stigma and social exclusion they suffer. It urged states to take all measures necessary to ensure the effective protection of persons with albinism and their family members.⁴⁴ These concerns were echoed by the Office of the UN High Commissioner for Human Rights (OHCHR) in a preliminary report on persons with albinism, published on 12 September 2013.⁴⁵

Similarly, the Human Rights Council's Advisory Committee has emphasised that attacks against persons with albinism 'underscore the urgent need for [s]tates 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'.⁴⁶ It has further highlighted the obligation of states to ensure persons with albinism are provided with 'safe and secure spaces where they are able to live dignified lives, free from the fear of being attacked'.⁴⁷

Further, treaty bodies, such as the Human Rights Committee (HR Committee), the Committee on Economic, Social and Cultural Rights (CESCR), the Committee against Torture (herein after CoAT), the Committee on the Rights of the Child (herein after CoRC), the Committee on the Elimination of Discrimination against Women (herein after CoEDAW) and the Committee on the Rights of Persons with Disabilities (herein after CoRPD) have all repeatedly expressed concerns at attacks and the prevalence of harmful practices against persons with albinism, including children and women, in Burundi,⁴⁸ Republic of Congo,⁴⁹ Guinea-Bissau,⁵⁰ Tanzania,⁵¹ Kenya,⁵² Ethiopia,⁵³ Malawi⁵⁴ and Swaziland.⁵⁵

44 Human Rights Council, 'Attacks and discrimination against persons with albinism', A/HRC/RES/23/13 (24 June 2013), http://ap.ohchr.org/documents/alldocs.aspx?doc_id=21920 accessed 21 April 2017.

45 See n 4 above, para 84.

46 See n 3 above, Human Rights Council, para 19.

47 *Ibid.*

48 CRC/C/BDI/CO/2, paras 33–34; CAT/C/BDI/2, para 12.

49 CRC/C/COG/2-4 paras 28 and 34–35.

50 CRC/C/GNB/CO/2-4, paras 28–29.

51 CRC/C/OPSC/TZA/CO/1, paras 20–21; CRC/C/TZA/3-5 paras 25–26; CCPR/C/TZA/CO/4, para 15; CEDAW/C/TZA/7-8 paras 18–19.

52 CCPR/C/KEN/CO/3, para 17; CRPD/C/KEN/1, paras 19–20.

53 CRPD/C/ETH/CO/1, paras 21–22.

54 CEDAW/C/MWI/7 paras 20–21.

55 CEDAW/C/SWZ/CO/1-2, paras 22–23.

The treaty bodies have also raised concerns that, in some cases, measures taken by states with the intention of protecting persons with albinism and preventing human rights violations against them do not comply with international human rights standards, and have in fact violated human rights.

For example, in its review of the reports of Tanzania, the CoRC expressed serious concern that ‘children with albinism have been placed in boarding schools/shelters for children with special needs’. It noted that:

‘these shelters, while offering immediate protection, are not temporary as originally intended and are unhygienic, overcrowded, and have limited human and financial resources. Children placed in these boarding schools/shelters are separated from their families and segregated from their community’.

The CoRC also noted with concern reports that children with albinism in these shelters are punished, especially by prolonged exposure to the sun, which can lead to the rapid development of skin cancer, and that they are also subjected to threats and even sexual abuse.⁵⁶

Special rapporteurs have also raised concern about the attacks, particularly with regard to the failure of the respective governments of Burundi,⁵⁷ Malawi,⁵⁸ South Africa,⁵⁹ Tanzania⁶⁰ and Zambia⁶¹ to provide adequate protection to persons with albinism in relation to attacks, including kidnapping, murder, and severing and maiming of body parts for use by witch doctors.⁶² The Special Rapporteur on torture has referred to attacks against persons with albinism as ‘manifestations of the worst forms of cruel, inhuman or degrading treatment’.⁶³

56 Review of the third to fifth combined periodic reports of Tanzania, in January 2015, CRC/C/TZA/3-5, paras 29–31.

57 BDI 4/2016 and Case No BDI 1/2015.

58 Case No MWI 1/2015.

59 Case No ZAF 2/2015.

60 Case No TZA 2/2014.

61 ZMB 1/2016.

62 The Special Rapporteurs include the Special Rapporteur on extrajudicial, summary or arbitrary executions; the Special Rapporteur on the independence of judges and lawyers; the Special Rapporteur on violence against women; the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment; the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance; the Special Rapporteur on the rights of persons with disabilities; and the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism.

63 UN News Centre, ‘Persons with albinism must not be treated as “ghosts”, UN experts stress’ (4 May 2013), www.un.org/apps/news/story.asp?NewsID=44825#.WDa7N4XXJZU accessed 21 April 2017.

In a communication to the Tanzanian government on 5 March 2015, the Special Rapporteur on torture concluded that the state had violated Articles 1 and 16 of the CAT ‘by failing to provide protection to persons with albinism and to investigate attacks on persons with albinism’.⁶⁴ In most cases, it is reported that government authorities have not responded to concerns raised.

It is not only UN treaty bodies and special procedures that have registered concern regarding the attacks. States themselves have also recognised attacks against persons with albinism as a human rights concern by making recommendations regarding attacks during the Universal Periodic Review (UPR).⁶⁵ Within the context of this process, the governments of Burundi,⁶⁶ Uganda⁶⁷ and Tanzania⁶⁸ have all received recommendations to take preventive and protection measures to address attacks and discrimination against persons with albinism.

DUTY TO TAKE LEGAL AND OTHER MEASURES

The ICCPR,⁶⁹ CRC,⁷⁰ CEDAW,⁷¹ CAT,⁷² CRPD⁷³ and Protocol to Prevent, Suppress and Punish Trafficking in Persons⁷⁴ are clear that, in protecting the rights of individuals and preventing human rights violations, states have a duty to take positive action, including legal and other measures, to ensure these rights are implemented.

64 ‘Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E Méndez: Addendum’, A/HRC/28/68/Add.1 (6 March 2015), pp 90–91, www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Pages/ListReports.aspx accessed 21 April 2017.

65 A process that involves a periodic review of the human rights records of all 193 UN Member States, and provides an opportunity for all UN Member States to take part in the discussion/dialogue with the state under review. For more information on the UPR, see www.ohchr.org/EN/HRBodies/UPR/Pages/BasicFacts.aspx accessed 21 April 2017.

66 A/HRC/10/71, para 80.5; A/HRC/23/9, paras 126.31 and 126.84.

67 A/HRC/19/16, para 111.35.

68 A/HRC/19/4, paras 85.33–85.35 and 85.39–85.42.

69 ICCPR Art 2.

70 CRC Arts 4 and 19(1).

71 CEDAW Art 3.

72 CAT Art 2(1) and 16(1).

73 CRPD Art 15(2).

74 Art 9.

They require states to ensure that such measures include taking effective legislative, administrative, judicial or other measures to prevent violations; as well as addressing the root causes of violations, such as discrimination, prejudice, superstition, misconception and stigma; and conducting research aimed at assisting in preventing violations. States also have a duty to seek international assistance and cooperation.⁷⁵

Legal measures

In order to protect the rights of persons with albinism and prevent violations against their human rights, states must adopt legislation to criminalise attacks against persons with albinism, including harmful practices, as well as trafficking in persons and the participation as an accomplice, organisation or directing of such acts.

In this context, the OHCHR's preliminary report on persons with albinism also recommended that states take the necessary legislative measures to criminalise harmful practices.⁷⁶ It noted that the practical prevention of violations requires establishing a legislative and institutional framework for prevention, including the regular and systematic review of existing and proposed legislation for compliance with a state's human rights obligations.⁷⁷

Furthermore, the Human Rights Council's Advisory Committee has recommended that states enact a clear ban on the use of harmful practices against persons with albinism and clarify ambiguities, where they exist, in laws relating to witchcraft and traditional health practices. The Advisory Committee also recommends the consideration of attacks against persons with albinism as an aggravated form of crime incurring a more severe punishment, so that additional deterrence may be achieved.⁷⁸

Treaty bodies such as CoEDAW have echoed these recommendations. For example, it noted that Tanzania has taken various measures to accelerate the elimination of harmful practices, including adopting legislation. However, CoEDAW raised concerns regarding the high prevalence of such practices,

75 Art 7 of the CERD; Arts 8, 12 and 16 of the CRPD; Art 19(2) of the CRC; Arts 2 and 6 of CEDAW; Art 9 of the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children.

76 See n 4 above, para 86.

77 OHCHR, 'The Role of Prevention in the Promotion and Protection of Human Rights', A/HRC/30/20 (16 July 2015), pp 8–13.

78 See n 3 above, Human Rights Council, para 63.

including prescribing sex with girls or women with albinism as a cure for HIV, ritual killings and attacks, and the use of fingers, limbs and other body parts for purposes of witchcraft. It urged Tanzania to ‘effectively implement... the existing legal provisions prohibiting harmful practices [and] also adopt new legal provisions, as necessary’.⁷⁹ These recommendations were repeated in its review of the seventh periodic report of Malawi in November 2015.⁸⁰

CoRC and CoEDAW have further stressed that legislation aimed at eliminating harmful practices must include appropriate budgeting, implementing, monitoring and effective enforcement measures.⁸¹

Other measures

Legal reform is necessary, but insufficient on its own, for protecting the rights of persons with albinism. Both the OHCHR and the Human Rights Council’s Advisory Committee have indicated that:

‘laws [to protect persons with albinism from attacks and prevent these violations] should be accompanied by concrete measures that would facilitate their implementation. They have called on States to take measures, such as advocacy and the training of law enforcement personnel and judicial authorities’.⁸²

In addition, the OHCHR has also recommended that states:

- address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating superstition and stigma vis-à-vis albinism, including through education and awareness-raising campaigns;
- evaluate and address the needs of persons with albinism, including through a census of the population and the mandatory birth and death registration of persons with albinism;

79 CEDAW/C/TZA/CO/7-8, para 19 (b), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CEDAW%2fC%2fTZA%2fCO%2f7-8&Lang=en accessed 21 April 2017.

80 While welcoming the prohibition of harmful practices by the Gender Equality Act and the Child Care, Protection and Justice Act, CoEDAW remained seriously concerned about the prevalence of harmful practices, and urged the State Party to ‘effectively implement the existing legal provisions prohibiting harmful practices’, CEDAW/C/MWI/7 paras 20–21, <http://undocs.org/CEDAW/C/MWI/7> accessed 21 April 2017.

81 CEDAW/C/GC/31-CRC/C/GC/18, para 12.

82 *Ibid*, para 64; see n 4 above.

- increase efforts to put an end to the various forms of crimes affecting persons with albinism, strengthen the legal response to such crimes and bring perpetrators to justice through prompt and impartial investigations;
- develop national institutional mechanisms for the protection and promotion of rights of persons with albinism, including by ensuring that national human rights institutions effectively address the human rights situation of persons with albinism; and
- support civil society organisations working for the promotion and protection of rights of persons with albinism.⁸³

Moreover, the Human Rights Council's Advisory Committee has recommended a comprehensive strategy involving protection, accountability measures and broad public education campaigns involving persons with albinism and other stakeholders, such as traditional health practitioners involved in witchcraft.

Among the measures to raise awareness, the Advisory Committee highlighted the need to:

- implement active public education and awareness-raising campaigns aimed at combating prejudice, superstition, misconception and stigma, which states would first target to specific key groups, including law enforcement officers, members of the judiciary, educators, social workers, medical service providers, and the families and communities of persons with albinism;⁸⁴
- include in educational curricula courses to instruct people on the rights of persons with albinism;⁸⁵ and
- allocate resources, both financial and otherwise, to develop activities designed to decrease and eliminate prejudice and create an environment conducive to respect for their rights and dignity.⁸⁶

Other UN human rights experts have also stressed the need to raise awareness. In a joint statement issued in 2013, a group of UN human rights

83 See n 4 above, paras 30–31.

84 *Ibid*, para 57.

85 *Ibid*.

86 *Ibid*, para 71.

experts⁸⁷ called on African governments to raise awareness and educate the public at large about the true nature of albinism and the needs of people with the condition.

