

# PEOPLE WITH ALBINISM WORLDWIDE

A Human Rights Perspective



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“Child with albinism” © Rick Guidotti

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## ACRONYMS

CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
HPAWR	Harmful Practices Related to Witchcraft Accusations and Ritual Attacks
UDHR	Universal Declaration of Human Rights
OHCHR	Office of the High Commissioner for Human Rights
UN	United Nations

## FOREWORD

Over the course of my mandate as Independent Expert, I have witnessed the human rights situation of persons with albinism in many countries shift and evolve. On the one hand, there are remarkable trends of progress. In some countries, laws and policies of general application are so well-implemented that persons with albinism are able to enjoy their human rights with minimal hindrance. Human rights studies on albinism, data gathering, and situational analyses on persons with albinism around the world have increased dramatically. In some countries where attacks occur, cases of attacks are on the decline. International



Albinism Awareness Day (June 13) has been a resounding success globally and continues to hold enormous potential in furthering public education on the condition and raising awareness on persons with albinism and their human rights. There has also been an unprecedented growth in civil society groups representing persons with albinism. The capacity of these groups is improving as well, in part because of the unprecedented mobilization of resources to support them.

A particularly exciting development has been the growth of regional alliances and cooperation in Europe, the Americas, and Africa. In 2019, the Executive Council of the African Union adopted the Regional Action Plan on Albinism as a continent-wide policy, making it the first-ever regional mechanism to proactively address eradicating discrimination and violence against persons with albinism. In January 2020, the first Global Albinism Alliance was formed to support persons with albinism across the world.

On the other hand, many serious challenges remain. Though attacks have declined in some countries, they continue to be reported in others. Further investment is required with respect to capacity-building for civil society groups representing persons with albinism around the world. Funding remains a challenge, particularly for grassroots groups representing persons with albinism. The COVID-19 pandemic and its associated impacts have

exacerbated funding issues, which in turn has affected the implementation of the Regional Action Plan in some African countries.

Despite these challenges, I am deeply encouraged by the progress to date and the momentum that has been built. I hope this report propels further action toward the full enjoyment of all human rights by persons with albinism, no matter where they happen to live.

**Ikponwosa Ero** (Nigeria)

*UN Independent Expert on the enjoyment of human rights by persons with albinism*

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### **Editorial Note:**

This report is the extended version of the report: Albinism Worldwide (Report number: A/74/190), submitted to the United Nations General Assembly in 2019.



# PART I: INTRODUCTION



"Woman from USA" © Rick Guidotti

## 1. Executive Summary

Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people regardless of race, ethnicity or gender. The condition is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment in any part or all of the skin, hair, and eyes. Albinism often results in two congenital and permanent health conditions: visual impairment to varying degrees and high vulnerability to skin damage from ultraviolet rays, including skin cancer.

Though people with albinism represent a relatively small segment of the population across the globe, they are disproportionately affected by poverty, particularly in developing countries and least developed countries. Moreover, they face multiple and intersecting forms of discrimination on the grounds of disability and colour, and are often excluded from public policies in the key areas of health and education. Women and girls with albinism face unique and compounded discrimination on the basis of gender.

The human rights situation of people with albinism varies worldwide, but certain challenges are common throughout all regions as a result of deep misunderstanding and mystification of the condition. Across the world, people with albinism suffer from discrimination, stigmatization, and social exclusion. Parents of children with albinism, especially mothers, are also subjected to stigma, isolation, and ostracism. Worldwide, people with albinism encounter multiple and convergent barriers to the full enjoyment of their rights to health, education, and work, as well challenges in accessing social services, particularly health-related social services.

In some countries—primarily in some parts of Africa, where people with albinism are hypervisible—the physical appearance of people with albinism has been the object of erroneous beliefs and myths influenced by superstition, witchcraft, or both. Witchcraft-related myths have fostered acute marginalization, social exclusion, and physical attacks. Related harmful practices include accusations of witchcraft, killing, maiming, rape, grave robbery, trafficking in persons, and trafficking in body parts. Women and children with albinism are particularly vulnerable to violence, including sexual violence, which is often driven by harmful myths about, and fetishization of,



albinism. Despite these severe forms of persecution and discrimination, people with albinism are often denied justice and face barriers to accessing effective remedies for human rights violations.

People with albinism are entitled to civil, political, economic, social, and cultural rights recognized in international human rights law. The International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Rights of Persons with Disabilities are particularly relevant; both guarantee protection against discrimination. Equality and non-discrimination are essential human rights principles for people with albinism, owing to their vision impairment and their needs regarding preventive measures to address their vulnerability to skin cancer.

States have specific duties grounded in international human rights law to respect, protect, and fulfill the human rights of people with albinism, and to prevent further violations of those rights. Owing to the complex and intersecting human rights issues faced by people with albinism, States are encouraged to take a multisectoral and collaborative approach to fulfilling their duties, including by following best practices and through cooperation with civil society, other States, and international and regional organizations. In particular, States are encouraged to develop national plans of action on albinism. A national plan of action should provide the framework for governments to outline objectives, establish timelines, assign responsibility to particular entities, and allocate the necessary resources, financial or otherwise, to meet their objectives.

## **2. Objective**

This report aims to provide a comprehensive account of the human rights situation of people with albinism around the world. A global account of the human rights situation of people with albinism will help to build solidarity among the global albinism community by illustrating the experiences that unite them. It will also bring visibility to human rights abuses, and thus support albinism communities, particularly those that face extreme human rights violations. The expectation is that this report will prompt much-needed research, data collection, and discussion on issues affecting people with albinism so that progress may be made in the respect, protection, and fulfilment of their human rights.

### **3. Overview**

This report focuses on six interrelated human rights issues: multiple and intersecting discrimination, the right to life, access to justice, the right to education, the right to work and adequate standard of living, and the right to health. This report also draws attention to the aggravated human rights abuses faced by women and children with albinism.

Part I serves as the introduction to this report, outlining its methodology, the condition and prevalence of albinism, and the applicable international human rights framework. Part II consists of chapters dedicated to each of the six focal human rights issues, as well as a chapter dedicated to the special human rights issues faced by women and children. Part III sets out the main responsibilities of States to respect, protect, and fulfil human rights, and highlights examples of best practices by governments. Part IV explains the role of civil society, including national, regional, and international human rights institutions, in advocating for and supporting the full enjoyment of all human rights by people with albinism, and provides examples of best practices in human rights advocacy. Finally, Part V outlines key enduring challenges that have impeded progress on the human rights issues affecting people with albinism, and then offers a comprehensive set of recommendations to States, civil society, and the international community to guide and support their work in this field going forward.

### **4. Methodology**

In March 2019, the Independent Expert distributed a human rights questionnaire to stakeholders around the world, including United Nations Member States, United Nations offices, national human rights institutions, civil society organizations, academics, and individuals. The questionnaire consisted of 53 questions related to an array of human rights issues, and was available in English, French, Spanish, Portuguese, and Arabic.

In July 2019, the Independent Expert published a report to the United Nations General Assembly (A/74/190) based on the questionnaire responses of 97 stakeholders. Since the publication of the General Assembly report, the Independent Expert has continued to collect questionnaire responses from stakeholders across the globe.

The present report is a compilation of all the questionnaire responses the Independent Expert has received since March 2019, in addition to research and findings from the Independent Expert's country visits. The information received has been compiled into an account of the human rights situation of people with albinism, focused on six fundamental human rights issues: multiple and intersecting discrimination, right to life, access to justice, right to education, right to work and adequate standard of living, and right to health. In recognition of the unique challenges faced by women and children, the human rights issues specific to women and children are summarized in a separate section.

In detailing the human rights situation of people with albinism, reference was made primarily to international human rights standards, namely the International Covenant on Civil and Political Rights ("ICCPR"), the International Covenant on Economic, Social and Cultural Rights ("ICESCR"), the Convention on the Rights of Persons with Disabilities ("CRPD"), the Convention on the Elimination of all Forms of Discrimination Against Women ("CEDAW"), the Convention on the Rights of the Child ("CRC"), and the International Convention on the Elimination of All Forms of Racial Discrimination ("ICERD").

This report has certain limitations. First, the questionnaire responses that form the foundation of this report may not fully represent the experiences of people with albinism throughout each country. Some of the civil society organizations that responded work within defined geographical areas, so their responses may not be consistent with the experiences of people with albinism within that country or outside that defined area. Second, countries are included in the footnotes only where a questionnaire response from that country specifically mentioned a situation or experience. The absence of a citation does not mean that any given experience does not occur in that country; rather, it simply means that this experience was not noted in the

submissions from the country. Third, by forming a global view of the human rights situation, some specificity may have been lost, resulting in simplification of the actual experiences of people with albinism within a country. This report aims to balance emphasis on common experiences to promote solidarity and recognition of the unique circumstances of people with albinism in each country. In attempting to strike this balance, the report summarizes the general situation with respect to each focal human rights issue, and then elaborates on each issue through region- or country-specific examples.

### **i. Countries surveyed**

In total, 113 responses were received from 63 countries. The majority of submissions including a majority of statistical data, were received from the Africa region (66 responses in total), followed by the Americas and Caribbean (22 responses), Europe (14 responses), Asia and the Pacific (9 responses), and the Middle East and North Africa (3 responses). Responses were received from a variety of stakeholders, including civil society organizations (91 responses), States (7 responses), academics (6 responses), individuals (6 responses), national human rights institutions (2 responses), and one United Nations office.