Treaty bodies have made similar appeals to states. In the review of Kenya in July 2012, while welcoming the adoption of the Counter Trafficking in Persons Act of 2010, the HR Committee expressed concern at continuing reports of trafficking in persons, including of persons with albinism for body parts. It recommended that the State Party continue to strengthen its efforts to eradicate human trafficking by targeting the hospitality industry through awareness-raising initiatives.⁸⁸

Following its review of the combined second to fourth periodic report of the Republic of the Congo in January 2014, the CoRC recommended that such awareness campaigns focus on the superstitious beliefs and related attacks and acts of homicide concerning children with albinism.⁸⁹ Similarly, it recommended that Tanzania should target awareness raising campaigns at ‘witch doctors’, to fully ensure the immediate and long-term protection of children with albinism and address the root causes of the violence they suffer.⁹⁰

In the case of Guinea-Bissau, it highlighted the need for the state to ‘undertake a study on the extent and root causes of killings to strengthen the advocacy and awareness’.⁹¹

CoEDAW has made similar recommendations to Tanzania,⁹² Malawi⁹³ and Swaziland.⁹⁴

87 The Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment; the Special Rapporteur on extrajudicial, summary or arbitrary executions; the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance; the Independent Expert on Minority Issues; the Special Rapporteur on the right to health; and the Special Rapporteur on the right to education.

88 CCPR/C/KEN/CO/3, para 17.

89 CRC/C/COG/2-4 paras 28 and 34–35.

90 *Ibid*, paras 29–31.

91 CRC/C/GNB/CO/2-4, paras 28–29.

92 *Ibid*, paras 42–43.

93 CEDAW/C/MWI/7 paras 20–21.

94 CEDAW/C/SWZ/CO/1-2, paras 22–23.

DUTY TO REFRAIN FROM REFOULMENT

Individuals with a well-founded fear of being persecuted – for reasons of race, religion, nationality, political opinion or membership of a particular social group – have the right to apply for asylum in a third country. Attacks against persons with albinism may warrant them to seek asylum in other countries when their own country is unable to adequately protect them. The obligation to protect the right to life, physical integrity and security requires that states do not expel or return ('refouler') a refugee against their will, in any manner whatsoever, to a territory where they fear threats to life or freedom, as stated in Article 1 and 33 of the Convention and Protocol Relating to the Status of Refugees. This principle also applies to those seeking asylum, but who have not yet been granted refugee status (ie, asylum seekers), until their claim has been decided.

Article 3 of the CAT also prohibits parties from returning, extraditing or refouling any person to a state 'where there are substantial grounds for believing that he would be in danger of being subjected to torture'. The CoAT has held that this danger must be assessed not just for the initial receiving state, but also for states to which the person may be subsequently expelled, returned or extradited.⁹⁵

DUTY TO SEEK INTERNATIONAL ASSISTANCE AND COOPERATION TO PREVENT VIOLATIONS

The UDHR,⁹⁶ the International Covenant on Economic, Social and Cultural Rights (ICESCR),⁹⁷ the Trafficking Protocol⁹⁸ and the CRC⁹⁹ demand that States Parties seek international cooperation to protect human rights and prevent violations.

In this context, in its report on persons with albinism, the OHCHR recommended that the international community:

- provides financial assistance for the development of technical cooperation activities aimed at supporting measures to prevent and combat

95 CAT General Comment 1 (1998), para 2.

96 UDHR Arts 22 and 28.

97 ICESCR Arts 2(1), 11(1), 11(2), 15(4), 22 and 23.

98 Trafficking Protocol Art 9.

99 CRC Art 25.

discrimination and attacks against persons with albinism, and at providing assistance to the victims and their family members; and

- strengthen international, regional and bilateral cooperation for the prevention of cross-border crimes affecting persons with albinism – notably human, child and organ trafficking.¹⁰⁰

The CoRC has also stressed the need for international cooperation to address trafficking of children, including children with albinism. In October 2008, in its review of Tanzania under the Optional Protocol to the CRC on the sale of children, child prostitution and child pornography, it urged the State Party to:

- take all necessary steps to strengthen international cooperation by multilateral, regional and bilateral arrangements for the prevention, detection, investigation, prosecution and punishment of those responsible for acts involving the sale of children;
- continue its cooperation through bilateral arrangements to strengthen institutions working with children;
- address the root causes, such as poverty and underdevelopment, contributing to the vulnerability of children to the sale of children; and
- seek international support for cooperation projects relating to implementation of the provisions of the Optional Protocol, in particular in order to provide assistance for child victims.¹⁰¹

The Independent Expert on Albinism has also stressed the importance of close international cooperation to tackle the sale in and trafficking of body parts of persons with albinism. The Independent Expert has called on Malawi to facilitate international law enforcement cooperation with neighbouring countries, for example, through memoranda of understanding, shared databases and the signing of extradition treaties.¹⁰²

In addition, UN Member States are urged to seek international cooperation to implement the universal development agenda agreed for 2016–2030, which includes 17 Sustainable Development Goals (SDGs). When committing to work towards these SDGs, states pledged to ensure that ‘no one would be left

¹⁰⁰ See n 4 above, para 88.

¹⁰¹ CRC/C/OPSC/TZA/CO/1, paras 36 and 41–43.

¹⁰² See n 13 above, ‘Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on her mission to Malawi’, para 85.

behind’, and to see all goals and targets met for all nations, all people and all parts of society, ‘endeavouring to reach the furthest behind first’.¹⁰³

A fundamental part of meeting the SDGs is addressing inequality, including through international cooperation. The SDGs include targets on key areas, such as poverty, hunger, health, education, gender equality and decent work, which are fundamental to guaranteeing the full protection of human rights of persons with albinism.

2.2 Obligation of states to prevent human rights violations and protect persons with albinism against attacks at the African regional level

Relevant rights in regional law

Similar concerns were repeated at the African Commission on Human and Peoples’ Rights 20th Extra-Ordinary Session, held from 9–18 June 2016. While noting the Malawi government’s commitment to fight this serious violation of rights to life, dignity and protection from inhuman treatment, the Commission expressed concerns at the ‘continuing systematic attacks and killings against persons with albinism’ in the country.¹⁰⁴ In addition, the Chairpersons of both the Working Group on Death Penalty, Extra-Judicial, Summary and Arbitrary Killings in Africa and the Working Group on the Rights of Older Persons and People with Disabilities in Africa raised concerns in 2015 about similar attacks in Tanzania, Malawi and Burundi, and strongly condemned such crimes.¹⁰⁵

Concerns about the ‘extremely vulnerable position of children with albinism’ were raised by ACERWC following its investigative mission on the situation in temporary holding shelters in Tanzania. In the report issued in March 2016, the African Committee stated that attacks and killings against children with albinism

103 UN Resolution A/RES/70/1, 21 September 2015, para 4.

104 Resolution on the Attacks on Persons with Albinism in Malawi - ACHPR/Res. 349 (EXT.OS/XX) 2016, www.achpr.org/sessions/20th-eo/resolutions/349 accessed 21 April 2017.

105 Joint statement by the Working Group on Death Penalty, Extra-Judicial, Summary and Arbitrary Killings in Africa and the Working Group on the Rights of Older Persons and Persons with Disabilities in Africa, www.achpr.org/press/2015/03/d251 accessed 21 April 2017.

were widespread and demonstrated that the Tanzanian government had largely failed to comply with its obligation in fulfilling and protecting their rights.¹⁰⁶

African states' obligation to prevent human rights violations against persons with albinism is defined in African human rights instruments, including:

- the African Charter on Human and Peoples' Rights (the 'African Charter');
- the African Charter on the Rights and Welfare of the Child (ACRWC); and
- the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (the 'Maputo Protocol').¹⁰⁷

African states' obligation to protect the right to life, integrity and security extends to non-nationals seeking refuge. Article 12(3) of the African Charter and Article 4(2)(f) of the Maputo Protocol guarantee the right to seek asylum when a person is at risk of persecution.

In addition to these human rights instruments, on 20 April 2016, the ACHPR adopted a Draft Protocol on the Rights of Persons with Disabilities in Africa (the 'Draft Protocol'), intended to complement the African Charter and address continued exclusion, harmful practices and discrimination affecting persons with disabilities. In its preamble, the Member States of the African Union expressed concern at the harmful practices that persons with disabilities often experience, in particular the maiming or killing of persons with albinism in many parts of the continent. In so doing, the Draft Protocol recognises persons with albinism as persons with disabilities in the African context.

Although not yet in force, the Draft Protocol indicates African states' intention to expand on the protection of the rights of persons with disabilities, including persons with albinism. The expansion of protection includes the rights to life, integrity and dignity (Article 4); security of person (Article 5); not to be subjected to torture and other forms of cruel, inhuman or degrading treatment (Article 5); and to be protected from exploitation (Article 5). In addition, Article 3 prohibits discrimination against persons with disability on multiple grounds.¹⁰⁸

106 See n 20 above.

107 The rights to life, dignity, integrity and security of person are guaranteed under Arts 4, 5 and 6 of the African Charter, Art 5 of the ACRWC, and Arts 3 and 4 of the Maputo Protocol.

108 'States Parties shall prohibit discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. States Parties shall ensure that persons with disabilities are not discriminated, on one or more grounds, on the basis of their birth, age, gender, sex, race or ethnicity, economic status, social status or other such status.'

Special protection to persons with disabilities, in particular children and women, is guaranteed under Article 23 of the Draft Protocol, as well as under Article 18 of the African Charter and Article 13 of the ACRWC.

Article 22 of the Draft Protocol and Article 23 of the Maputo Protocol also guarantee the rights of women with disabilities to freedom from violence (including sexual abuse), discrimination based on disability and the right to be treated with dignity.

Response by regional human rights bodies

Concerns about reports of systematic attacks against persons with albinism in Africa, including against women and children, were first raised at the regional level by the ACHPR at its 54th Ordinary Session held from 22 October to 5 November 2013.¹⁰⁹

‘I spent my childhood waiting to disappear’

There were two of us in my family with albinism – my sister and I. When I was young, I was told that I would not die. They said I would disappear because people like me – people with albinism – are not like other people and do not die. I spent my childhood waiting to disappear. Every day I wondered whether that would be the day I would disappear until the day my sister died in a tragic car accident. That is when I realised that, just like everyone else, people with albinism die.

There were a lot of people at my sister’s funeral. At first, I thought it was because we had many friends, but I soon discovered it was because people couldn’t believe someone with albinism had died. They wanted to see for themselves that she had actually died.

My father spent many nights sleeping next to my sister’s grave. He wanted to make sure no one came to take her body because people think you can get powers from body parts of persons with albinism. They don’t know that we are just human like everyone else.

* Peter Ogik, Source of the Nile Union of People with Albinism, Uganda

109 Resolution ACHPR/Res.263 (LIV) 2013.

DUTY TO TAKE MEASURES TO PROTECT AND PREVENT VIOLATIONS AT THE AFRICAN REGIONAL LEVEL

Similar to international human rights standards, African regional instruments also require that states implement measures to protect human rights enshrined in regional human rights instruments and to take actions to prevent violations. For example, Articles 3, 4 and 5 of the Maputo Protocol require that States Parties take actions to protect women and girls with albinism from attacks and prevent violations to their rights. These include legislative, administrative, social, economic and other measures, encompassing:

- awareness-raising and education;
- monitoring;
- outreach programmes; and
- protection and support to victims, including health services, legal and judicial support, and emotional and psychological counselling, as well as vocational training to make them self-supporting.

In addition, Article 2 of the Draft Protocol requires states to ‘take appropriate and effective measures, including policy, legislative and administrative’ measures that, inter alia:

- modify or abolish existing policies, laws, regulations, customs and practices that constitute discrimination, as well as harmful practice;
- put in place adequate resources;
- promote positive representations of persons with disabilities through training and advocacy; and
- consult and actively engage persons with disabilities and their representative organisations.