## Countries Surveyed (Number of Responses)

Eastern, Western, Southern and Central Africa

- Angola (1)
- Burkina Faso (1)
- Burundi (3)
- Cameroon (3)
- Côte d'Ivoire (3)
- Democratic Republic of the Congo (4)
- Eswatini (2)
- Ghana (3)
- Guinea (2)
- Kenya (4)
- Malawi (2)
- Mali (2)
- Mozambique (3)
- Namibia (1)
- Niger (1)
- Nigeria (3)
- Rwanda (1)
- Senegal (1)
- Sierra Leone (2)
- South Africa (1)
- Somalia (1)
- United Republic of Tanzania (8)
- Togo (1)
- Uganda (9)
- Zambia (2)
- Zimbabwe (2)

Americas and the Caribbean	<ul style="list-style-type: none"> <li>- Argentina (2)</li> <li>- Bolivia (1)</li> <li>- Brazil (2)</li> <li>- Chile (2)</li> <li>- Colombia (4)</li> <li>- Ecuador (3)</li> <li>- Guatemala (1)</li> <li>- Haiti (1)</li> <li>- Mexico (1)</li> <li>- Panama (2)</li> <li>- Paraguay (1)</li> <li>- United States of America (1)</li> <li>- Venezuela (1)</li> </ul>
Asia and the Pacific	<ul style="list-style-type: none"> <li>- Australia (1)</li> <li>- Fiji (1) *</li> <li>- India (2) *</li> <li>- Japan (1)</li> <li>- Malaysia (1)</li> <li>- Nepal (1)</li> <li>- New Zealand (1)</li> <li>- Pakistan (1) *</li> </ul>
Europe	<ul style="list-style-type: none"> <li>- Azerbaijan (1)</li> <li>- Belgium (1)</li> <li>- Denmark (1)</li> <li>- Finland (1)</li> <li>- France (1)</li> <li>- Germany (2)</li> <li>- Italy (1)</li> <li>- Netherlands (1)</li> <li>- Norway (1)</li> <li>- Slovenia (1)</li> <li>- Spain (1)</li> <li>- Turkey (1)</li> <li>- UK and Ireland (1)</li> </ul>
Middle East and North Africa	<ul style="list-style-type: none"> <li>- Jordan (1)</li> <li>- Iran (1)</li> <li>- Israel (1)</li> </ul>

\*Some countries' submissions were based on written reports submitted in lieu of, or in addition to a questionnaire response.



## ii. Why a human rights approach?

This report follows a human rights-based approach,<sup>1</sup> which is aimed at promoting and protecting the human rights of people with albinism. The approach recognizes that people with albinism are rights-holders and States are the primary duty-bearers. This means that people with albinism are entitled to universal, inalienable, and interdependent human rights, and States have an obligation to protect and promote those rights. Ultimately, the human rights-based approach aims to empower people with albinism to claim their rights and to hold States accountable for responding to such claims.

The human rights-based approach works toward the realization of human rights by promoting the following principles:

**Non-discrimination and Equality:** All forms of discrimination, whether by the state, communities, or family, and including multiple and intersectional discrimination, must be prohibited, prevented, and eliminated.

**Accountability:** Laws, policies, institutions, administrative procedures, and mechanisms of redress are required to secure human rights. States must comply with these laws, and where they fail to do so, people are entitled to redress.

**Participation:** Everyone has the right to active, free, and meaningful participation in the decisions that affect their human rights.

**Empowerment:** Everyone must know their rights and must be supported in claiming their rights.

**Legality:** Rights must be recognized as legally enforceable entities that are linked to national, regional, and international human rights law.<sup>2</sup>

The human rights approach taken in this report is also in line with a broader shift to a human rights model of disability. Under the Convention on the Rights of Persons with Disabilities (CRPD), people with albinism are considered people with disabilities due to their vision impairments. Previously, disability

was understood through a medical or charitable model, which did not treat people as rights-holders, and often excluded people with albinism. People with albinism were not seen as having a physical disability or were categorized as blind. This approach tended to hinder the enjoyment of human rights by people with albinism.<sup>3</sup> People were reduced to their impairments. Discrimination was justified and legitimized by the very fact of having a disability.<sup>4</sup>

Since the adoption of the CRPD, which came into effect in 2008, disability has come to be understood through a human rights model.<sup>5</sup> Under this model, people with albinism are treated as rights-holders and disability is merely one aspect of their identities. They are ‘people with albinism’—their personhood is put ahead of their condition.<sup>6</sup> Impairments are not a legitimate basis to deny or restrict human rights.<sup>7</sup>

The human rights-based approach in this report focuses on international human rights instruments rather than regional and national instruments. This is a function of the scope of the report and not a comment on the relevance or importance of regional and national instruments. To fully realize the rights of people with albinism around the world, advocates and the like must consider national and regional instruments in addition to the international instruments covered in this report.

### **iii. Translation**

The surveys received in French, Spanish, Arabic and Portuguese were translated either in-house (for French and Spanish) or with the assistance of reliable translation software and the verification of professional translators (for Arabic and Portuguese).

## **5. What is Albinism?**

Albinism is a relatively rare, non-contagious, genetic condition. It affects people around the world, regardless of gender, race, or ethnicity. Regardless of whether the parents themselves have albinism, if both parents carry the relevant gene, there is a 25% chance that their child will be born with albinism.<sup>8</sup>



Albinism is characterized by a deficit in the production of melanin and a consequent lack of pigmentation in the skin, hair, and/or eyes.<sup>9</sup> Most people with albinism therefore appear pale relative to their families and communities, with pale skin and light hair.<sup>10</sup> Most people with albinism have blue, hazel, or brown eyes; however, lighting conditions can highlight the blood vessels at the back of the eye, which at times can make eyes appear reddish or violet.<sup>11</sup>

Levels of pigmentation vary by type of albinism. Types of albinism include but are not limited to: oculocutaneous albinism, which affects the eyes, hair, and skin; ocular albinism, which affects only the eyes; and Hermansky-Pudlak Syndrome, which affects the eyes, hair, and skin and contributes to bleeding problems.<sup>12</sup> The most common and visible type of albinism is oculocutaneous albinism.<sup>13</sup>

Due to the lack of melanin in their skin, people with albinism are particularly vulnerable to skin cancer. The melanin in their skin would otherwise protect them from the sun.<sup>14</sup> Skin cancer is a life-threatening condition for most.<sup>15</sup> The lack of melanin in their eyes, as well as an unusual development of

the retina and nerve connections, contributes to vision impairments.<sup>16</sup> As a result, people with albinism are extremely sensitive to bright light.<sup>17</sup> Further impairment varies from mild to severe, and many people with albinism are considered legally blind.<sup>18</sup> The impairments are not correctable with eyeglasses.<sup>19</sup>

### i. Prevalence and Data



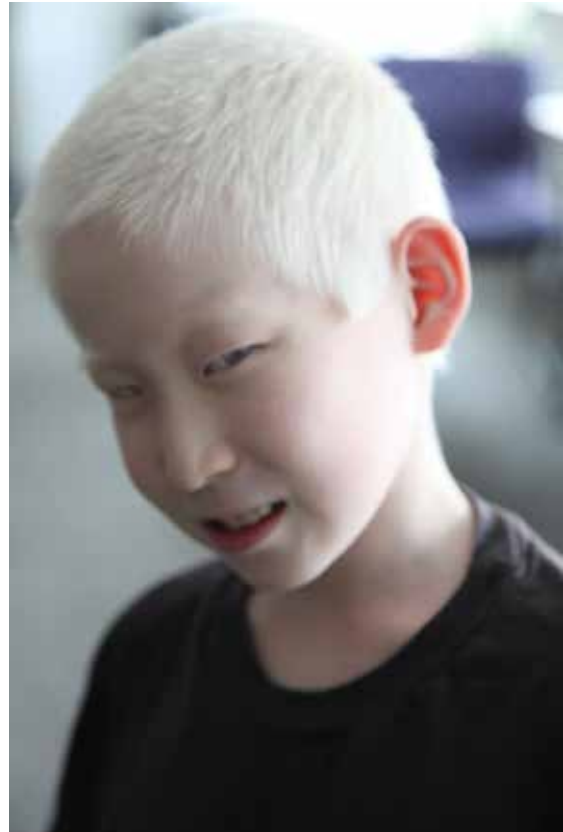
"Kuna Indian, Panama" © Rick Guidotti

Albinism occurs in all racial and ethnic groups across the world, but the proportion of people affected by albinism in a given population varies by region. In Africa, the prevalence of albinism generally ranges from 1 person in 5,000 to as low as 1 person in 15,000. It has been reported that some selected populations in Southern Africa have prevalence rates as high as 1 in 1,000 people.

Until recently, the frequency of albinism was estimated to be between 1 person in 17,000 and 1 person in 20,000 in Europe and North America. However, developing research suggests that these numbers may have been arbitrary and unreliable, and that albinism prevalence is actually much higher globally. For example, prevalence in the Netherlands and in Northern Ireland has recently been reported to be as high as 1 in 12,000 and 1 in 4,500-6,600, respectively.<sup>20</sup> In

various indigenous communities of southern Brazil, southern Mexico, eastern Panama and south-western United States of America, the prevalence of oculocutaneous albinism type 2 ranges from 1 in 28 to 1 in 6,500.<sup>21</sup> It is estimated that the Hopi indigenous peoples of Arizona, United States of America have a prevalence of 1 in 200, while the Kuna indigenous peoples of Panama have an estimated prevalence of 1 in 160.<sup>22</sup>

In Asia and the Pacific, rates of albinism vary greatly. In Japan, prevalence ranges from 1 in 7,900 to 1 in 27,000.<sup>23</sup> Unofficial data from India and China suggest that the total number of people with albinism in the country is 150,000 and 90,000, respectively.<sup>24</sup> Estimates by a civil society organization put the prevalence in Australia at 1 in every 17,000 people.<sup>25</sup> In New Zealand, prevalence is estimated to be 1 person in 16,000.<sup>26</sup> The Pacific region, including Fiji, has potentially one of the highest prevalence of albinism in the world, with a rate of oculocutaneous albinism type 2 of 1 person in 700.



“Young boy, China” © Rick Guidotti

There is little to no data about people with albinism living in the Middle East and North Africa. Various clinical studies indicate that people with albinism reside in Algeria, Egypt, the Islamic Republic of Iran, Jordan, Morocco, and Tunisia, but no information is known about the prevalence of albinism in these countries.

Reliable and robust data are important in human rights advocacy because they help determine where to direct efforts in order to maximize the impact of the given resources. Disaggregated data—meaning data that are broken down into subcategories, such as region, gender, or ethnicity—are especially useful for this reason as they can reveal inequalities between sub-categories of people with albinism that aggregated data cannot. For instance, data disaggregated by region may reveal that albinism prevalence is higher in certain areas of the country, and thus more sun-protective products should be stocked in those regions.

Despite the utility of reliable data, few countries collect official data on albinism,<sup>27</sup> and even fewer collect disaggregated data.<sup>28</sup> A growing number of African countries are undertaking surveys targeting people with albinism and some are including people with albinism in censuses. These include Côte d’Ivoire, Malawi, Namibia, Sierra Leone, Kenya, Uganda, Nigeria, and



the United Republic of Tanzania; however, the majority of prevalence figures are sourced from the work of civil society organizations or independent researchers. Although this has been a valuable resource for albinism advocacy, it should be noted that some of these studies may be flawed in their methodology or incomplete, and thus unreliable. Governments are best equipped to collect accurate and comprehensive data because they have the resources and reach to do so.

## 6. What are Human Rights?

All human beings are born free and equal in dignity and rights.  
*UDHR, Article 1*

Human rights are rights inherent to all human beings, regardless of race, sex, disability, language, religion, or any other status.<sup>29</sup> Human rights include economic, social, and cultural rights, as well as civil and political rights. Economic, social, and cultural rights include, for example, the right to work, the right to an adequate standard of living, and the right to education. Civil and political rights include, but are not limited to, the right to life and the right to freedom from torture. International human rights law protects these rights and sets out the duty and obligation of States as primary duty-bearers, to respect, protect, and fulfil human rights.

**Human rights are universal and inalienable.** The principle of universality is the cornerstone of international human rights law, first emphasized in the Universal Declaration of Human Rights. The principle of universality holds that human rights must be the same everywhere, for every person. By simply being human, one is entitled to inalienable human rights. This means the rights may not be given away or taken away, other than in certain specified situations and in accordance with due process.

**Human rights are indivisible and interdependent.** All human rights—civil and political rights, and economic, social, and cultural rights—must all be respected. The realization of any human right depends on the realization of others. Progress on one right facilitates progress on others, and the violation of one leads to the violation of others.



People with albinism's skin is threatened by cancers. Several die before the age of 40 in some parts of sub-Saharan Africa due to a lack of information on skin care and protection, as well as access to sun protection lotion and sun protective clothing. It may also be partly because people with albinism are forced to work outdoors or undertake work that requires them to work outside in the sun than indoors. More often than not this is a result of the quality of education obtained as work indoors often require better or higher education qualifications. The education dropout rate for person with albinism in some countries is linked to their vision impairment and absence of any reasonable step taken to accommodate it, stigma and discrimination.

*Respondent from Uganda*

**Non-discrimination and equality are core principles of international human rights law.**<sup>30</sup> All major human rights instruments<sup>31</sup> protect against discrimination, which is defined as any “distinction, exclusion, restriction or preference” based on race, color, disability, sex, or other status that impairs the enjoyment of all rights by all persons on equal footing.<sup>32</sup> The principle applies to everyone and to all human rights. States must respect and ensure the rights of all without distinction and take affirmative steps to eliminate conditions which cause discrimination.<sup>33</sup>

Increasingly, there is a recognition of multiple and intersecting discrimination. Multiple discrimination occurs when discrimination occurs on more than one ground—discrimination is compounded or aggravated. Intersecting discrimination occurs when several grounds for discrimination interact with one another at the same time, such that the grounds become inseparable.<sup>34</sup> Therefore, relying on various human rights conventions provides the most adequate protection for persons with albinism around the world. It facilitates understanding of the violations faced, grasps the depth of the consequences, leads to the design of practical and useful interventions.<sup>35</sup>

## Endnotes

- 1 United Nations Sustainable Development Group. (2003). The Human Rights Based Approach to Development Cooperation: Towards a Common Understanding Among UN Agencies. [unsdg.un.org/sites/default/files/6959- The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](https://www.unsdg.un.org/sites/default/files/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf) [Hereinafter: UNSDG Common Understanding Among UN Agencies].
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- 3 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Applicable International Human Rights Standards and Related Obligations Addressing the Issues Faced by Persons with Albinism. U.N. Doc. A/72/131 (July 14, 2017) (by Ikonwosa Ero). Available from [undocs.org/en/A/72/131](https://undocs.org/en/A/72/131). [Hereinafter: UNIE, Applicable International Human Rights Standards].
- 4 UN Committee on the Rights of Persons with Disabilities. General Comment No. 6 (2018) on Equality and Non-Discrimination. U.N. Doc. CRPD/C/GC/6 (April 26, 2018). Available from [undocs.org/en/CRPD/C/GC/6](https://undocs.org/en/CRPD/C/GC/6). [Hereinafter: CRPD, General Comment No. 6].
- 5 Ibid.
- 6 Under the Same Sun. (n.d.). What is Albinism? <https://www.underthesamesun.com/content/issue> [Hereafter: UTSS, What is Albinism].
- 7 CRPD, General Comment No.6, supra, note 4.
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- 11 NOAH, Information Bulletin, supra, note 9.
- 12 Ibid.
- 13 UNIE, Witchcraft and the Human Rights of Persons with Albinism, supra, note 10.
- 14 UTSS, What is Albinism, supra, note 6.
- 15 UNIE, Witchcraft and the Human Rights of Persons with Albinism, supra, note 10; NOAH, Information Bulletin, supra, note 9.
- 16 NOAH, Information Bulletin, supra, note 9.
- 17 UNIE, Witchcraft and the Human Rights of Persons with Albinism, supra, note 10.
- 18 UTSS, What is Albinism, supra, note 6.
- 19 NOAH, Information Bulletin, supra, note 9; UTSS, What is Albinism, supra, note 6.
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Mozambique (Amor); Mozambique (Shade Tree); Nigeria (NHRC); Niger (ANAN); Nigeria (OAM); Nigeria (TAF); Pakistan (Pakistan Albinism Society); Panama (OBSAP); Senegal (DIOP); Slovenia (State); Somalia (APHAD); Tanzania (Saffitz) [though Lund and Roberts use Tanzanian census data collected in 2012]; Turkey (AA); Uganda (HUPA); Uganda (NCD); Venezuela (AG); Zambia (DAZ); Zimbabwe (GAM); Brazil (APALBA); Guatemala (AdG)

28 Australia (AFA); Denmark (ADK); Eswatini (Albinism Society); Germany (NOAH); Ghana (ENA); Ghana (NCPD); Japan (JAN); Kenya (AFEA) [disaggregated data will be captured in the 2019 August national population census]; Kenya (PE); Kenya (State); Malawi (MACOHA); Mozambique (Amor); Nigeria (OAM); Norway (NFFA); Somalia (APHAD); UK & Ireland (RP); Zimbabwe (GAM).

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32 CCPR, General Comment No. 18, *supra*, note 30; CRPD, General Comment No. 6, *supra*, note 4.

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34 UNIE, Applicable International Human Rights Standards, *supra*, note 3.

35 *Ibid.*

# PART II: A WORLDWIDE ACCOUNT OF THE HUMAN RIGHTS SITUATION OF PEOPLE WITH ALBINISM

**ALBINISM WORLDWIDE**  
**WE ARE NOT ALONE**

Albinism is a non-contagious genetic condition occurring in all countries of the world. 80% of the father and mother must carry the gene for it to be passed on. Albinism is a lack of pigmentation in the hair, skin and eyes, resulting in low vision as well as vulnerability to sun exposure and bright light.

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**Ch. and Daphne - Kenya**  
**Smile - South Africa**  
**Tanzania**  
**Lauren - Australia**  
**Cecilia - New Zealand**  
**Jayde - Japan**  
**Fabi - India**  
**Mara - Fiji**



## Chapter 1: Multiple and Intersecting Discrimination experienced by people with albinism

### i. Human Rights Overview

People with albinism experience multiple and intersecting discrimination based on visual impairment<sup>36</sup> and colouring.<sup>37</sup> This discrimination affects all aspects of their lives—in social, educational, health, and employment contexts.<sup>38</sup> People are mocked, ostracized, and excluded at work and school, and in their communities and families. In the most brutal cases, they are denied access to health care, or they are mutilated, trafficked, and killed.<sup>39</sup> Notably, women and children also face discrimination based on gender and age.<sup>40</sup> Chapter 7 details the unique obstacles faced by women and children.

The complex intersecting discrimination faced by people with albinism necessitates reference to and application of multiple human rights instruments, including the CRPD and the ICERD, which protects against discrimination based on colour.

**Prohibition of discrimination based on disability:** People with albinism are entitled to protection under the CRPD based on their vision impairments. In fact, the Committee on the Rights of Persons with Disabilities has stated that people with albinism are among the most stigmatized.<sup>41</sup>

The CRPD specifically enshrines the principles of equality and non-discrimination in Article 5, though the principles are evoked consistently throughout the Convention with the repeated use of “on an equal basis with others.” Article 10, for instance, affirms the right to life and requires States to take “all necessary measures to ensure its effective enjoyment by persons with disabilities *on an equal basis with others*.”<sup>42</sup> The principle of non-discrimination is thus linked to all substantive rights in the CRPD, recognizing the right to non-discrimination in all aspects of life.<sup>43</sup>

The CRPD requires States to promote and achieve ‘inclusive equality,’ which includes: (i) fair redistribution to address socioeconomic disadvantage; (ii) recognition to combat stigma, stereotyping, prejudice, and violence; (iii)

participation to reaffirm people's social nature and to recognize their humanity through inclusion; and (iv) accommodation to make space for difference as a matter of human dignity.<sup>44</sup>

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

*CRPD, Article 5*

**Prohibition of discrimination based on colour:** The ICERD recognizes that people with albinism are subject to racial discrimination based on their colouring and has expressed concern over this discrimination.<sup>45</sup> Their light colouring makes people with albinism hypervisible in many environments — particularly where the majority of the population has darker pigmentation — and thus particularly vulnerable to stigmatization and discrimination.<sup>46</sup>

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

*ICERD, Article 1*



Article 2 enshrines States' fundamental obligations to eliminate racial discrimination. These obligations include, for instance, prohibiting racial discrimination in law and taking effective measures to review and amend government policies that perpetuate racial discrimination.<sup>47</sup> The ICERD also recognizes the links between discrimination and all other substantive rights. Article 5 obliges States to prohibit and eliminate racial discrimination with respect to certain specified rights, including the right to security of the person and protection from violence or bodily harm, political and civil rights, and the right to economic, social, and cultural rights.<sup>48</sup>

## ii. Stigma and Exclusion

Albinism is profoundly misunderstood around the world.<sup>49</sup> Many countries do not have any public campaigns to raise awareness about the condition.<sup>50</sup> Even where there are campaigns, they are not always effective. In Finland, for instance, international campaigns on albinism have enforced the idea that albinism is an African issue only.<sup>51</sup> In Italy, some people with albinism may resist joining the albinism movement because they refuse to recognize their condition.<sup>52</sup>

A persistent lack of awareness and ignorance about the condition has contributed to stigmatization, stereotyping, and prejudice. People with albinism are subjected to name-calling and verbal abuse, as well as harmful myths and misconceptions, which in turn “have the effect of stripping persons with albinism of their humanity, paving the way for exclusion and attacks.”<sup>53</sup> These myths and misconceptions provide a rationale for discrimination and present ostracism and exclusion as natural.<sup>54</sup>

Most of them responded that they feel isolation, untouchability and refusal by common people at public place. According to them, common people are having misconception about their condition due to lack of awareness. Some of them also reported use of abusive language quoting the gene responsible for their condition came from foreigner and other mental harassment by public.