As stated above, the ACHPR¹¹⁰ and ACERWC have called on states to fulfil these duties. The ACERWC has recommended that states take legislative and administrative measures, including reviewing legislative instruments and policies, and the adoption of a comprehensive strategy to eliminate the attacks, killings and discrimination against children with albinism. It

110 See n 104 above.

specifically called for the amendment of The Witchcraft Act in Tanzania,¹¹¹ and recommended the launch of campaigns and awareness-raising events with a view to addressing the root causes of attacks and discrimination against persons with albinism, particularly children.¹¹²

Furthermore, with a view to addressing the cross-border aspect of the violations, ACERWC recommended collaboration with neighbouring countries to combat the violations and prosecute perpetrators.¹¹³

The ACHPR also requested that States Parties include information on the situation of persons with albinism in their reports, including good practices in protecting and promoting the rights of persons with albinism. The ACHPR invited them to promote – in collaboration with relevant regional and international organisations – bilateral, regional and international initiatives aimed at protecting persons with albinism.¹¹⁴

111 See n 20 above.

112 *Ibid.*

113 *Ibid.*

114 *Ibid.*

Chapter 3: Accountability

Practice has consistently and convincingly shown that, unless individuals have an effective right to recourse to independent and impartial courts or administrative authorities when their rights have been violated, the true enjoyment of human rights remain illusory.¹¹⁵ Impunity for human rights violations sends a message that such acts are tolerated by the state, giving way to further human rights violations.¹¹⁶

The Independent Expert on Albinism and international human rights bodies including the OHCHR,¹¹⁷ the Human Rights Council¹¹⁸ and the Council's Advisory Committee,¹¹⁹ have repeatedly raised concerns about the impunity surrounding human rights violations against persons with albinism.

Among the challenges to ending impunity, the Independent Expert has highlighted the 'lack of confidence in the law enforcement or judicial system owing to fear of reprisals or stigmatization, ignorance of their rights or lack of financial resources'.¹²⁰ The Independent Expert has also identified the existence of barriers at the investigations level (ie, difficulties in finding witnesses owing to stigmatisation and discrimination, a fear of reprisal, a lack of comprehensive witness protection programmes and financial resources, and involvement of family members), barriers at the prosecution stage (ie, restrictions in the implementation of the right to a fair trial and due process, such as the lack of adequate legal representation) and other barriers at the policy and legislative levels, including the need for a clear and adequate legal framework regarding albinism that covers attacks and the effect of witchcraft on persons with albinism's human rights.¹²¹

115 See Yogi Praven, *Human Rights and Equal Opportunities* (Gyan 2006) 293.

116 See, for example, 'Report on torture and other cruel, inhuman or degrading treatment or punishment, submitted by Sir Nigel Rodley, Special Rapporteur of the Commission on Human Rights, in accordance with General Assembly resolution 53/139', A/54/426 (1 October 1999), para 48.

117 See n 4 above.

118 Human Rights Council Resolution 24/33 'Technical cooperation for the prevention of attacks against persons with albinism', A/HRC/RES/24/33 (27 September 2013).

119 See n 3 above, Human Rights Council, paras 65–66.

120 See n 4 above, para 23.

121 *Ibid.*

Reports received by the Independent Expert indicate that, even when perpetrators are successfully prosecuted, too often the sentence is not proportionate to the gravity of the crime committed.¹²²

Concerns about the lack of accountability for violations to the rights to life, security and physical integrity against persons with albinism have also been raised by UN treaty bodies and human rights experts.

In the case of Tanzania, while noting the State Party's commitment to prevent, investigate and prosecute cases of mutilations and killings of persons with albinism, the HR Committee expressed concern 'at the high number of reported killings... and the limited number of court cases and slow proceedings in this regard'.¹²³ Similar concerns were also raised by the HR Committee at 'continuing reports of trafficking in persons for labour, sexual exploitation and for body parts, particularly of persons with albinism' and the lack of accountability in Kenya.¹²⁴

The CESCR, CoAT, CoRC, CoEDAW and CoRPD have all raised similar concerns regarding lack of accountability for:

- violations of the right to non-discrimination in Burundi;¹²⁵
- the sale of children with albinism in Burundi,¹²⁶ Guinea-Bissau¹²⁷ and Tanzania;¹²⁸ and
- the murder of persons with albinism in Malawi,¹²⁹ Ethiopia,¹³⁰ Kenya¹³¹ and Tanzania.¹³²

In addition, CoEDAW has expressed concern that, in Swaziland, 'perpetrators of [the gruesome murders of women and girls with albinism,

122 *Ibid*; see n 13 above, para 22.

123 CCPR/C/TZA/CO/4, para 15.

124 CCPR/C/KEN/CO/3, para 17.

125 CESCR has expressed concerns at the lack of accountability for violation to the right to non-discrimination in the case of Burundi, E/C.12/BDI/1, paras 15–16.

126 CRC/C/BDI/CO/2, paras 33–34.

127 CRC/C/GNB/CO/2-4, paras 28–29.

128 CRC/C/OPSC/TZA/CO/1 paras 20–21; CRC/C/TZA/3-5 paras 29–21.

129 CEDAW/C/MWI/7 paras 20–21.

130 CRPD/C/ETH/CO/1, paras 21–22.

131 CRPD/C/KEN/1, paras 19–20.

132 CEDAW/C/MWI/7 paras 18–19.

whose body parts are harvested for rituals had been] prosecuted for less-serious crimes, such as causing grievous bodily harm, and therefore received lenient sentences upon conviction'.¹³³

The CoAT has also noted, with regret, the absence of comprehensive, disaggregated data on complaints, investigations, prosecutions, convictions and penalties, including in cases of violations against persons with albinism.¹³⁴

UN human rights experts have echoed these concerns. In the case of Tanzania, in a joint communication issued in August 2014, the Special Rapporteur on the independence of judges and lawyers, the Special Rapporteur on violence against women, the Special Rapporteur on torture and the Special Rapporteur on contemporary forms of racism all raised concerns at 'the lack of investigation and prosecution of such attacks [and] of due process in legal proceedings'. In March 2015, the Special Rapporteur on torture concluded that Tanzania had failed to comply with its obligations 'by failing to investigate attacks on persons with albinism'.¹³⁵



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133 CEDAW/C/SWZ/CO/1-2, paras 22–23.

134 CAT/C/BDI/2, paras 12 and 25.

135 Case No TZA 2/2014 and SR on torture conclusion in A/HRC/28/68/Add.1.

3.1 The duty to guarantee redress to persons with albinism who are victims of human rights violations

Victims of human rights violations have a right to claim redress (access to an effective remedy and adequate reparation) for harm suffered. This right is enshrined in several universal human rights instruments and has been developed in international jurisprudence.

The duty of states to guarantee an effective remedy

International human rights law and jurisprudence requires that states provide domestic remedies and bring those responsible for human rights violations to account by investigating, prosecuting and punishing such offences, and offering reparations to victims.

The right to a remedy for victims of human rights violations is guaranteed in international human rights instruments, including:

- the UDHR (Article 8);
- the ICCPR (Article 2(3));
- the CAT (Articles 4, 6, 7 and 13);
- the ICERD (Article 6);
- the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (Article 2(c));
- the Declaration on the Elimination of Violence Against Women (Article 4);
- the UN Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law; and
- the UN Principles on the Effective Prevention and Investigation of Extra-Legal, Arbitrary and Summary Executions.

In interpreting Article 2 of the ICCPR, the HR Committee has indicated that States Parties must ensure that individuals have accessible and effective remedies. It has stated that violations can be committed 'as a result of States Parties permitting or failing to take appropriate measures or to exercise due diligence to prevent, punish, investigate or redress the harm caused... by private

persons or entities'. Furthermore, it has noted that states have an obligation to investigate promptly, thoroughly and effectively through independent and impartial bodies, to ensure that those responsible are brought to justice, and offer reparation to individuals whose rights have been violated.¹³⁶

The duty to investigate and victims' right to effective remedy have also been stated by the HR Committee in its General Comment 20 in relation to the prohibition of torture,¹³⁷ as well as by CoAT in its General Comment 2,¹³⁸ CoEDAW in its General Recommendation 28 and 19,¹³⁹ and CoRC and CoEDAW in their joint General Recommendation 31 in relation to harmful practices.¹⁴⁰

CoAT, CoRC and CoEDAW have also called upon States Parties to explicitly prohibit by law and adequately sanction or criminalise these human rights violations, in accordance with the gravity of the offence and harm caused.¹⁴¹ The three committees have further stressed that the right to claim redress must be equal and accessible to all victims.¹⁴²

The duty to guarantee adequate reparation

The right of human rights violation victims to receive fair and adequate reparation for the damage suffered – including means of full rehabilitation from the state and individual perpetrators – is guaranteed in international human rights instruments, including:

- the CAT (Articles 14);
- the CRC (Article 29);
- Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children (Article 6);

¹³⁶ HR Committee General Comment 31 (2004), paras 8, 15, 16 and 18.

¹³⁷ HR Committee General Comment 20 (1992), paras 14–15.

¹³⁸ CAT, General Comment 2 (2008), para 21.

¹³⁹ CoEDAW General Recommendation 18 (2010), para 19 and General Recommendation 19 (1992), para 9.

¹⁴⁰ Joint General Recommendation No 31 of CoEDAW/General Comment 18 of CRC on harmful practices, para 13.

¹⁴¹ *Ibid*; see also n 138 above.

¹⁴² See n 140 above, para 55; CAT General Comment 3 (2012), para 5.

- the UN Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law (the ‘Basic Principles on the Right to a Remedy and Reparation’); and
- the UN Principles on the Effective Prevention and Investigation of Extra-Legal, Arbitrary and Summary Executions.

In interpreting Article 14 of the CAT, the CoAT has indicated that the right to reparation is applicable to all victims of torture and acts of cruel, inhuman or degrading treatment or punishment without discrimination of any kind, and that the term ‘victim’ also includes affected immediate family or dependants of the victim, as well as persons who have suffered harm in intervening to assist victims or to prevent victimisation. The CoAT has also emphasised the importance of victims’ participation in the redress process.¹⁴³

In its interpretation, the CoAT refers to the UN Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law. The Basic Principles indicate that reparation must be adequate, effective, prompt and proportional to the gravity of the harm suffered. It should include:

- restitution: restoration of enjoyment of human rights, family life, return to one’s place of residence, employment and return of property;
- compensation: economically assessable damage, as appropriate and proportional to the gravity of the violation and the circumstances of each case, such as:
 - physical or mental harm;
 - lost opportunities, including employment, education and social benefits;
 - material damages and loss of earnings, including loss of potential earnings;
 - moral damage;
 - costs required for legal or expert assistance, medicine and medical services; and

143 *Ibid*, CAT General Comment 3, paras 1–4.

- psychological and social services;
- rehabilitation satisfaction: medical and psychological care, as well as legal and social services; and
- guarantees of non-repetition.

In addition, the Basic Principles on the Right to a Remedy and Reparation make it clear that the state's duty is not limited to providing a remedy, but extends to ensuring individuals are aware of all available remedies. This includes dissemination of such information through public and private means.¹⁴⁴

Human rights bodies and experts have repeatedly stressed the duty of states to hold accountable those responsible for human rights violations against persons with albinism and to guarantee their right to reparation. For example, the Independent Expert on Albinism has urged states to guarantee 'immediate investigation of allegations and prosecution of alleged perpetrators, legal representation... and sensitization of the judiciary and law enforcement officers on the issue'. She has also reminded states that '[v]ictims of attacks should be provided with the appropriate remedy and redress, not only legal, but also social, psychological and medical'.¹⁴⁵

In the case of Malawi, the Independent Expert has urged the state to 'ensure that all cases of offences against persons with albinism are promptly and thoroughly investigated and documented, with a view to identifying the masterminds behind the attacks and the chain of perpetrators', and to guarantee enough resources and adequate training for police officers, magistrates, prosecutors and investigators.¹⁴⁶

OHCHR has recommended that states increase efforts to put an end to crimes affecting persons with albinism; strengthen the legal response to such crimes and bring perpetrators to justice through prompt and impartial investigations; guarantee the victims' right to justice and redress; and provide medical, psychosocial and legal support to victims of attacks.¹⁴⁷

144 Principle 12(a).

145 See n 5 above, para 46.

146 See n 13 above, para 85.

147 See n 4 above, paras 31 and 86.

Similar calls have been made by the Human Rights Council in its 24th session,¹⁴⁸ and reiterated in the report by the Human Rights Council's Advisory Committee on the situation of human rights of persons with albinism. In the latter, the Council recommended that states 'fight impunity' and 'ensure that cases of violence and attacks are prosecuted successfully', including through ensuring redress in the form of compensation and rehabilitation. It further highlighted that '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'.¹⁴⁹ Treaty bodies have also made similar recommendations.

The HR Committee has urged states to strengthen efforts to ensure timely and efficient investigations, prosecutions and public awareness-raising campaigns 'with a view to prevent future attacks'.¹⁵⁰ It has further called on states to ensure appropriate sanctions and adequate compensation to victims.¹⁵¹

The CESCR,¹⁵² CoRC¹⁵³ and CoRPD¹⁵⁴ have also all called on states to tackle the impunity of perpetrators of attacks against persons with albinism, including the sale and killings of children with albinism for ritual purposes.¹⁵⁵ They have further reiterated calls to ensure speedy and effective investigations, prosecutions and redress, including rehabilitation for victims.¹⁵⁶ While CoEDAW has also called on States Parties to ensure the effective prosecution of the perpetrators of harmful practices, including the practise of prescribing sex with girls or women with albinism as a cure for HIV, and abductions, ritual killings and attacks for purposes of witchcraft.¹⁵⁷

148 See n 118 above.

149 See n 3 above, Human Rights Council, paras 65–66.

150 Review of the fourth periodic report of Tanzania, CCPR/C/TZA/CO/4, para 15.

151 Review of the third periodic report of Kenya, in July 2012, CCPR/C/KEN/CO/3, para 17.

152 Review of the initial periodic report of Burundi, in September 2015, E/C.12/BDI/1, paras 15–16.

153 Review of Tanzania under the Optional Protocol on the sale of children, child prostitution and child pornography, in October 2008, CRC/C/GNB/CO/2-4, paras 28–29.

154 Review of Ethiopia's report, CRPD/C/ETH/CO/1, paras 21–22; review of Kenya's report, CRPD/C/KEN/1, paras 19–20.

155 Review of the initial periodic report of Burundi in September 2015 E/C.12/BDI/1, paras 15–16.

156 CRC/C/TZA/3-5 paras 29–31; CoRC review of Burundi's report CRC/C/BDI/CO/2, paras 29–34; CoRC review of the report of Guinea-Bissau CRC/C/GNB/CO/2-4, paras 28–29.

157 Review of Tanzania, CEDAW/C/TZA/7-8, paras 18–19; Malawi, CEDAW/C/MWI/7 paras 20–21 and 44–25; Swaziland, CEDAW/C/SWZ/CO/1-2, paras 22–23.

Furthermore, the CoAT emphasises the need for states to: ‘on a regular basis, collect and publish reliable and up-to-date data, disaggregated by sex, ethnicity, age, location... on the complaints... received during the reporting period, the corresponding investigations, prosecutions, convictions and penal or disciplinary sanctions imposed and any redress and compensation awarded to victims’.¹⁵⁸

Several UN Special Procedures have also made statements calling on African states to guarantee access to justice for persons with albinism victims of attacks.¹⁵⁹

The duty to protect the safety and integrity of victims of human rights violations

The Independent Expert on Albinism has raised concerns about the safety of persons with albinism who are victims of human rights violations, their families and witnesses to the attacks. The Independent Expert has noted that one of the barriers to guarantee accountability for human rights violations is the ‘fear of reprisals... [and] lack of comprehensive witness protection programmes’.¹⁶⁰ In the case of Malawi, the Independent Expert has called on the state to ‘ensure the provision of psychological, medical and legal assistance to persons with albinism who are victims of attacks, as well as to their families’.¹⁶¹

International human rights law and standards protect the rights of victims of human rights violations and their relatives – as well as witnesses – to be treated with dignity and protected from interference, intimidation or retaliation. States are therefore required to take appropriate measures to guarantee their safety, and their physical and psychological wellbeing during and after judicial, administrative or other proceedings.

In addition, states are required to make available all appropriate legal, diplomatic and consular means to ensure that victims can exercise their rights to remedy.

158 Review of the report of Burundi, CAT/C/BDI/2, paras 12 and 25.

159 See n 63 above.

160 See n 5 above, para 23.

161 See n 13 above, para 86.

International human rights standards on the treatment of victims of human rights violations are included in:

- the UN Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law;
- the Principles on the Effective Prevention and Investigation of Extra-Legal, Arbitrary and Summary Executions; and
- the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children.

In November 2015, CoEDAW called on Malawi to guarantee women and girls with albinism, who are victims of harmful practices, access to ‘adequate protections mechanisms’. The same calls were made to Tanzania in February 2016.¹⁶² In the case of Kenya, CoRC has recommended that the state ‘[c]reate shelters and redress services for victims of attacks, including health care, counselling and free legal aid’.¹⁶³

3.2 The obligation of states to guarantee redress at the African regional level

Regional human rights institutions have raised concerns at the level of impunity of violations against persons with albinism. For example, in the ACERWC report on the situation of children with albinism in temporary holding shelters in Tanzania, it was noted that the majority of attacks and killings of children with albinism end with impunity. The ACERWC reported that there had only been five known convictions out of 139 violations, including murder, mutilation and kidnapping.¹⁶⁴

The duty of states to guarantee an effective remedy at the African regional level

African regional human rights standards and jurisprudence require that states in the region provide sufficient, fair, effective and accessible remedies to

¹⁶² CEDAW/C/MWI/7, paras 20–21; CEDAW/C/TZA/7-8, paras 18–19.

¹⁶³ CRPD/C/KEN/1, paras 19–20.

¹⁶⁴ See n 20 above, pp 14, 16 and 17.

persons with albinism who have had their human rights violated. The right to such remedies are guaranteed in regional human rights instruments, including:

- the African Charter (Article 7(1)(a), Article 26);
- the Maputo Protocol (Articles 4 and 25);
- the Draft Protocol (Article 29); and
- the Principles and Guidelines on the Right to a Fair Trial and Legal Assistance in Africa (the 'Fair Trial Guidelines').

The jurisprudence of the ACHPR has clarified the duty of states to guarantee effective remedies to victims of human rights. Thus, although the right to an effective remedy for victims of human rights is not expressly recognised in the African Charter, the ACHPR has interpreted Article 7(1) to include victims' right to a remedy, noting that the protection afforded by Article 7 is not limited to the protection of the rights of arrested and detained persons, but encompasses the rights of every individual to access the relevant competent judicial bodies to have their causes heard and be granted adequate relief.¹⁶⁵

Furthermore, in *Jawara v The Gambia*,¹⁶⁶ the ACHPR set out the three required elements of a remedy: availability, effectiveness and sufficiency. A remedy is considered *available* if the petitioner can pursue it without impediment; *effective* if it offers a prospect of success; and it is found *sufficient* if it is capable of redressing the complaint.

The ACHPR's resolutions have also noted these obligations. For example, in its Resolution on the Right to a Remedy and Reparation for Women and Girls Victims of Sexual Violence, in November 2007, the ACHPR called on States Parties to the African Charter to ensure accountability of perpetrators of sexual violence.¹⁶⁷ More recently, in April 2016, in its Resolution on the fight against impunity in Africa, the ACHPR urged States Parties to:

165 ACHPR, *Zimbabwe Human Rights NGO Forum v Zimbabwe*, Communication 245/02, para 213. The Commission held further that 'where the competent authorities put obstacles on the way which prevent victims from accessing the competent tribunals, they would be held liable'. See ACHPR, 'Sudan Human Rights Organisation & Centre on Housing Rights and Evictions (COHRE)/Sudan, Communications 279/03-296/05', para 181, www.achpr.org/files/sessions/45th/comunications/279.03-296.05/achpr45_279.03_296.05_eng.pdf accessed 21 April 2017.

166 See ACHPR, 'Sir Dawda K Jawara/Gambia, 147/95-149/96', para 32, www.achpr.org/files/sessions/27th/comunications/147.95-149.96/achpr27_147.95_149.96_eng.pdf accessed 21 April 2017.

167 ACHPR, 'Resolution on the Right to a Remedy and Reparation for Women and Girls Victims of Sexual Violence' (November 2011), www.achpr.org/sessions/42nd/resolutions/111 accessed 21 April 2017.

‘[c]omply with their obligations to investigate serious human rights violations, and hold perpetrators accountable in accordance with applicable regional and international human rights standards; [t]ake the necessary legislative and other measures to put an end to impunity and ensure that all the perpetrators of serious human rights violations are prosecuted; [and] [a]dopt the necessary laws, policies and mechanisms to guarantee the rights to justice, truth and reparation for victims of serious human rights violations and international crimes’.¹⁶⁸

The ACHPR and Special Mechanisms have also made specific calls to states to fulfil their obligation to investigate the attacks against persons with albinism and bring those responsible to justice. For example, in November 2013, the ACHPR issued a resolution urging states to ‘ensure accountability through the conduct of impartial, speedy and effective investigations into attacks against persons with albinism, the prosecution of those responsible, and by ensuring that victims and members of their families have access to appropriate remedies’.¹⁶⁹

Following this resolution, the Committee for the Prevention of Torture in Africa requested that states report on the measures taken to address acts of torture or ill-treatment against persons with albinism, including attacks.¹⁷⁰

The ACHPR has also expressly referred to states’ duty to guarantee the rights of persons with albinism to remedies. The ACHPR did so in recommendations made to African states in 2013, repeated in June 2016, in relation to the ‘continuing systematic attacks and killings against persons with albinism in the Republic of Malawi’. In both cases, it called on states ‘to ensure accountability by duly investigating and bringing perpetrators of these gross human rights violations to justice, and by ensuring that victims and members of their families have access to appropriate remedies’.¹⁷¹

168 CHPR/Res.344(LVIII) 2016, 20 April 2016, www.achpr.org/sessions/58th/resolutions/344 accessed 21 April 2017.

169 Commission’s Resolution ACHPR/Res.263 (LIV) 2013: Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism, www.achpr.org/sessions/54th/resolutions/263 accessed 21 April 2017.

170 See series of questions prepared by the Committee for the Prevention of Torture in Africa to guide States Parties as they prepare periodic state reports for presentation to the ACHPR in terms of Art 62 of the Charter, ‘State Periodic Reporting under Article 62 of the African Charter on Human and Peoples’ Rights’. Indicative Questions to State Parties in respect of Art 5 of the African Charter: www.achpr.org/news/2016/06/d221 accessed 21 April 2017.

171 See n 104 above.

In addition, following reports that at least 12 persons with albinism in Tanzania, Malawi and Burundi had been victims of attacks, including children, women and older persons, the Chairpersons of the Working Group on Death Penalty, Extra-Judicial, Summary and Arbitrary Killings in Africa and the Working Group on the Rights of Older Persons and Persons with Disabilities issued a joint statement in March 2015, calling on the relevant authorities to ‘assume full responsibility, and to duly investigate and bring perpetrators of these gross human rights violations to justice; in accordance with their regional and international human rights obligations’.¹⁷²

ACERWC has also urged Tanzania to investigate allegations against some members of the police and government officials who are thought to be involved in the sale of children with albinism’s body parts, and to ensure the victims’ right to justice.¹⁷³

The duty to guarantee reparation at the African regional level

African regional human rights standards guarantee persons with albinism their right to fair, adequate and comprehensive reparation, including rehabilitation, in the following human rights instruments:

- the African Charter (Article 27);
- the Maputo Protocol (Article 4(f));
- the Fair Trial Guidelines; and
- the Guidelines and Measures for the Prohibition and Prevention of Torture and Cruel, Inhuman or Degrading Treatment or Punishment in Africa ‘Robben Island Guidelines’.

In this respect, the African Court has made specific calls to states in the region to guarantee victims of human rights violations the right to reparation. For example, in its Resolution on the Right to a Remedy and Reparation for Women and Girls Victims of Sexual Violence, it has called on States Parties

172 Joint Statement by the Working Group on Death Penalty, Extra-Judicial, Summary and Arbitrary Killings in Africa and the Working Group on the Rights of Older Persons and Persons with Disabilities in Africa, www.achpr.org/press/2015/03/d251 accessed 21 April 2017.