*Respondent from India*

The degree and severity of stigmatization varies by region. In Europe and Australia, for instance, people with albinism often go unnoticed, as their appearance is not as clearly distinguishable from the general population.<sup>55</sup> There are nonetheless reports of discrimination. In Turkey, for instance, there are reports that children are subjected to name-calling.<sup>56</sup> In the United Kingdom, there are incidents of bullying.<sup>57</sup> In the Netherlands and Norway, some assume that red eyes and white hair characterize albinism.<sup>58</sup> In Norway, there is a misconception that people with albinism are incapable of completing normal tasks.<sup>59</sup>

In Europe, most discrimination is based on visual impairment.<sup>60</sup> People with albinism are generally able to access services, education, and employment opportunities, largely without barriers.<sup>61</sup> However, separate legislative frameworks do not exist to protect people with albinism or to ensure accommodations.<sup>62</sup> For instance, people with albinism may not meet the European Commission's vision requirements for a driver's license, which can be a barrier to enjoying human rights in sparsely populated areas.<sup>63</sup> In Turkey, the rights of people with disabilities depend on their statutorily defined disability level. Designations are inconsistent and so too is the application of rights.<sup>64</sup> In Italy, social benefits and eligibility for affirmative action programmes are determined based on an individual's disability ranking. These rankings, determined by a committee of doctors, are not consistent for people with albinism and arbitrarily deny benefits to some people with albinism.<sup>65</sup>

Similarly, in North America, there are no specific legislative frameworks to protect the rights of people with albinism. In the United States, people with albinism are generally covered under provisions of the Americans with Disabilities Act and the Individuals with Disabilities Education Act. These frameworks generally protect people with albinism in the context of work and education.<sup>66</sup>

Japanese are considered as having a homogeneous appearance (black hair, black pupil, beige skin color). Therefore, the different appearance of people with albinism receives negative reaction in Japan. For example, individuals with albinism are forced to blacken their hair and are mocked and stared at because of their physical appearance in schools, at workplace, and in public places. In order to protect them from trouble, families of children with albinism change the children's hair color to black.

*Respondent from Japan*

In various parts of Africa, Asia, and South America<sup>67</sup>—where people with albinism are hypervisible<sup>68</sup>—many people with albinism face rampant aggravated discrimination. A study from the Democratic Republic of the Congo found that 22% of people with albinism face discrimination within their families, and 66% are discriminated against in the broader community.<sup>69</sup> A survey conducted in India found that two-thirds of the respondents felt unsafe going out in public because of verbal or psychological harassment by others.<sup>70</sup> They face discrimination from others in their communities, irrespective of their class.<sup>71</sup>

In South America, reactions to people with albinism vary from admiration and curiosity to rejection and bullying.<sup>72</sup> For instance, in Colombia, people with albinism are insulted for not conforming to the prevailing standards of ‘beauty.’<sup>73</sup> Yet, women in Mexico are subject to harassment because blonde, white women are considered more attractive.<sup>74</sup> According to one study from Brazil, 70% of people with albinism have psycho-social issues,<sup>75</sup> presumably due to years of discrimination.<sup>76</sup>

In these regions, people with albinism are subjected to name-calling.<sup>77</sup> A study from Sierra Leone found that 80% of people with albinism are called derogatory names.<sup>78</sup> In Malawi, people with albinism are called “azungu” (white person) or “napwere” (yellow tomatoes);<sup>79</sup> in Brazil, “peeled cockroaches” and “white rates”;<sup>80</sup> in Malaysia, “ghost,” “white people,” or “alien”;<sup>81</sup> in India, “snowman” or “yeti.”<sup>82</sup>

A member of parliament with albinism appointed relatively recently, Hon. Isaac Mwaura, was also mocked by a fellow member of parliament. The words of mockery were directed at Hon Mwaura’s wide-brimmed hat which persons with albinism tend to use as a shield from the sun. These incidents directed against successful persons with albinism shows a clear indication of low awareness about albinism in Kenya and the amount of public awareness work that remains to be done.

*Respondent from Kenya*

Myths around the condition are also common. They include: (i) albinism is a contagious disease;<sup>83</sup> (ii) people with albinism are foreigners;<sup>84</sup> and (iii) people with albinism are inferior and incapable of completing normal mental and physical tasks.<sup>85</sup> Consequently, the presence of people with albinism elicits fear in many regions.<sup>86</sup> People with albinism must make additional—and often futile—efforts to be accepted and to succeed. In Japan, for instance, it was reported that students with albinism must dye their hair to enroll in school and are rejected from employment opportunities due to their appearance.<sup>87</sup>

Particularly harmful myths have taken root in many countries in Africa. The myths position albinism as a supernatural phenomenon:<sup>88</sup> a form of evil or a “curse” or “punishment” imposed by higher beings.<sup>89</sup> In Ghana, some believe that the presence of a person with albinism in the community prevents rainfall.<sup>90</sup> In Zambia, there is a common superstition that in order to avoid having a child with albinism or becoming a person with albinism, one must spit on their shirt whenever they see a person with albinism.<sup>91</sup> Others view people with albinism as having mystical powers,<sup>92</sup> or as lucky<sup>93</sup> or non-human.<sup>94</sup> In Burundi, people with albinism are viewed as monsters and ghosts.<sup>95</sup> Similar myths have developed in other countries. In India, for instance, some believe that marrying a woman with albinism will make one rich.<sup>96</sup>

In some African countries, women who give birth to children with albinism are disproportionately impacted by this lack of understanding.<sup>97</sup> They are subjected to violence,<sup>98</sup> and rejected or excommunicated by their husbands and families.<sup>99</sup> Often, they are viewed as being cursed<sup>100</sup> or unfaithful for giving birth to a child with albinism.<sup>101</sup> In Uganda, clan members encourage men to abandon their wives and children with albinism based on myths that their union will bring bad luck upon the community.<sup>102</sup>

Clan members usually influence the men to run away. Even if the man really wants to remain with his family, when the family members tell him “we shall all die if you remain with that woman”, they run away.

*Respondent from Uganda*

Parents of children with albinism also have difficulty accepting or fully embracing their child,<sup>103</sup> and may feel ashamed of their child.<sup>104</sup> In some cases, children with albinism are neglected or abandoned by their families<sup>105</sup> and

are instead raised by grandparents or other guardians.<sup>106</sup> Some children with albinism are killed or banished immediately after birth by parents, midwives, or communities. Throughout their childhood, children with albinism face discrimination and bullying from parents, peers, and teachers.<sup>107</sup> Adults fuel exclusion of children with albinism by warning their children not to interact with them.<sup>108</sup> Boys with albinism are expected to tolerate bullying and discrimination as ‘men.’<sup>109</sup>

Most countries in these regions do not have national laws or policies that guarantee access or accommodation in education, health, employment, or law to people with albinism.<sup>110</sup> This is in part due to exclusion from political participation. In certain countries in Africa, for instance, people with albinism are not considered during decision-making or in policy formulation in matters that concern them,<sup>111</sup> and are prevented from civic participation and political representation.<sup>112</sup> People with albinism in Eswatini are unable to participate in public and political life because of health risks.<sup>113</sup>

Similarly, the lack of official forums for participation<sup>114</sup> and the low prevalence of albinism in the Americas means that albinism-related issues are ignored or invisible, and are not taken into consideration at social and institutional levels.<sup>115</sup> People with albinism must rely on constitutions, international human rights conventions, general human rights legislation, or general disability legislation<sup>116</sup>—whether specifically defined to include albinism or not.<sup>117</sup> These alternatives are not always adequate. For example, in Mozambique, people with albinism are required to stand in the sun to access public services and are not given priority, even in the absence of shade in the waiting area.<sup>118</sup>

In Eswatini, the culture dictates that men cannot wear a hat when going to community meetings, which are usually conducted out in the open sun, this then becomes a problem for a person with albinism as he cannot sit in the open sun without the hat on his head as he would be at risk of exposure to skin cancer, and at the same time if he does not attend such meetings he will be liable to a hefty fine which he cannot afford due to being poor. And also missing such meetings put him in a position of missing out in social and economic discussions at a community level.

*Respondent from Eswatini*



Even where disability legislation does exist, a lack of awareness about albinism renders these guarantees ineffective or meaningless.<sup>119</sup> In many countries, for instance, people with albinism are not considered persons with disabilities, and therefore do not receive the protections available to other people with disabilities.<sup>120</sup> In Ecuador, disability laws recognize the needs associated with blindness, but not low vision. As a result, people with albinism do not have access to the disability regime.<sup>121</sup> In Colombia, people with albinism are unaware of their condition or do not consider themselves to be living with a disability, and consequently do not know that they are able to obtain benefits through the disability registry.<sup>122</sup>

Although albinism has low vision, it is not considered a visual disability because it does not have the necessary percentage. This leaves persons with albinism in a ‘limbo’, where they do not belong to the populations with recognized disabilities, because still have a functional vision, but neither fit in that “normal” population because of our low vision and physical characteristics.