173 ACERWC, Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania, March 2016, www.acerwc.org/download/report-on-the-investigation-mission-on-children-with-albinism-in-tanzania/? accessed 21 April 2017.

to ‘put in place efficient and accessible reparation programmes that ensure information, rehabilitation and compensation for victims of sexual violence’. In complementing Article 4(f) of the Maputo Protocol, the Resolution further provides that, in setting up such reparation programmes and mechanisms, states must ensure that women participate in the elaboration, adoption and implementation of such programmes.¹⁷⁴

Furthermore, in a resolution issued in May 2015, encouraging states to put into practice the provisions of the Robben Island Guidelines, the ACHPR urged states to ensure ‘that all victims of torture and their dependants are offered appropriate medical care, have access to appropriate social rehabilitation and are provided with adequate compensation’ and ‘rehabilitation for victims of torture, in particular through the adoption and implementation of national strategies’.¹⁷⁵

In relation to the right to reparation and rehabilitation of persons with albinism, ACERWC has urged Tanzania to ensure children with albinism have a ‘right to justice and redress’ and that victims of attacks should be provided with ‘medical, psychosocial and legal support’.¹⁷⁶

The duty of states to protect the safety and integrity of victims of human rights violations at the African regional level

States’ duty to protect victims’ safety and integrity is stated in the following African regional human rights standards:

- the Fair Trial Guidelines; and
- the Robben Island Guidelines.

However, human rights mechanisms in the region have so far not stressed the need to guarantee the safety and integrity of persons with albinism who are victims of human rights violations, the relatives of persons with albinism, as well as witnesses to the attacks. Stressing this need in their recommendations to states would be an important step in addressing the barriers which prevent persons with albinism from accessing justice.

¹⁷⁴ See n 167 above.

¹⁷⁵ ACHPR, ‘Resolution on the Right to Rehabilitation for Victims of Torture - ACHPR/Res.303 (LVI) 2015’ www.achpr.org/sessions/56th/resolutions/303 accessed 21 April 2017.

¹⁷⁶ See n 20 above.

Chapter 4: Equality and non-discrimination

Discrimination against persons with albinism has been reported around the world. Its impact in preventing their enjoyment of the full range of human rights they are entitled to has been the subject of serious concern of several human rights bodies, including the Human Rights Council,¹⁷⁷ the OHCHR,¹⁷⁸ treaty bodies and international human rights experts. The Working Group of Experts on People of African Descent has identified the prevalence of discrimination against persons with albinism in Africa as one of the ‘indicative examples of racial discrimination in Africa... which adversely affected the development of the continent’.¹⁷⁹

As noted by the Independent Expert on Albinism, persons with albinism (particularly women and children) and their families routinely face prejudice and stigmatisation, and are exposed to multiple and intersecting forms of discrimination, including discrimination based on their colour, gender, age and visual impairment.¹⁸⁰ The Independent Expert has cited discrimination and stigmatisation as ‘one of the main barriers to the implementation of the human rights of persons with albinism’, which in Sub-Saharan Africa can range from bullying at school to more severe forms of discrimination, such as ostracism of entire families, infanticide, physical threats and attacks.¹⁸¹

The OHCHR has noted the impact of such discrimination in preventing persons with albinism from fulfilling other human rights, such as their right to education, the right to the highest attainable standard of health and their right to work. As stated by the OHCHR:

‘these forms of discrimination are interrelated, and the principle of the indivisibility and interdependence of human rights should be highlighted. The right to education of persons with albinism, for instance, is adversely affected due to the visual impairment they suffer. A poor education, in turn,

177 See n 3 above, Human Rights Council, paras 26–28.

178 See n 4 above, paras 64–76.

179 Report of the Working Group of Experts on People of African Descent on its 15th and 16th sessions, A/HRC/30/56, 6 August 2015, para 23.

180 See n 5 above, para 41.

181 See n 5 above, paras 29–31.

affects the right to an adequate standard of living, consigning many persons with albinism to poverty.¹⁸²

Concerns about the stigmatisation and discrimination against persons with albinism on the basis of disability, age, gender and/or colour, as well as about the interrelated forms of discrimination against them, have also been raised by the HR Committee,¹⁸³ CESCR,¹⁸⁴ CoRC, CoEDAW, CoRPD and CERD in relation to Burundi, the Democratic Republic of the Congo, Ethiopia, South Africa and Tanzania.

For example, in its review of the second periodic report of Burundi in September 2010, CoRC expressed concern that de facto discrimination of children prevails and is tolerated in the State Party, in particular against children with albinism.¹⁸⁵

CoEDAW expressed concern at ‘the lack of adequate protection and assistance for disadvantaged groups of women such as... women [with albinism]’ in the Democratic Republic of the Congo, and recommended that the State Party provide protection and assistance to women who face multiple forms of discrimination, including women with albinism.¹⁸⁶

Concerns about discrimination that persons with albinism face on the basis of their visual impairment were raised by CoRPD in its review of Ethiopia initial report in August 2016.

In addition, CERD has raised the issue of discrimination of persons with albinism on the basis of colour in the concluding observations of the combined fourth to eighth periodic reports of South Africa in August 2016.¹⁸⁷

Human rights experts and special rapporteurs have echoed these concerns, including the UN Independent Expert on Minority Issues, the Special Rapporteur on racism, the Special Rapporteur on the right to health and the Special Rapporteur on the right to education.¹⁸⁸ In a statement, the Independent Expert on Minority Issues stated that one of the major challenges

182 See n 4 above, para 71.

183 CCPR/C/BDI/CO/2.

184 E/C.12/COD/CO/4, para 19; E/C.12/TZA/CO/1-3, para 5; E/C.12/BDI/1, paras 15–16.

185 CRC/C/BDI/CO/2, paras 29–30.

186 CEDAW/C/COD/6-7 paras 35–36.

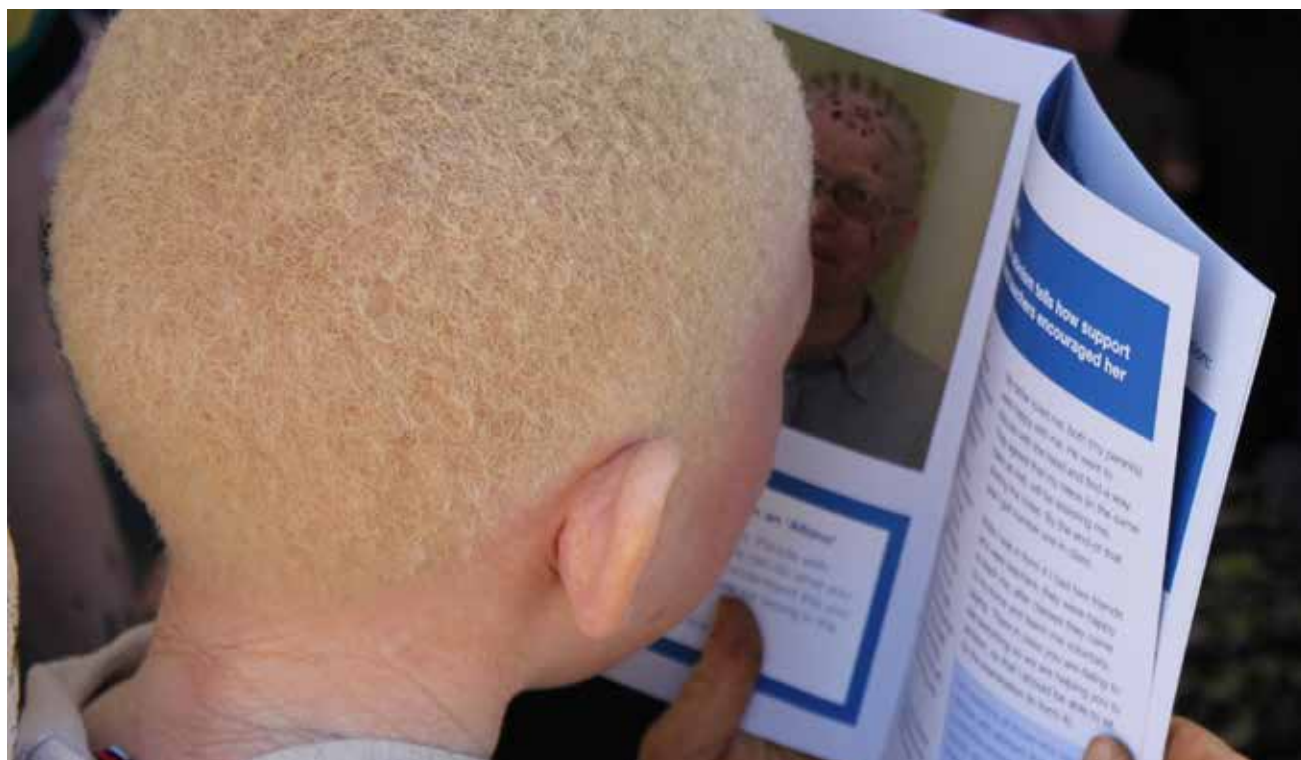
187 CERD/C/ZAF/CO/4-8, para 20–21.

188 See n 63 above.

for persons with albinism is that they are often rejected and abandoned by their own families under societal pressure. She also noted that, while persons with albinism ‘do not fall under the internationally accepted definition of minorities... their stigma, the lifelong social exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour’.¹⁸⁹

In addition, the UN Special Rapporteur on racism urged states to ensure that persons with albinism enjoy their human rights without distinction and have the same opportunities as anyone else, stating that ‘[r]egardless of whether one has a lighter or a darker skin compared to the majority population in a country or a community, everyone is entitled to the same rights, dignity and treatment’.¹⁹⁰

States have also raised concern regarding discrimination against persons with albinism during the UPR. For example, in April 2014, during the UPR of the Democratic Republic of the Congo, Guatemala made the following recommendation, which had the support of the country: ‘To combat all forms of discrimination against persons with albinism.’¹⁹¹



Child with albinism holds an information booklet close to his eyes to read. © Private

189 *Ibid.*

190 *Ibid.*

191 A/HRC/27/5, recommendation 134.47.

4.1 The duty of states to guarantee the right to equality and non-discrimination in international human rights standards

The right to equality and non-discrimination is enshrined in international human rights standards, including:

- the UDHR (Article 2);
- the ICCPR (Articles 2.1, 3, 14, 24.1 and 26);
- the ICESCR (Articles 2.2 and 3);
- the CRPD (Article 5);
- the ICERD; and
- the CEDAW.

The HR Committee, CESCR, ICERD and CEDAW defined ‘discrimination’ as any distinction, exclusion, restriction or preference that is based on any ground, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.¹⁹²

The duty to address multiple forms of discrimination

International human rights bodies have stressed the need to give special attention to multiple forms of discrimination. For example, CESCR notes that ‘some individuals or groups of individuals face discrimination on more than one of the prohibited grounds’ and has indicated that ‘such cumulative discrimination has a unique and specific impact on individuals and merits particular consideration and remedying’.¹⁹³

The CESCR and CoRC, in relation to gender and disabilities, have noted that ‘the double discrimination suffered by women [and girls] with disabilities is often neglected’ and have urged States Parties ‘to address the situation

¹⁹² Art 1.1 of CERD; Art 1 of the CEDAW; HRC General Comment 18 (1998) para 7; CESCR General Comment 20 (2009) para 7.

¹⁹³ CESCR General Comment 20 (2009).

of women with disabilities, with high priority being given in future to the implementation of economic, social and cultural rights-related programmes'.¹⁹⁴ CoRC has called on States Parties to 'pay particular attention to girls with disabilities by taking the necessary measures, and when needed extra measures, in order to ensure that they are well protected, have access to all services, and are fully included in society'.¹⁹⁵

The effect of multiple forms of discrimination on persons with disabilities has been stressed in the preamble of the CRPD, which expressly mentions 'the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status'.

Relatedly, the Special Rapporteur on violence against women noted that gender-based discrimination and violence against women, including witchcraft-related killings perpetrated against women and girls with albinism, is deeply rooted in multiple layers of discrimination and inequality. As these layers of discrimination intersect, violence against women intensifies, which makes addressing systematic discrimination and marginalisation crucial to ending violence against women.¹⁹⁶

The duty to take measures to address discrimination, in consultation with the persons and groups affected

The obligation to protect persons and groups' right to equality and non-discrimination requires states to take concrete, deliberate and targeted measures. This should include legislation prohibiting discrimination on any grounds, as well policies, plans and strategies to ensure that formal (in legislation and policies) and substantive (in practice) discrimination, direct and indirect, by both state actors and non-state actors, is eliminated.¹⁹⁷ States violate the right to equality and non-discrimination by action or omission.¹⁹⁸

194 CESCR General Comment 5 (1994).

195 CoRC General Comment 9 (2006).

196 A/HRC/17/26 and A/HRC/20/16, paras 14 and 16.

197 HRC General Comment 18 (1998); HRC General Comment 28 (2000); CESCR General Comment 5 (1994); CESCR General Comment 20 (2009); CoEDAW General Recommendation 28 (2010); CoRC General Comment 9 (2006).