*Respondent from Colombia*



“Siblings, Brazil” © Laurentiu Garofeanu / Barcroft U

In other countries, people with albinism as a group are not barred from the disability regime, but must prove their disability on an individual basis. For example, in Brazil, there is a social security benefit programme for the elderly or extremely poor with disabilities—Benefício de Prestação Continuada (BPC) programme. Many people with albinism cannot access this programme on the basis that they do not meet the required impairment test.<sup>123</sup>

In certain African countries, the rights of persons with albinism are captured within albinism-specific laws and policies.<sup>124</sup> Even so, implementation and enforcement of these instruments is often stunted or ineffective.<sup>125</sup> For example, in 2015, the Mozambican government wrote an action plan for persons with albinism, but due to lack of political will, it has yet to allocate a budget for this plan.<sup>126</sup>



## Endnotes

36 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Applicable International Human Rights Standards and Related Obligations Addressing the Issues Faced by Persons with Albinism. U.N. Doc. A/72/131 (July 14, 2017) (by Ikponwosa Ero). Available from [undocs.org/en/A/72/131](http://undocs.org/en/A/72/131). Multiple and intersecting discrimination to be defined below. See also: Angola (Movimento); Kenya (KNCHR); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (OAM); Sierra Leone (SLAFo); Rwanda (OIPPA); Somalia (APHAD); South Africa (Kromberg); Tanzania (KCBRP); Tanzania (Mesaki); Tanzania (UTSS); Uganda (Albinism Umbrella); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zambia (DAZ); Japan (JAN); Belgium (Ecran Total); Denmark (ADK); France (Genespoir); Germany (NOAH); Norway (NFFA); Colombia (FAC); Colombia (AdC); Ecuador (Comunidad); Ecuador (PdA); Mexico (FPLAM); Venezuela (AG); United States (NOAH); Fiji (MR).

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38 Argentina (Albinismo Argentina); Argentina (SA); Brazil (APALBA); Chile (ANGOC); Colombia (AdC); Colombia (FAC); Ecuador (PdA); Haiti (ALBHA); Mexico (FPLAM); Panama (GG); Paraguay (AP).

39 UN High Commissioner for Human Rights. Persons with Albinism: Report of the Office of the United Nations High Commissioner for Human Rights. U.N. Doc. A/HRC/24/57 (September 12, 2013). Available from [undocs.org/en/A/HRC/24/57](http://undocs.org/en/A/HRC/24/57) [Hereinafter: OHCHR, Persons with Albinism]; UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. U.N. Doc. A/HRC/37/57 (December 20, 2017) (by Ikponwosa Ero). Available from [undocs.org/en/A/HRC/37/57](http://undocs.org/en/A/HRC/37/57). [Hereinafter: UNIE, Enjoyment of Human Rights by Persons with Albinism].

40 Angola (Movimento); Kenya (KNCHR); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (OAM); Sierra Leone (SLAFo); Rwanda (OIPPA); Somalia (APHAD); South Africa (Kromberg); Tanzania (KCBRP); Tanzania (Mesaki); Tanzania (UTSS); Uganda (Albinism Umbrella); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zambia (DAZ); Colombia (FAC); Colombia (AdC); Ecuador (Comunidad); Mexico (FPLAM); Paraguay (AP); Venezuela (AG).

41 UNIE, Applicable International Human Rights Standards, *supra*, note 3.

42 CRPD, General Comment No. 6, *supra*, note 4.

43 *Ibid.*

44 *Ibid.*

45 UNIE, Applicable International Human Rights Standards, *supra*, note 3.

46 *Ibid.*

47 ICERD, Art. 2.

48 ICERD, Art. 5.

49 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Albinism Worldwide. U.N. Doc. A/74/190 (July 18, 2019) (by Ikponwosa Ero). Available from [undocs.org/en/A/74/190](http://undocs.org/en/A/74/190). [Hereinafter: UNIE, Albinism Worldwide]

50 Jordan (Rasha); Slovenia (State). Several civil society organizations have effectively campaigned on albinism; for example, NOAH will react to negative portrayals of albinism or published reports of discrimination or mistreatment of people with albinism. The New York Dermatological Group Foundation is also working on an albinism awareness campaign. See Part V of this report for further information and examples.

51 Finland (FAA).

52 Italy (Albinit).

53 UNIE, Applicable International Human Rights Standards, *supra*, note 3.

54 UNIE, Preliminary Survey on the Root Causes of Attacks and Discrimination, supra, note 54.

55 Denmark (ADK); Finland (FAA); Germany (NOAH); Australia (AFA).

56 Turkey (AA).

57 UK & Ireland (RP).

58 Netherlands (AO); Norway (NFFA).

59 Norway (NFFA).

60 Belgium (Ecran Total); France (Genespoir); Norway (NFFA); Spain (ALBA).

61 Azerbaijan (State); Denmark (ADK).

62 Azerbaijan (State); Belgium (Ecran Total); Finland (FAA); France (Genespoir); Germany (NOAH); Netherlands (AO); Norway (NFFA); Slovenia (State); Spain (ALBA).

63 Finland (FAA).

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69 DRC (GI).

70 India (WPRA).

71 India (WPRA); India (JT).

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73 Colombia (AdC).

74 Mexico (FPLAM).

75 Brazil (IE).

76 Colombia (AdC); Ecuador (PdA); Colombia (FAC); Colombia (FVF).

77 UNIE, Preliminary Survey on the Root Causes of Attacks and Discrimination, supra, note 54. See also: Angola (Movimento); Burkina Faso (ABIPA 1); Burundi (Femmes Albinos); Burundi (OPAB); Mozambique (AAAM); Mozambique (Shade Tree); Kenya (KNCHR); Rwanda (OIPPA); South Africa (Kromberg); Tanzania (KCBRP); Tanzania (Mesaki); Tanzania (UTSS); Uganda (HUPA); Uganda (Lund & Goodman); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).

78 Sierra Leone (SLAFo).

79 Malawi (MACOHA).

80 Brazil (IE).

81 Malaysia (KLSAA).

82 India (JT).

83 Colombia (AdC); India (WPRA); India (JT); Turkey (AA).

84 Kenya (PE); Malawi (MACOHA); Colombia (AdC); Japan (JAN).

85 Angola (Movimento); Kenya (KNCHR); Mozambique (Shade Tree); Zimbabwe (GAM); Pakistan (Pakistan Albinism Society).

86 India (WPRA); India (JT).

87 Japan (JAN).

88 Côte d'Ivoire (APIFA); Côte d'Ivoire (BEDACI); Guinea (UBEAG); Malawi (MACOHA); Rwanda (OIPPA); Senegal (DIOP); Uganda (SNUPA); Zambia (Albinism Foundation of Zambia).

89 Angola (Movimento); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Cameroon (ANAPRODH); Eswatini (Minerva); Eswatini (Albinism Society); Ghana (ENA); Kenya (KNCHR); Kenya (PE); Mozambique (AAAM); Mozambique (Amor); Nigeria (NHRC); Nigeria (TAF); Rwanda (OIPPA); Senegal (DIOP); Sierra Leone (SLAFo); Somalia (APHAD); Tanzania (KCBRP); Uganda (DOTACM);

Uganda (HUPA); Uganda (Lund & Goodman); Uganda (NCD); Uganda (UAA); Zimbabwe (GAM).  
 90 Ghana (ENA).  
 91 Zambia (Albinism Foundation of Zambia).  
 92 Côte d'Ivoire (APIFA); Nigeria (NHRC); Uganda (Lund & Goodman); Uganda (SNUPA); Zambia (DAZ).  
 93 Angola (Movimento); Mozambique (Amor); Uganda (DOTACM); Uganda (NCD).  
 94 Burundi (OPAB); Eswatini (Albinism Society); Kenya (PE); Tanzania (KCBRP); Tanzania (Mesaki); Uganda (Lund & Goodman); Zambia (DAZ).  
 95 Burundi (Femmes Albinos); also the case in Kenya (KNCHR); Tanzania (UTSS); Uganda (DOTACM); Uganda (Lund & Goodman); and Uganda (UAA).  
 96 India (JT).  
 97 Burundi (Femmes Albinos); Cameroon (ANAPRODH); Kenya (KNCHR); Kenya (PE); Malawi & Tanzania (SV); Nigeria (OAM); Rwanda (OIPPA); South Africa (Kromberg); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).  
 98 Uganda (DOTACM).  
 99 Burundi (Femmes Albinos); Eswatini (Albinism Society); Ghana (ENA); Kenya (KNCHR); Kenya (PE); Rwanda (OIPPA); Nigeria (NHRC); Nigeria (TAF); Zimbabwe (GAM).  
 100 Eswatini (Albinism Society); Kenya (PE); Mozambique (AAAM); Mozambique (Amor); Uganda (SNUPA); Uganda (UAA); Zimbabwe (GAM).  
 101 Eswatini (Minerva); Ghana (ENA); Kenya (PE); Mozambique (AAAM); Mozambique (Amor); Uganda (SNUPA); Uganda (UAA); Zimbabwe (GAM).  
 102 Uganda (Lund & Goodman).  
 103 Burundi (OPAB); Cameroon (APAC); Congo (AF); Eswatini (Minerva); Senegal (DIOP); Togo (CAS); Uganda (UAA).  
 104 Kenya (KNCHR); Senegal (DIOP).  
 105 Uganda (DOTACM); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).  
 106 Burundi (Femmes Albinos); Cameroon (APAC); Kenya (PE).  
 107 Angola (Movimento); Burundi (Femmes Albinos); Cameroon (APAC); DRC (AF); Eswatini (Minerva); Eswatini (Albinism Society); Nigeria (NHRC); Nigeria (OAM); Nigeria (TAF); Senegal (DIOP); South Africa (Kromberg); Zimbabwe (GAM).  
 108 Zimbabwe (GAM).  
 109 Kenya (AFEA); Kenya (PE).  
 110 Argentina (SA); Brazil (IE); Brazil (APALBA); Colombia (FAC); Colombia (AdC); Ecuador (PdA); Guatemala (AdG); Haiti (ALBHA); Mexico (FPLAM); Panama (OBSAP); Paraguay (AP).  
 111 Eswatini (Minerva); Mozambique (Shade Tree).  
 112 Malawi & Tanzania (SV); Nigeria (OAM); Somalia (APHAD).  
 113 Eswatini (Minerva).  
 114 Argentina (SA); Chile (ANGOC); Colombia (AdC); Colombia (AdC); Ecuador (Comunidad).  
 115 Argentina (SA); Argentina (Albinismo Argentina); Brazil (IE); Chile (ANGOC); Colombia (AdC); Colombia (FAC); Colombia (FVF); Ecuador (Comunidad); Ecuador (PdA); Paraguay (AP).  
 116 Australia (AFA); Fiji (MR); New Zealand (AT).  
 117 Angola (Movimento); Burkina Faso (ABIPA 1); Burundi (ASP); Cameroon (BEDACI); DRC (AF); Ghana (NCPD); Kenya (PE); Kenya (AFEA); Kenya (KNCHR); Kenya (State); Mali (CORPA); Malawi (MACOHA); Niger (ANAN); Nigeria (OAM) [The Federal Government passed the Prohibition of Discrimination Against Persons with Disability Act on 23rd Jan. 2019]; South Africa (Kromberg); Tanzania (KCBRP); Tanzania (Mesaki); Uganda (NCD); Zambia (Albinism Foundation of Zambia); Zambia (DAZ); Japan (JAN); Brazil (IE); Colombia (AdC) Colombia (FAC); Ecuador (PdA); Ecuador (State); Guatemala (State); Mexico (FPLAM); Paraguay (AP); Fiji (MR).  
 118 Mozambique (AAAM).  
 119 Colombia (FAC); India (WPRA); Japan (JAN); Malaysia (KLSAA).  
 120 Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM); Azerbaijan (State); France (Genespoir); Germany (NOAH); Netherlands (AO); Norway (NFFA); Slovenia (State); Spain (ALBA); Turkey (AA); UK & Ireland (RP); Colombia (AdC); Mexico (FPLAM).  
 121 Ecuador (PdA).

122 Colombia (AdC); Colombia (FAC).

123 Brazil (IE).

124 Guinea (UBEAG); Malawi (MACOHA); Nigeria (TAF).

125 DRC (AF); DRC (GI); Kenya (AFEA) ["Under the Kenya Constitution 2010 and accompanying myriad of policy and legislation targeting people with disability, PWA are not yet able to fully exercise their rights and access services prescribed by the beautiful legislations."]; Kenya (State); Mali (CORPA); Mozambique (AAAM); Mozambique (Shade Tree); Sierra Leone (SLAFo); South Africa (Kromberg); Uganda (NCD); Uganda (UAA).

126 Mozambique (Shade Tree) referring to the Plano de Acção Multisectorial para responder a Problemática da Pessoa Albina e Sua Protecção; Mozambique (AAAM); Mozambique (Amor).

## Chapter 2: Right to Life



"Sleeping Babies, DRC" © Patricia Willocq

### i. Human Rights Overview

Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

*ICCPR, Article 6(1)*

The right to life is central in international human rights law. It protects against the arbitrary deprivation of life.<sup>127</sup> This is a “supreme right” from which no State may make an exception.<sup>128</sup> People must be free from acts which are intended to, or may be expected to, cause their unnatural or premature death.<sup>129</sup> States must respect and protect the right without distinction of any kind.<sup>130</sup> States must not engage in conduct that would result in arbitrary deprivation of life and have a duty to protect against the acts of others that are a reasonably foreseeable threat to life.<sup>131</sup>



It is most precious for its own sake as a right that inheres in every human being, but it also constitutes a fundamental right whose effective protection is the prerequisite for the enjoyment of all other human rights.

*ICCPR, General Comment 36 on Article 6*

In many countries, the life expectancy of people with albinism is much lower than the national average.<sup>132</sup> In Uganda, for instance, 70% of people with albinism die before 40 years of age.<sup>133</sup> Research shows that prior to present-day health interventions, an estimated 2% of people with albinism in Tanzania live beyond the age of 40 years, with similar rates reported in neighbouring countries.<sup>134</sup> In Brazil, the life expectancy of people with albinism is as low as 33 years of age.<sup>135</sup>

The right to life of people with albinism is consistently threatened by violations of, and barriers to, several interrelated rights. For instance, discrimination and lack of awareness contribute to limited protection against skin cancer<sup>136</sup>—which people with albinism are up to 1,000 times more likely to get compared to the average population.<sup>137</sup> Discrimination in school and employment means that people with albinism are often forced to work outdoors, leading to skin cancer.<sup>138</sup> The isolation that results from discrimination means people with albinism are at higher risk of death by suicide.<sup>139</sup> Perhaps the most egregious violations of the right to life of people with albinism occurs in parts of Africa, in the context of harmful practices related to accusations of witchcraft and ritual attacks.<sup>140</sup>

In order to protect the right to life of people with albinism, all rights discussed in this report must be recognized and upheld. Particularly important in the context of attacks is the prohibition against torture, harmful practices, and human trafficking.<sup>141</sup> States have an obligation to investigate and prosecute all cases of attacks and to ensure the adequacy of national legislative frameworks and criminal sanctions, they have an obligation to fight impunity.<sup>142</sup>

**Prohibition of torture and inhuman and degrading treatment:** The Convention against Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment (CAT) provides the most comprehensive protections against torture. Torture is (i) very serious and cruel mental or physical suffering, (ii) intentionally inflicted on a person, (iii) for any discriminatory



reason, (iv) inflicted by, instigated by, or with the consent of a public official.<sup>143</sup> The Committee against Torture has confirmed that the attacks against people with albinism, as described below, fall within the scope of the CAT.<sup>144</sup> The Committee on the Rights of the Child has also recognized that violence against children with albinism amounts to torture.<sup>145</sup> The intensity of attacks against people with albinism undeniably causes severe pain and suffering. Government officials often fail to take adequate measures to protect against, investigate, and adequately prosecute those responsible for attacks.<sup>146</sup>

**Prohibition of harmful practices:** Harmful practices are prohibited in a number of international human rights instruments.<sup>147</sup> Harmful practices are defined as (i) practices grounded in discrimination, (ii) involving violence, (iii) which cause physical and/or mental harm or suffering.<sup>148</sup> The Committee on the Elimination of Discrimination against Women has confirmed that people with albinism are subject to harmful practices. As will be explained below, “the practice of prescribing sex with girls or women with albinism as a cure for HIV, ritual killings and attacks on persons with albinism, including women and girls, the use of their body parts for purposes of witchcraft, and the stigma and social exclusion suffered by mothers of children with albinism” are recognized as harmful practices.<sup>149</sup>

**Prohibition of trafficking in persons and trafficking in body parts:** The Protocol to Prevent, Suppress and Punish Trafficking in Persons is the primary protection in international human rights law against trafficking. Trafficking is defined as (i) the recruitment or transfer of persons, (ii) by use of force, coercion, abduction, or vulnerability, (iii) for a purpose, such as sexual exploitation, forced labour, or the removal of organs. As described below, the bodies of people with albinism are trafficked, and black markets exist for their body parts. As currently interpreted, however, the Protocol to Prevent, Suppress and Punish Trafficking in Persons does not specifically protect against trafficking in body parts—it protects against the trafficking of people.<sup>150</sup> However, as noted by the Independent Expert, other instruments do not directly exclude body parts.<sup>151</sup> In applying these instruments, it should be enough to show that exploitation is the end goal of trafficking especially when it includes recruitment, transportation, transfer, harbouring or receipt of a person. A common characteristic of all forms of trafficking is that victims are treated as merchandise ‘owned’ by their traffickers, with scant regard for their human rights and dignity. The removal of body parts – for economic or

other exploitative purpose, -- such as toes, nails or hair, therefore, falls within the meaning of exploitation under relevant laws on human trafficking.<sup>152</sup>

## ii. Harmful Practices

As of April 2019, this particular misconception has caused 208 people to be murdered, and 585 to be attacked, across 28 African countries since 2006. But while the situation has improved in countries like Tanzania—once the epicenter of violence, but now without any murders for four years—the crisis has exploded in Malawi, where 26 murders and a total of 161 reports of human rights violations have emerged since 2014. Amnesty International this year reported a total of 39 illegal exhumations targeting the graves of persons with albinism in Malawi. According to the latest data from albinism societies and the police service in Malawi, 57 reports of violence have occurred in the southern region, 53 in the eastern region, 41 in central Malawi and 10 in the northern region. The situation is made more urgent by the country's impending national elections in May 2019 and a corresponding spike in violence that UN experts attribute to the rising demand for body parts by politicians seeking electoral fortune.

Respondent from *Malawi & Tanzania*

In the last decade, over 700 people with albinism across 30 countries in the region of Africa have been killed, mutilated, or traumatized by harmful practices related to accusations of witchcraft and ritual attacks (HPAWR).<sup>153</sup> Even so, the prevalence of HPAWR is not well-known and is generally believed to be underreported.<sup>154</sup>

As described in Chapter 1, common myths about albinism associate people with albinism with supernatural phenomena. Their existence is thought to be a curse, or their bodies to be the source of good fortune.<sup>155</sup> These myths incite attacks. People are bullied, beaten, banished, mutilated, tortured, and killed in an effort to either eliminate an imagined threat or to bring about wealth and fortune.<sup>156</sup> Myths also render people all the more vulnerable to attacks. They minimize the social impact of attacking or killing people with albinism and contribute to ostracizing people with albinism.<sup>157</sup> People with albinism, including children,<sup>158</sup> are targeted by their families<sup>159</sup> and neighbours<sup>160</sup>—many of whom rightly believe they will not be reported.<sup>161</sup> People with albinism thus live in constant fear of being attacked.<sup>162</sup>



"Girls holding each other, DRC" © Patricia Willocq

Women and children suffer disproportionately. The Special Rapporteur on Violence against Women has identified HPAWR as a form of violence against women.<sup>163</sup> For instance, myths around sexual intercourse expose women to violence, exploitative relationships, unwanted pregnancies, and sexually transmitted infections.<sup>164</sup> Traditional gender roles (e.g., fetching wood and water for women) and social isolation predispose women and girls with albinism to a higher risk of physical harm.<sup>165</sup> Women who give birth to children with albinism are also at risk of violence.<sup>166</sup> The ostracism and isolation of mothers of children with albinism increases the vulnerability of both mother and child to attacks.<sup>167</sup>

I learnt from a family of five children - that they were having sleepless nights because bad people wanted to steal these children and sacrifice them and get body parts.