198 CESCR General Comment 20 (2009), para 14.

International standards require that such measures should be selected and implemented on the basis of close consultation with, and involvement of, representative groups of the persons concerned.¹⁹⁹ This, as stated by CESCR, is particularly important in the case of individuals and groups who may be distinguished by one or more of the prohibited grounds.²⁰⁰

The issue of consultation was raised by the Independent Expert on Albinism in the case of Malawi, where she called on the government to ‘ensure the full participation of persons with albinism in all decisions and measures taken for the full implementation and enjoyment of their rights’.²⁰¹

International standards developed by international human rights bodies, treaty bodies and special procedures indicate that, in order to fully protect the right to equality and non-discrimination, states must:

- take legislative measures;
- implement plans of action, human rights education and training; and
- evaluate the extent of the problem and assess the impact of the measures taken.

DUTY TO TAKE POLICY AND LEGISLATIVE MEASURES

Human rights law requires states to take effective measures to amend, rescind or nullify any laws and regulations that create or perpetuate discrimination. It also requires states to prohibit and bring to an end – by all appropriate means, including legislation – discrimination by any persons, group or organisation.²⁰²

In this context, treaty bodies have recommended African states to adopt, review or implement legislation to tackle discrimination against persons with albinism.

For example, in its review of the initial to third periodic reports of Tanzania, CESCR expressed concern that ‘the State Party has not yet adopted a comprehensive anti-discrimination bill [and that] persons with albinism face social stigma and discrimination, despite policy and legislative measures taken by the State Party’. It recommended that Tanzania adopt a ‘comprehensive

199 CESCR General Comment 5 (1999).

200 CESCR General Comment 20, para 36.

201 See n 13 above, para 93.

202 Art 2 of CERD; Arts 2 and 3 of CEDAW; Arts 5, 6 and 7 of CRPD.

anti-discrimination bill [and] take steps to combat and prevent discrimination and societal stigma, in particular against... persons with albinism'.²⁰³

The CoRC has made similar recommendations to Tanzania. In its review of the third to fifth combined periodic reports, while noting the anti-discriminatory provisions contained in the laws of the State Party, it expressed concern that 'discrimination against certain groups of children still exists, in law and in practice, particularly against... children with albinism' and that 'almost no systematic measures have been undertaken, including with religious leaders, opinion makers and the mass media, to combat and change the discriminatory laws, attitudes and practices'. The CoRC urged the State Party 'to continue revising all its legislation'.²⁰⁴

DUTY TO IMPLEMENT PLANS OF ACTION, INCLUDING HUMAN RIGHTS EDUCATION AND TRAINING

Among the measures that states must take to address discrimination, international human rights standards have highlighted the need to implement plans of action and human rights education and training. For example, CESCR has indicated that, in order to guarantee the right to equality and non-discrimination, public and private institutions are required to develop plans of action, and the state must conduct human rights education and training programmes for public officials, including judges and candidates for judicial appointments.²⁰⁵ Additionally, it recommended that teaching on the principles of equality and nondiscrimination is integrated in formal and non-formal inclusive and multicultural education.²⁰⁶

Several human rights bodies have also recommended that, where discrimination against persons with albinism is prevalent, states in Africa should implement plans of action, as well as public awareness campaigns and education programmes. For example, the OHCHR has recommended states to:

- address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating superstition and stigma vis-à-vis albinism, including through education and awareness-raising campaigns;

203 E/C.12/TZA/CO/1-3, para 5.

204 CRC/C/TZA/3-5 paras 25–26.

205 CESCR General Comment 20 (2009) and CoRC General Comment 9 (2006).

206 *Ibid*, para 38.

- adopt a comprehensive strategy to eradicate violence and discriminatory practices affecting persons with albinism;
- develop national institutional mechanisms for the protection and promotion of rights of persons with albinism, including by ensuring that national human rights institutions effectively address the human rights situation of persons with albinism; and
- integrate the situation of persons with albinism into human rights national action plans or action plans to combat discrimination.²⁰⁷

In addition, the Human Rights Council has urged states to take ‘effective measures to eliminate any type of discrimination against persons with albinism, and to accelerate education and public awareness-raising activities.’²⁰⁸ The Council’s Advisory Committee stated the necessity of a multipronged and holistic approach in response to violence and discrimination against persons with albinism.²⁰⁹

The Advisory Committee has indicated that states must launch and sustain education and awareness-raising campaigns aimed at combating prejudice, superstition, misconception and stigma against persons with albinism, gradually targeting 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. Furthermore, it has highlighted that states must include standardised courses to instruct people on the rights of persons with albinism in their educational curricula.²¹⁰

The necessity of implementing such plans has also been highlighted by treaty bodies such as CESCR, CoRC, CoRPD, CoAT and CERD.

For example, in the review of the combined second to fourth periodic reports of the Democratic Republic of the Congo in November 2009, CESCR urged the State Party to:

‘apply itself to combating the discrimination against persons with albinism which takes place in the State party, and to this end, to establish close cooperation with and financially support the work of the associations

207 See n 4 above.

208 See n 44 above.

209 See n 3 above, para 65.

210 See n 3, para 68.

promoting and protecting the rights of persons with albinism, and conduct awareness-raising campaigns to combat superstitious beliefs which are detrimental to their well-being'.²¹¹

CoRC made similar recommendations with regard to Tanzania, as it had previously in Burundi.²¹²

In addition, to address concerns about discrimination against persons with albinism on the basis of impairment, CoRPD has urged Ethiopia to 'adopt a national disability awareness strategy to effectively prevent and combat disability stereotypes, as well as discrimination'.²¹³

'Go buy glasses'

In August 2016, I was travelling to Arusha by plane. After I finished with the formalities, I entered the bus which was to take us to the plane. I started reading my WhatsApp messages on my mobile. Suddenly, a man aged around 55 started laughing at me because I needed the screen so close to my eyes to see. Nearly all people who were on the bus started laughing to themselves as well. Then he said harshly, 'you go find some glasses'. When I did not react he continued, 'why don't you go find some glasses and then read it?' The others laughed out loud this time. Then I stopped reading and turned to them with these words: 'would a 36-year-old man like me read like this if glasses actually worked for me? Do you think that I am reading like this because I can't afford some glasses? Do you think that laughing at me like that could actually help draw attention to the risks I am taking?' Then I proceeded to explain to them that a consequence of albinism is that medical glasses rarely work for persons with albinism, and that they should be more courteous and patient with persons with albinism regarding this matter. When I finished my two-minute talk, they apologised and asked for my forgiveness because they did not have the right information before.

* Houetehou C Franck Hounsa, Founder of Divine Connexion Worldwide, Benin

211 E/C.12/COD/CO/4, para 19.

212 CRC/C/TZA/3-5 paras 25–26; CRC/C/BDI/CO/2, paras 29–30.

213 CRPD/C/ETH/CO/1, paras 17–18.

DUTY OF STATES TO EVALUATE THE PROBLEM AND ASSESS THE IMPACT OF THE MEASURES TAKEN

When implementing measures to fulfil the right of persons with albinism to non-discrimination, international standards require that states evaluate and produce data to analyse the extent of the problem in order to determine what measures and resources are required. For example, CESCR indicated that when addressing discrimination against persons with disabilities, states need to:

- ascertain, through regular monitoring, the nature and scope of the problems existing within the state;
- adopt appropriately tailored policies and programmes to respond to the requirements identified; and
- make appropriate budgetary provisions or, where necessary, seek international cooperation and assistance.²¹⁴

Similarly, CoRC, focusing on the rights of children with disabilities, stated that, in order to fulfil their obligations, it is necessary for States Parties to ‘set up and develop mechanisms for collecting data which are accurate, standardized and allow disaggregation, and which reflect the actual situation of children with disabilities’. CoRC notes that the importance of this issue is often overlooked and not viewed as a priority, despite the fact that it has an impact not only on the measures that need to be taken in terms of prevention, but also on the distribution of very valuable resources needed to fund programmes.²¹⁵

CoEDAW has stressed states’ responsibility ‘to create and continuously improve statistical databases and the analysis of all forms of discrimination against women in general and against women belonging to specific vulnerable groups in particular’.²¹⁶

In addition, international standards require that states carry out regular assessments to guarantee the effectiveness of the measures taken. Thus, CESCR has stressed that monitoring should assess both the steps taken and the results achieved in the elimination of discrimination and recommended that ‘national strategies, policies and plans... use appropriate indicators

²¹⁴ CESCR General Comment 5 (1999), para 13.

²¹⁵ CoRC General Comment 9 (2006).

²¹⁶ CoEDAW General Recommendation 28, para 10.

and benchmarks, disaggregated on the basis of the prohibited grounds of discrimination'.²¹⁷

Equally, when referring to the rights of children with disabilities, CoRC has stressed the need for comprehensive plans and strategies with measurable outcomes.²¹⁸

Regarding persons with albinism in Africa, there is a conspicuous lack of data to determine the numbers of persons with albinism and their situation, including in relation to the human rights violations against them and the response by the authorities. This issue has been highlighted by the OHCHR,²¹⁹ Human Rights Council Expert Committee²²⁰ and Independent Expert on Albinism.²²¹

In the case of Malawi, the Independent Expert has recommended that, as part of data collection on persons with disability, the government insert the variable of persons with albinism in the next national census, and ensure that all data collected relating to the situation of persons with albinism is disaggregated at a minimum by sex and age. In addition, she has called on the authorities to provide adequate safeguards for all data amassed on persons with albinism to ensure the protection of their right to privacy and to prevent misuse of data for attacks, discrimination or other illicit acts.²²²

The duty of states to guarantee equality and non-discrimination in the enjoyment of economic, social and cultural rights

Nondiscrimination, together with equality before the law and equal protection of the law without any discrimination, constitutes a basic and general cross-cutting principle relating to the protection of human rights. States' obligation to respect, protect and fulfil the right to non-discrimination is essential to the enjoyment of economic, social and cultural rights.

217 CESCR General Comment 20, para 36.

218 CoRC General Comment 9 (2006).

219 See n 4 above.

220 See n 3 above, Human Rights Council.

221 See n 5 above.

222 See n 13 above, para 82.

Violations to the right of non-discrimination and equality prevent individuals and groups, including persons with albinism, from exercising other human rights enshrined in international and regional human rights standards, including the right to work, and to just and favourable conditions of work;²²³ the right to social security;²²⁴ the right to an adequate standard of living, including adequate food, clothing and housing, and to the continuous improvement of living conditions;²²⁵ the right to education;²²⁶ and the right to the highest attainable standard of health.²²⁷

The link between discrimination and the enjoyment of economic, social and cultural rights has been noted by several human rights bodies. For example, CESCR has highlighted this link in relation to discrimination on the basis of disability. It has noted that:

‘through neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation, persons with disabilities have very often been prevented from exercising their economic, social or cultural rights on an equal basis with persons without disabilities. The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing... and access to public services’.²²⁸

CoRC has also expressed concerns regarding this issue. It has noted that discrimination in service provision excludes children with disabilities from education, and denies them access to quality health and social services. The lack of appropriate education and vocational training discriminates against them by denying them job opportunities in the future.²²⁹

The OHCHR has raised similar concerns in relation to violations of the right to equality and non-discrimination of persons with albinism and the impact

223 Arts 6 and 7 of the ICESCR; Art 11 of the CEDAW; Art 27 of the CRPD; Art 15 of the African Charter; Art 13 of the Maputo Protocol; Art 15 of the Draft Protocol.

224 Arts 22 and 25 of the UDHR; Art 9 of the ICESCR; Art 5 (e) (iv) of the ICERD; Art 11, para 1 (e) of the CEDAW; Art 26 of the CRC; Art 27 of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.