*Respondent from Uganda*

### a. Witchcraft Accusations

People are subject to accusations of witchcraft due to beliefs that individuals can cause harm using supernatural powers. These accusations are used to interpret misfortune, apportion blame, and seek redress.<sup>168</sup> They are thus often made during periods of misfortune, illness or death.<sup>169</sup> Those accused are often subject to violence and banishments. In some cases, they are subject to forced confessions and forced exorcisms.<sup>170</sup>

People with albinism often do not face accusations of witchcraft in a strict sense, but are affected in analogous ways.<sup>171</sup> That is, they are believed to be

bad omens, and face similar consequences. In Ghana, for instance, some believe that the presence of a person with albinism in the community prevents rainfall. Children with albinism are thus killed after birth.<sup>172</sup>

Accusations most frequently affect women. As the UNHCR has explained, “The bulk of available cases indicate that women are more often subjected to witchcraft accusations, although exceptions do exist.”<sup>173</sup> They appear to be, “a hallmark of intra-gender struggles.”<sup>174</sup> The accused are “insubordinate wives, obstinate daughters-in-law, and elderly infertile women.”<sup>175</sup> These women are considered no longer useful to society.<sup>176</sup> They are abandoned or banished, and often fall into poverty.<sup>177</sup> Among women, elderly women experience some of the highest rates of witchcraft accusations.<sup>178</sup>

Witchcraft accusations are also linked to infanticide. Accusations against children have increased in recent years.<sup>179</sup> In several countries, children with albinism are killed immediately after birth by parents, midwives or communities, as they are seen as a curse.<sup>180</sup> In Cameroon, for instance, children with albinism are often killed immediately after birth and then are classified as still-births.<sup>181</sup> Their mothers are also vulnerable to attacks, based on the belief that a child with albinism is a sign of the mother’s involvement with witchcraft.<sup>182</sup>

### **b. Ritual Attacks**

Ritual attacks result from the belief that appealing to the supernatural will bring about fortune or power. In muti and juju practices, for instance, some believe that using body parts—and those of people with albinism in particular—make the practices more effective. These beliefs lead to violent attacks, including forced mutilation, dismemberment, and sex acts.<sup>183</sup> These crimes increase at specific times of year—including, for instance, near election periods.<sup>184</sup>

It has been reported that miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold, and that fishermen weave the hair of persons with albinism into their nets to improve their catches.

Respondent from *Tanzania*

Beyond *muti* and *juju* practices, the bodies of people with albinism are broadly believed to bring wealth and good luck and are therefore desired for use in various charms and potions.<sup>185</sup> People are kidnapped, attacked, murdered, and mutilated.<sup>186</sup> They are called derogatory terms such as “money,” “pesa,”<sup>187</sup> and “deal.”<sup>188</sup> Healers in Burundi “concoct potions” made from the limbs of people with albinism for their clients “in search of success.”<sup>189</sup> In Mozambique, where the hair of people with albinism is believed to be gold, there is a growing business of stealing hair.<sup>190</sup> In Ghana, children are sacrificed for bumper harvest or rituals related to power and riches.<sup>191</sup> In Tanzania, these types of myths resulted in the murder of 76 people with albinism between 2006 and 2015.<sup>192</sup>



“Victim from attack” © UTSS

These practices have spread across countries in the last decade.<sup>193</sup> People with albinism and their body parts are being trafficked across borders for these purposes,<sup>194</sup> and black markets have developed at the national, regional, and international levels.<sup>195</sup> In Kenya, people with albinism have been lured to Tanzania by the prospect of a job, only to be attacked once they arrive.<sup>196</sup> In Burundi, more than 23 people with albinism have been killed and mutilated, with the aim of trafficking their bodies for rituals in Tanzania.<sup>197</sup> Many attacks occur in rural areas, especially in regions that share a border with another country in order to facilitate trafficking.<sup>198</sup>



Women and girls with albinism also experience ritual rape.<sup>199</sup> There is a widespread belief that sexual intercourse with a person with albinism brings luck and cures diseases, including HIV.<sup>200</sup> Women with albinism experience unwanted pregnancies as a result.<sup>201</sup> Women often remain silent after these attacks,<sup>202</sup> believing that abuses committed against them are normal.<sup>203</sup> In fact, in some cases, women are congratulated for having “found a man”.<sup>204</sup> In Burundi, the woman’s family will often oblige the perpetrator to live with the woman.<sup>205</sup>



## Endnotes

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129 Ibid; Ibid.

130 ICCPR, Art. 6; OHCHR, General Comment No. 36, supra, note 128.

131 Ibid; Ibid.

132 Angola (Movimento); Mozambique (Shade Tree); UNIE, Applicable International Human Rights Standards, supra, note 3.

133 Uganda (HUPA).

134 Kenya (PE).

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136 UNIE, Applicable International Human Rights Standards, supra, note 3.

137 UNIE, Preliminary findings on her visit to Brazil, supra, note 135.

138 UNIE, Applicable International Human Rights Standards, supra, note 3.

139 Colombia (FVF).

140 It is important to note that belief in witchcraft is not at issue in this report. Indeed, some forms of “witchcraft” (or certain practices so described) have been recognized as legitimate forms of treatment, and have been associated with empowerment, healing, and cleansing. This report does not intend to interfere with the right to freedom of religion or belief, cultural practices, or indigenous rights. However, the serious human rights violations caused by harmful practices related to accusations of witchcraft and ritual attacks can never be justified on the grounds of such beliefs and the right to manifest them. UNIE, Applicable International Human Rights Standards, supra, note 3.

141 Ibid; UN Committee against Torture. Concluding Observations on the Second Periodic Report of Burundi. U.N. Doc. CAT/C/BDI/CO/2 (December 12, 2014). Available from [undocs.org/CAT/C/BDI/CO/2](https://undocs.org/CAT/C/BDI/CO/2) [Hereinafter: CAT, Concluding Observations on the Second Periodic Report of Burundi]; UN Committee on the Rights of the Child. Concluding Observations on the Second Periodic Report of the Central African Republic. U.N. Doc. CRC/C/CAF/CO/2 (March 8, 2017). Available from [undocs.org/CRC/C/CAF/CO/2](https://undocs.org/CRC/C/CAF/CO/2).

142 UNIE, Applicable International Human Rights Standards, supra, note 3.

143 CAT, Art. 1.

144 CAT, Concluding Observations on the Second Periodic Report of Burundi, supra, note 141.

145 Ibid.

146 UNIE, Applicable International Human Rights Standards, supra, note 3.

147 CEDAW, Art. 5; CRC, Art. 24.

148 UN Committee on the Elimination of Discrimination against Women & UN Committee on the Rights of the Child. Joint General Recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/General Comment No. 18 of the Committee on the Rights of the Child on Harmful Practices. U.N. Doc. CEDAW/C/GC/31-CRC/C/GC/18 (November 14, 2014). [Hereinafter: CEDAW & CRC, Joint General Recommendation No. 31].

149 UN Committee on the Elimination of Discrimination against Women. Concluding Observations on the Seventh Periodic Report of Malawi. U.N. Doc. CEDAW/C/MWI/CO/7 (November 24, 2015). Available from [undocs.org/CEDAW/C/MWI/CO/7](https://undocs.org/CEDAW/C/MWI/CO/7).

150 UNIE, Applicable International Human Rights Standards, supra, note 3.

151 UNIE, Applicable International Human Rights Standards, supra, note 3 at para. 50.

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154 See for example: McVeigh, K. (2014, October 8). Child witchcraft claims increasing as 'hidden crime' is investigated. *The Guardian*. <https://www.theguardian.com/uk-news/2014/oct/08/child-witchcraft-claims-hidden-crime-met-police-under-reported>; see also Evans, R. (2015, October 11). Witchcraft abuse cases on the rise. *BBC News*. <http://www.bbc.com/news/uk-34475424>

155 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. U.N. Doc. A/HRC/34/59 (January 10, 2017) (by Ikponwosa Ero). Available from [undocs.org/en/A/HRC/34/59](http://undocs.org/en/A/HRC/34/59). [Hereinafter: UNIE, Doc. A/HRC/34/59].

156 Ibid; UNIE, Preliminary Survey on the Root Causes of Attacks and Discrimination, *supra*, note 54; Angola (Movimento); Burkina Faso (ABIPA 1); Côte d'Ivoire (APIFA); Côte d'Ivoire (BEDACI); DRC (GI); Ghana (NCPD); Kenya (AFEA); Kenya (PE); Mali (CORPA); Malawi (MACOHA); Mozambique (AAAM); Mali (Traore); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (TAF); Senegal (DIOP); Sierra Leone (SLAFo); South Africa (Kromberg) [though incidents have been quite rare in the last 30 years]; Tanzania (KCBRP); Tanzania (UTSS); Tanzania (UNICEF); Togo (CAS); Uganda (AAAU); Uganda (DOTACM); Uganda (HUPA); Uganda (NCD); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zambia (DAZ); Zimbabwe (GAM).