225 Art 24 of the UDHR; Art 11 of the ICESCR; Art 28 of the CRPD; Art 14 of the CEDAW; Art 27 of the CRC.

226 Arts 13 and 14 of the ICESCR; Arts 23 and 28 of the CRC; Art 10 of CEDAW; Art 24 of the CRPD; Art 17 of the African Charter; Art 11 of the ACRWC; Art 12 of the Maputo Protocol; Art 12 of the Draft Protocol.

227 Art 12 of the ICESCR; Art 12 of the CEDAW; Art 25 of the CRPD; Arts 23 and 24 of the CRC; Art 16 of the African Charter; Art 14 of the ACRWC; Art 14 of the Maputo Protocol; Art 13 of the Draft Protocol.

228 See CESCR General Comment 5 (1995), para 15.

229 CoRC General Comment 9 (2006).

of such discrimination in preventing them from fulfilling other human rights, such as their right to education, their right to the highest attainable standard of health and their right to work. In this context, the OHCHR has urged states to ensure that persons with albinism have adequate access to healthcare, social services, employment and education.²³⁰

The Human Rights Council's Advisory Committee has also stressed the need to address the lack of access of persons with albinism to economic and social rights and stated that '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'.²³¹

Concerns about the discrimination faced by persons with albinism and the impact on their right to education and health have also been raised by the UN Independent Expert on minority issues, the Special Rapporteur on racism, the Special Rapporteur on the right to health and the Special Rapporteur on the right to education. In particular, the Special Rapporteur on the right to health has noted that persons with albinism 'often do not receive the necessary special attention, health care or treatment that corresponds to their health needs'.²³²

DUTY TO PRIORITISE ACCESS TO ECONOMIC, SOCIAL AND CULTURAL RIGHTS FOR THE MOST VULNERABLE AND MARGINALISED

When taking measures towards the progressive realisation of economic, social and cultural rights – in particular the right to health, education, decent work and adequate housing – states are required to prioritise access to the most vulnerable or marginalised.²³³

In this context, where appropriate, states are required to adopt temporary special measures. As noted by the HR Committee:

230 See n 4 above, para 71.

231 *Ibid.*

232 See n 63 above.

233 CESCR General Comment 13 (1999), General Comment 14, General Comment 18 (2005) and General Comment 4 (1992).

‘the principle of equality sometimes requires States to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination... 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.’²³⁴

CESCR has also indicated that:

‘to eliminate substantive discrimination, States parties may be, and in some cases are, under an obligation to adopt special measures to attenuate or suppress conditions that perpetuate discrimination. Such measures are legitimate to the extent that they represent reasonable, objective and proportional means to redress de facto discrimination and are discontinued when substantive equality has been sustainably achieved. Such positive measures may exceptionally, however, need to be of a permanent nature, such as... reasonable accommodation of persons with sensory impairments in accessing health-care facilities.’²³⁵

In relation to persons with disabilities, CESCR has indicated that states have an obligation to take positive action to reduce structural disadvantages and to give them appropriate preferential treatment in order to achieve the objectives of full participation and equality within society: ‘This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.’²³⁶

In relation to persons with albinism, the Human Rights Council’s Advisory Committee has noted that resources, both financial and otherwise, are important for the success of any effort to improve the lives of persons with albinism, and has stated that ‘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

234 HR Committee General Comment 18 (1989), para 10.

235 CESCR General Comment 20 (2009), paras 8–9.

236 CESCR General Comment 5 (1999).

environment conducive to respect for their rights and dignity'.²³⁷ Moreover, it urges African states to 'evaluate the needs of persons with albinism and plan for the basic social services to which they are entitled'.²³⁸

Several international human rights bodies have also urged states in the region to guarantee persons with albinism access to economic and social rights. For example, the HR Committee and CESCR have urged Burundi²³⁹ and Tanzania²⁴⁰ to guarantee persons with albinism access to healthcare, social services and education.

Likewise, CoEDAW has urged the Democratic Republic of the Congo to provide protection and assistance to women who face multiple forms of discrimination, including those with albinism, and ensure that 'these women have access, without discrimination, to health care, education, clean water, sanitation and income-generating activities'.²⁴¹

International human rights bodies have also made specific recommendations in relation to the duties of states to guarantee persons with disabilities, including persons with albinism, equal access to:

- the right to the highest attainable standard of mental and physical health;
- the right to education;
- the right to work; and
- the right to social security.

DUTY TO GUARANTEE EQUAL ACCESS TO THE HIGHEST STANDARD OF MENTAL AND PHYSICAL HEALTH

The Special Rapporteur on the right to health has urged states, in particular Tanzania, to assess the needs of persons with albinism to increase their life chances and ensure their enjoyment of the right to physical and mental health.²⁴²

237 See n 3 above, para 71.

238 *Ibid*, para 66.

239 CCPR/C/BDI/CO/2.

240 E/C.12/TZA/CO/1-3, para 5.

241 CEDAW/C/COD/6-7 paras 35–36.

242 See n 63 above.

In guaranteeing the right to health, states have an immediate obligation to ensure that health facilities, goods, services and information about them are:

- accessible to everyone without discrimination, especially those most vulnerable and marginalised;
- within safe physical reach for all sections of the population, including in rural areas and for persons with disabilities; and
- affordable.²⁴³

In addition, in relation to accessibility for persons with disabilities, including those with albinism, CESCR has indicated that this right also implies the right to have access to, and to benefit from, those medical and social services that enable persons with disabilities to become independent, prevent further disabilities and support their social integration.²⁴⁴

In the case of persons with albinism, access to the right to health must include access to skin cancer preventative medicine (ie, affordable suitable sunscreen), access to information on skin cancer prevention, affordable and accessible skin cancer treatments, and access to glasses and other visual aids and adaptive devices, such as magnifying glasses.

In this regard, the Human Rights Council's Advisory Committee, noting that persons with albinism have particular needs, has urged states that '[i]n addition to issues pertaining to the rights to life and security of [persons with albinism, states should] address their special health needs, particularly in the area of skin cancer prevention'.²⁴⁵

Furthermore, the Independent Expert on Albinism urged states to ensure that fundamental goods and services for persons with albinism are provided in a reliable manner, in line with the principles of availability, accessibility, quality and affordability.²⁴⁶ She has urged Malawi to include sunscreen on the list of essential medicines, making it available free of charge and distributed regularly to all communities, and to provide free access to dermatological care to ensure that skin cancer is detected early and treatment is readily provided. She has also urged Malawi to give free access to clinical assessments by

243 CESCR General Comment 14 (2000) para 12.

244 CESCR General Comment 5 (1999), para 34.

245 See n 3 above, para 60.

246 See www.who.int/mediacentre/factsheets/fs323_en.pdf accessed 21 April 2017.

ophthalmologists and optometrists, along with glasses and adaptive devices. She has called on the state to use mobile clinics to ensure that persons with albinism in remote areas can be screened on a regular basis for skin cancer and vision assessment and care.²⁴⁷

In addition, she has called on the state to provide training and make information on albinism and related health issues readily available to health workers and mothers of children with albinism at an early stage, to ensure that adequate protection is provided to their babies.²⁴⁸

DUTY TO GUARANTEE EQUAL ACCESS TO THE RIGHT TO EDUCATION

The Human Rights Council's Advisory Committee has stressed the need for states to address the special needs of persons with albinism in terms of education due to their poor eyesight.²⁴⁹

In this regard, CESCR has noted that '[s]chool programmes in many countries... recognize that persons with disabilities can best be educated within the general education system' and has thus recommended states to ensure that 'teachers are trained to educate children with disabilities within regular schools and that the necessary equipment and support are available to bring persons with disabilities up to the same level of education as their nondisabled peers'.²⁵⁰

The Special Rapporteur on the right to education has noted that 'there are now several educational methodologies and guides to teachers that have proved efficient in the course of educating children with albinism' and has recommended that they must be 'widely promoted and applied'. He also noted that '[e]asy tools like re-organizing the classroom so children with albinism sit in the front or shifting to larger prints can bring significant improvement and reduce drop-out rate'.²⁵¹

The Independent Expert on Albinism has also advocated for inclusive education in Malawi. She urged the state to provide the necessary resources for special needs educators to regularly access all schools where there are children with albinism, and to ensure the availability of low-vision and adaptive

247 See n 13 above, paras 71–75.

248 *Ibid.*

249 See n 3 above, para 60.

250 CESCR General Comment 5 (1999), para 35.

251 *Ibid.*

devices, as well as large-print materials in all schools as a measure of reasonable accommodation.²⁵²

In addition, she has called for systematic teacher training around children with albinism's particular needs, including that they be seated in the front row of classrooms, that they be provided with teachers' notes, that large-print writing should be used on the chalkboard or markerboard, and that awareness on albinism should be raised among other teachers and students.²⁵³

'I always had to ask for materials'

I learnt about my albinism when I was in standard eight. Until then, I just knew that I was short-sighted and had to keep out of the sun because it hurt my skin. I grew up in a particularly hot area; this caused me problems and meant that I could not go out to play with my friends. I now use sun cream, an umbrella, hats and sunglasses to protect myself from the sun.

I always sat at the front of the class because of my poor eyesight; students made fun of me and called me 'teacher's pet'. I was provided with large print papers for exams but always had to ask for materials, they were never just given. Even at college, some of the lecturers are not supportive and some students won't let me sit at the front.

Being an advocate for the local Association of Persons with Albinism in Malawi (APAM) has helped me realise I am not alone and not the only person going through these struggles.^v

* Tumeliwa Mphepho, Association of Persons with Albinism in Malawi.

v Interview conducted by Dr Patricia Lund, <http://blogs.coventry.ac.uk/dash-to-africa/category/achievers-with-albinism> last accessed 21 April 2017.

252 See n 13 above, para 92.

253 CESCR General Comment 5 (1999) para 39.

DUTY TO GUARANTEE EQUAL ACCESS TO THE RIGHT TO WORK

The right to work is particularly important for persons with albinism in terms of access to an adequate standard of living, but also because of the implications for their health. As noted by the Independent Expert on Albinism, persons with albinism who work outdoors, such as farmers or traders, are at particular risk of developing skin cancer.²⁵⁴

For persons with disabilities to have equal opportunities for productive and gainful employment, CESCR recommends that ‘governments... develop policies which promote and regulate flexible and alternative work arrangements that reasonably accommodate the needs of [workers with disabilities]’.²⁵⁵ In the case of persons with albinism, this should include provision to be able to carry out work indoors.

CESCR has also recommended that ‘technical and vocational guidance and training programmes reflect the needs of all persons with disabilities, take place in integrated settings, and are planned and implemented with the full involvement of representatives of persons with disabilities’.²⁵⁶

DUTY TO GUARANTEE EQUAL ACCESS TO THE RIGHT TO SOCIAL SECURITY

The Independent Expert on Albinism has noted that access to government social welfare programmes and other benefits for persons with albinism is necessary to ensure that they are not seen as burdens by their relatives; a factor that could contribute to the abandonment of children, ostracism of family members and the sale of persons with albinism by their own families.²⁵⁷

In relation to social security and income maintenance schemes for persons with disabilities, CESCR has recommended that ‘support should reflect the special needs for assistance and other expenses often associated with disability’. In addition, CESCR has stated that, as far as possible, the support provided should also cover individuals who undertake the care of a person with disabilities (these individuals are overwhelmingly female). Such persons,

254 See n 5 above, para 38.

255 CESCR General Comment 5 (1999), paras 21–22.

256 *Ibid*, para 24.

257 See n 13 above, para 65.

including members of the families of persons with disabilities, are often in urgent need of financial support because of their assistance role.²⁵⁸

CESCR has also stressed that institutionalisation of persons with disabilities, unless rendered necessary for other reasons, cannot be regarded as an adequate substitute for the social security and income support rights of such persons, and has recommended that ‘everything possible should be done to enable such persons, when they so wish, to live with their families’.²⁵⁹

DUTY TO GUARANTEE EQUAL ACCESS TO AN ADEQUATE STANDARD OF LIVING

In order to guarantee an adequate standard of living for persons with disabilities, CESCR indicates that states need to ensure that they have access to adequate food, accessible housing and other basic material needs. In the case of persons with albinism, as noted by the Independent Expert on Albinism, reasonable accommodation²⁶⁰ should include access to adaptive devices.²⁶¹

CESCR also notes that states must ensure that ‘support services, including assistive devices [are available] for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.’²⁶² In the case of persons with albinism, this should also include access to glasses and other sight aid devices.

Additionally, CESCR has stressed the importance of the right to adequate clothing for persons with disabilities who have particular clothing needs, so as to enable them to function fully and effectively in society.²⁶³ In the case of persons with albinism, this should include access to adequate clothing in order to protect themselves from the sun, and thereby reduce the risk of skin cancer.

258 CESCR General Comment 5 (1999), para 28.

259 *Ibid*, paras 29–31.

260 The right to reasonable accommodation is enshrined in Art 5.3 of the CRPD. The CRPD defines reasonable accommodation as ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’.

261 See n 13 above, para 73.

262 CESCR General Comment 5 (1999), para 33.

263 *Ibid*.

4.2 The duty of states to guarantee the right to equality and non-discrimination at the African regional level

The right to equality and non-discrimination is enshrined in regional human rights law and standards, including:

- the African Charter (Articles 2, 3 and 18.3);
- the ACRWC (Article 3);
- the Maputo Protocol (Article 2);
- the Draft Protocol (Articles 3 and 8 (2)); and
- the Pretoria Declaration of Economic Social and Cultural Rights (Article 4).

Similar to international human rights standards, regional standards also require that states take measures to tackle discrimination and guarantee equality by state actors, persons, organisations or private enterprises, including:

- enact, review and/or implement legislative measures prohibiting and curbing discrimination; and
- take other measures to modify or abolish existing discriminatory policies, regulations and customs, including corrective and positive actions and public education and communication strategies.

Both the ACHPR and ACERWC have urged states in the region to abide by their duty and take measures to address discrimination.

For example, the ACHPR has urged states ‘to take effective measures to eliminate all forms of discrimination against persons with albinism, and to increase education and public awareness-raising activities’.²⁶⁴

In addition, ACERWC has encouraged Tanzania to take legislative and administrative measures, including reviewing legislative instruments and policies, and to adopt a comprehensive strategy to eliminate discrimination against children with albinism.²⁶⁵

²⁶⁴ See n 169 above, para 3.

²⁶⁵ CERWC, *Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania*, March 2016, p 17, www.acerwc.org/download/report-on-the-investigation-mission-on-children-with-albinism-in-tanzania/? accessed 21 April 2017.

Furthermore, in relation to concerns about the lack of discrimination and adequate access to appropriate healthcare for children with albinism living in shelters, ACERWC has recommended that the government support and finance, to the maximum available resources, the production and provision of locally produced (or facilitate importation of) affordable, duty-free sun protective gear and sunscreen lotions in collaboration with civil society organisations and other stakeholders.²⁶⁶

In relation to discrimination against children with albinism and the impact on the right to education, ACERWC notes that health challenges such as visual impairments are a deterrent to some children pursuing their education. It has therefore recommended that children with albinism should be provided with large print and assistive devices. It has also recommended that the government strengthen its work on creating the right understanding of the disability of albinism in order to better accommodate students.²⁶⁷

²⁶⁶ *Ibid* 8.

²⁶⁷ *Ibid* 14.

Chapter 5: Conclusions and recommendations

5.1 Conclusions

Since 2006, hundreds of persons with albinism in Sub-Saharan Africa, particularly women and children, have reportedly been killed and mutilated in order to sell their body parts to be used in witchcraft rituals. In the vast majority of cases, these violations have gone unpunished. Many survivors have been forced to flee their homes, communities and even countries to seek protection.

Most persons with albinism in the region face some form of discrimination on the basis of their visual impairment, colour, gender or age, which prevents them from exercising their economic and social rights, condemns them to exclusion and poverty, and limits their life expectancy.

Attacks and discrimination against persons with albinism are contrary to international and regional human rights standards, including the right to life, physical integrity, liberty and security, equality and non-discrimination; the right to the highest attainable standard of physical and mental health; the right to education; and the right to an adequate standard of living, as well as their right to redress when those rights are violated by state or non-state actors.

International and regional human rights bodies and experts, particularly at the international level, have repeatedly expressed concerns at the violations against persons with albinism and called on states in the region to guarantee their human rights and implement measures to put an end to the violations. However, so far, the responses of states have not been sufficient.

States have clear duties under international human rights law and standards to take measures to protect the human rights of persons with albinism, prevent violations and end discrimination. In line with the recommendations from international and regional human rights bodies, they must:

- strengthen legal protection when necessary;
- protect victims and investigate, prosecute and punish the violators;
- implement policies, programmes and plans of actions that address the needs of persons with albinism; and

- put an end to the multiple and intersecting forms of discrimination that persons with albinism experience.

In this regard, it is essential that efforts are made to address the lack of data. This includes disaggregated data on the number of persons with albinism, both regionally and nationally, as well as their situation and needs, in order to adopt effective policies and programmes to respond to those needs; make appropriate budgetary provisions or, where necessary, seek international cooperation and assistance; and set up mechanisms to evaluate their progress.

In addition, to ensure comprehensive protection and promotion of the human rights of persons with albinism, it is key to have meaningful consultation with both them and their organisations in the selection, design and implementation of such policies and plans. Particular attention should be given to consultation and participation when defining policies and plans to address the multiple and intersecting forms of discrimination they face, in order to ensure that they reflect their experiences and respect their identity.

At both international and regional levels, there is a continued need to closely monitor individual situations. The implementation of recommendations at a national level should also be followed up, with international assistance being offered when needed.

Attention should also be given to strengthening international protection to persons with albinism in the African region, through the Draft Protocol, and internationally, through the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, by ensuring it applies to all forms of exploitation affecting persons with albinism, such as the sale of body parts.

5.2 Recommendations

Violence against persons with albinism

RECOMMENDATIONS TO STATES

- Review, reform or abolish, when necessary, existing legislation, policies and practices that do not comply with international and regional human rights standards or do not offer effective protection against violence to persons with albinism.

- Enact, when necessary, clear laws criminalising and punishing any acts of violence, including harmful practices against persons with albinism, clarifying ambiguities, where they exist, in laws relating to witchcraft and traditional health practice.
- Effectively implement the existing legal provisions that offer protection to persons with albinism.
- Guarantee effective protection to persons with albinism who have been displaced or are seeking refuge in other countries, in line with international human rights standard on the duties of states to protect the rights of asylum seekers and refugees.
- Develop national institutional mechanisms for the protection and promotion of rights of persons with albinism, including by ensuring that national human rights institutions effectively address the human rights situation of persons with albinism.
- Support civil society organisations working for the promotion and protection of the rights of persons with albinism.

RECOMMENDATIONS TO THE INTERNATIONAL COMMUNITY

- Continue to monitor the situation of persons with albinism and urge states to implement measures to address the human rights violations against them.
- Review the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, to ensure it applies to all forms of exploitation affecting persons with albinism, such as the sale of body parts.
- Provide assistance and support the efforts of civil society organisations working for the promotion and protection of the rights of persons with albinism, including through the provision and support of capacity-building.

Accountability

RECOMMENDATIONS TO STATES

- Promptly, thoroughly and independently investigate any allegation of human rights violations against persons with albinism, bring perpetrators to justice

and, if enough evidence is found against them, convict them according to the severity of the crime.

- Ensure that security forces and prosecutors are given enough resources to promptly and thoroughly investigate all allegations of violations against persons with albinism.
- Guarantee the safety of victims, their relatives and witnesses during and after legal proceedings, and guarantee victims the right to legal assistance.
- Guarantee the right of victims to prompt, adequate, fair and effective reparation, including compensation and rehabilitation.

RECOMMENDATION TO THE INTERNATIONAL COMMUNITY

- Take all necessary steps to strengthen international cooperation by multilateral, regional and bilateral arrangements for the prevention, detection, investigation, prosecution and punishment of cross-border crimes affecting persons with albinism, notably trafficking of persons, children and body parts.

Equality and non-discrimination

RECOMMENDATIONS TO STATES

- Urgently implement programmes and plans of action to address multiple and intersecting forms of discrimination affecting persons with albinism, including awareness-raising campaigns, human rights education and training among the judiciary, public security personnel, healthcare personnel, teachers, community leaders and family members.
- Ensure that such policies, programmes and plans are selected, designed and implemented through a process of meaningful consultation and engagement with persons with albinism; are adequately resourced; and have measurable outcomes and clear indicators.

Measures to guarantee the economic and social rights of persons with albinism

- Ensure that measures and resources to guarantee access to economic and social rights, including social services, include and give priority to the needs of persons with albinism who are among the most vulnerable and marginalised.
- Ensure adequate support, including financial resources, through social services, to families or carers of persons with albinism.

Measures to guarantee equal access to the highest standard of mental and physical health

In particular, priority should be given to the following measures:

- Include sunscreen on the list of essential medicines, make it available free of charge and distribute it regularly to all communities.
- Provide free access to dermatological care to ensure that skin cancer is detected early and treatment is readily provided, as well as access to protective clothing (wide-brimmed hats, long trousers and long-sleeved shirts).
- Provide access to clinical assessments by ophthalmologists and optometrists along with glasses, sunglasses and adaptive devices (eg, magnifying glasses and binoculars).
- Set up mobile clinics to ensure that persons with albinism in remote areas can be screened on a regular basis for skin cancer, vision assessment and care.
- Provide training and readily available information on albinism and related health issues to health workers and mothers of children with albinism at an early stage, to ensure that adequate protection is provided at every stage of life, beginning from infancy.

Measures to guarantee equal access to education

- Guarantee children with albinism access to free and compulsory primary education.
- Take appropriate measures to ensure that reasonable accommodation is made in schools to guarantee children with albinism receive equal access to education, including by providing the necessary equipment and support to bring children with albinism up to the same level of education as their non-disabled peers, including the availability of low-vision and adaptive devices as well as large-print materials.²⁶⁸
- Train teachers to educate children with albinism within schools. This should include that children with albinism should be seated in the front row of classrooms, teachers' notes should be provided to them, large-print writing should be used on the chalkboard or markerboard, and they should be permitted to wear long-sleeved clothing and hats or stay indoors during breaks. Further, teachers should receive training on how to support the learning process of children with albinism and how to keep them safe at school.
- Guarantee the safety of children with albinism in schools by providing schools with minimum-security measures such as fences, secure doors and windows.
- Guarantee the safety of children coming to and from school by training families, communities and teachers to take security measures to support children with albinism to travel to and from school.

²⁶⁸ These measures are often seen as providing for inclusive education. According to the CoRPD, inclusive education involves the right for all to access and progress in high-quality formal and informal education at all levels including pre-schools, primary, secondary and tertiary education, vocational training and lifelong learning, as well as extracurricular and social activities, without discrimination. See General comment No 4 (2016) Article 24: Right to inclusive education www.refworld.org/docid/57c977e34.html accessed 21 April 2017. People have a right to inclusive education. However, they can also opt out of this in certain circumstances and where the best interest of the child is taken into account.

Measures to guarantee equal access to work

- Create affirmative action programmes for persons with albinism or guarantee the inclusion of persons with albinism in existing affirmative action programmes with a view to guarantee them equal access to work and, in particular, access to indoor jobs.
- Promote technical and vocational guidance and training programmes that reflect the needs of persons with albinism. Ensure that they take place in integrated settings, and are planned and implemented with the full involvement of representatives of persons with albinism, with a view to guarantee them equal access to work and, in particular, access to indoor jobs.
- Develop policies that promote, regulate and encourage employers to arrange flexible and alternative work arrangements that reasonably accommodate the needs of persons with albinism, including the need to limit their exposure to the sun, and to include persons with albinism in apprenticeships and training programmes.

Data collection

- Set up and develop mechanisms for collecting data that are accurate, standardised and allow disaggregation, and that reflect the actual numbers of persons with albinism per country and in the region, as well as their personal situation.
- Provide adequate safeguards for all data amassed on persons with albinism to ensure the protection of their right to privacy and to prevent misuse of data for attacks, discrimination or other illicit acts.

RECOMMENDATIONS TO THE INTERNATIONAL COMMUNITY

- Adopt the Draft Protocol on the Rights of Persons with Disabilities and encourage ratification by all African States.
- Contribute via international cooperation to support states to evaluate the needs of persons with albinism through data collection and implement targeted and well-resourced policies and plans to protect and promote the human rights of persons with albinism.



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