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168 UN Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions. Report of the Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions, Philip Alston. U.N. Doc. A/HRC/11/2 (May 27, 2009) (by Philip Alston). Available from [undocs.org/A/HRC/11/2](http://undocs.org/A/HRC/11/2); UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on the Expert Workshop on Witchcraft and Human Rights. U.N. Doc. A/HRC/37/57/Add.2 (January 23, 2018) (by Ikponwosa Ero). Available from [undocs.org/A/HRC/37/57/Add.2](http://undocs.org/A/HRC/37/57/Add.2) [Hereinafter: UNIE, Expert Workshop on Witchcraft and Human Rights]; Schnoebelen, J. (2009). Witchcraft allegations, refugee protection and human rights: A review of the evidence. *New Issues in Refugee Research*, 169. [unhcr.org/research/working/4981ca712/witchcraft-allegations-refugee-protection-human-rights-review-evidence.html](http://unhcr.org/research/working/4981ca712/witchcraft-allegations-refugee-protection-human-rights-review-evidence.html)

169 Ibid.

170 UNIE, Doc. A/HRC/34/59, *supra*, note 156.

171 Witchcraft allegation, refugee protection and human rights, Schnoebelen, *supra*, note 169.

172 Ghana (ENA).

173 Witchcraft allegation, refugee protection and human rights, Schnoebelen, *supra*, note 169.

174 Ibid.

175 Ibid.

- 176 Whitaker, K. (2012, September 1). Ghana witch camps: Widows' lives in exile. BBC. [bbc.com/news/magazine-19437130](http://bbc.com/news/magazine-19437130)
- 177 Ibid; UNIE, Women and Children Impacted by Albinism, supra, note 169.
- 178 Witchcraft allegation, refugee protection and human rights, Schnoebelen, supra, note 169.
- 179 Ibid.
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- 181 Cameroon (APAC).
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## Chapter 3: Access to Justice

### i. Human Rights Overview

Each State Party to the present Covenant undertakes:

(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;

(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the State, and to develop the possibilities of judicial remedy;

(c) To ensure that the competent authorities shall enforce such remedies when granted.

*International Covenant on Civil and Political Rights, Article 2(3)*

States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

*Convention on the Rights of Persons with Disabilities, Article 13(1)*

Around the world, people with albinism struggle to access justice after being subjected to attacks, persecution, discrimination, and other human rights violations. Access to justice is a fundamental human right that is necessary for the protection and promotion of all other human rights.<sup>206</sup> It ensures that all people whose rights have been violated have access to just and timely remedies, which are determined and enforced by the state's appropriate legal authorities.<sup>207</sup> Access to justice encompasses the right to a fair trial, which includes equal access to and equality before the courts.<sup>208</sup> Access to justice is also an important tool to hold governments accountable for violations of economic, social, and cultural rights, such as the right to health or education.<sup>209</sup>

States need to take all necessary steps to provide fair, transparent, effective, non-discriminatory, and accountable services that promote access to justice for all.<sup>210</sup> In order to ensure people with albinism can access justice on an equal basis with others, deliberate measures need to be taken to eliminate existing barriers, promote active participation, and provide accommodation through all stages of the legal process.<sup>211</sup> As it currently stands, people with albinism—especially women and children with albinism—face significant barriers in accessing both the criminal and civil justice systems.<sup>212</sup> Unlike the criminal justice system, in which the government initiates a legal proceeding against an individual, a civil case is between two private parties and is commenced when one party wrongs the other. The criminal justice system is the appropriate avenue for people with albinism who are victims of physical attacks and other violence, whereas the civil system is more appropriate for those who face discrimination by an employer or a service provider.

As a result of barriers to accessing justice, human rights violations against people with albinism (including physical attacks) often go unreported or unpunished by the law.<sup>213</sup> It is reported that in many African countries, only a fraction of attacks have been prosecuted. For instance, a report from Malawi showed that the majority of cases of grave crimes have inordinate delays and were yet to be prosecuted.<sup>214</sup> In Malawi, impunity manifests in the form of early release of perpetrators back into their communities, whether because of light sentences, release on bail, or paying of fines. Perceived impunity contributes to feelings of injustice and reduces the deterrent effect of criminal law.<sup>215</sup>

Without active government support, victim assistance and rehabilitation largely fall to civil society organizations to provide.<sup>216</sup> People with albinism, particularly those in remote areas, may also be pushed toward seeking justice in the informal justice system because of these barriers. However, the informal justice system does not have the legal authority to impose appropriate punishments for severe crimes like murder.<sup>217</sup>

Barriers to accessing justice for people with albinism—including barriers related to access to information, structural and legal barriers, and socioeconomic and cultural barriers—are explored in more depth in the following sections.



## ii. Access to Information

People with albinism across the globe are prevented from accessing justice due to inaccessibility of information about their rights and how best to invoke them before legal authorities. Specifically, people with albinism struggle to find and receive legal information about the length, costs, available services or supports, and possible outcomes of legal proceedings.<sup>218</sup> Access to information is a significant element of access to justice. When there is effective access to information and communication, people with albinism are empowered to know and defend their rights.<sup>219</sup> In countries without adequate access to information, some people with albinism develop low self-esteem and are not motivated to assert their rights.<sup>220</sup>

States have a responsibility to promote accessible legal information to people with albinism at both an individual level and a societal level by using a variety of formats and modes of communication.<sup>221</sup> In order for there to be access to information, legal information and documents must be both available and accessible to people with albinism. This means they must be easy to obtain, written in simple terms in the appropriate language, and available in a format that is accessible to those with visual impairment, at all stages of the legal process.<sup>222</sup>

In many parts of the Africa, people with albinism, especially those who live in rural areas, are generally unaware of their rights and the proper procedures to follow when seeking justice.<sup>223</sup> Parents of children with albinism have limited access to information regarding their child's rights in education; for instance, in Kenya, mothers are not always aware that accommodation is available for their children in school.<sup>224</sup> Similarly, in the Americas and in some parts of Europe and Asia, people with albinism lack the information and know-how to access their entitlements and remedies and thus are unable to claim their rights.

People with albinism are also generally unaware of any legislative protections or support (such as legal aid) that are available to them, including where to go to access such services.<sup>225</sup> Although legal advice and support is available in Norway, people with albinism are not always informed of the existence of these resources.<sup>226</sup> Despite the fact that there is an ombudsman's office in each region of Colombia, through which all citizens have access to a



complaints mechanism, people with albinism do not have enough information about their rights to access these services.<sup>227</sup>



“Senator Mwaura of Kenya & J. Epelle, CEO TAF Nigeria, Action on Albinism Forumn, Dar es Salaam, 2016” © UTSS

The inaccessibility of information about rights and remedies in some countries is largely due to a lack of public education and awareness-raising on the subject.<sup>228</sup> Although police officers have the potential to be useful contact points for gaining information, interactions with law enforcement are not always helpful and require a significant amount of follow-up by the person with albinism.<sup>229</sup>

“The access to information with regards to rights is a challenge as most documents are written in English and generally complex yet most [persons with albinism] are not educated.”

*Respondent from Eswatini*

In these same countries, a lack of adequate funding further impairs the capacity of policy, judiciary and other institutions to provide accessible legal information.<sup>230</sup> In order for States to meet their obligations under international law, appropriate resources need to be allocated to ensuring people with albinism are informed about their rights and remedies available to them when their rights are violated.

### iii. Structural and Legal Barriers

The main challenge is the bureaucratic nature of the justice system. It is a long process and can be very exhausting and emotionally draining and embarrassing especially to victims of rape. Which is why most of the cases they decide not to report.

*Respondent from Zimbabwe*

Structural and legal barriers remain a significant obstacle to access to justice for people with albinism. Legal systems should support people with albinism and facilitate the resolution of the complex and unique legal issues they face; instead, current legal systems often deny people with albinism justice or deter them from even trying to access justice in the first place. Courts have denied justice to victims with albinism because of lack of evidence, confusing processes, loopholes in the law, or interference by the perpetrator in the proceedings.<sup>231</sup>

In some countries where people with albinism are at risk of physical attacks and violence, gaps in the law prevent people with albinism from accessing justice. For example, in some countries, existing laws do not criminalize the trafficking of non-organ body parts. This means that the trafficking of limbs of people with albinism may not technically be considered a crime in countries with that legislative gap.<sup>232</sup> In addition, many States' laws do not adequately address the issue of HPAWR. Even where adequate laws exist, enforcement is a continuing challenge.<sup>233</sup> Across countries where cross-border trafficking of body parts occurs, there are limited means of ensuring cooperation among the law enforcement authorities of the involved countries, even though such cooperation is necessary to stop and prevent these acts.<sup>234</sup> Further, many social and economic rights, such as the right to health or the right to education, are not capable of being enforced in most courts.<sup>235</sup>

Delay and long timelines in legal proceedings are common structural factors that prevent people with albinism from seeking remedies.<sup>236</sup> In many countries in Africa, when a person with albinism is killed, attacked, discriminated against, or banished, local authorities and courts are often slow to proceed or simply do not follow up at all.<sup>237</sup> For example, in Nigeria, a civil society organization decided to abandon a case they had brought against a woman accused of infanticide of a child with albinism after the judge continuously prolonged the case.<sup>238</sup>

Delayed justice is justice denied”: many murder cases involving the killing of persons with albinism have not been prosecuted to the end in law courts

*Respondent from Tanzania*

In addition to delays, the capabilities (or lack thereof) and attitudes of authorities and legal personnel pose a challenge to accessing justice. Law enforcement officers often lack the resources, training, or skills to properly address and investigate human rights abuses against people with albinism, including with respect to the proper handling of evidence.<sup>239</sup> In many countries, effective communication between the authorities and victims is lacking. In India, a report found that people with albinism who lodged complaints with local authorities over serious negative experiences were often not informed of any actions taken by the authorities related to their complaints.<sup>240</sup> In the Democratic Republic of the Congo, authorities were silent and secretive when dealing with a case of physical violence against a person with albinism.<sup>241</sup> In Eswatini, reports of attacks against people with albinism were not taken seriously by law enforcement.<sup>242</sup> In addition to law enforcement officials, lawyers and other legal personnel are generally not trained to deal with albinism-specific issues.<sup>243</sup>

#### **iv. Socioeconomic and Cultural Barriers**

People with albinism are deterred from accessing justice due to socioeconomic and cultural factors, such as stigma, discrimination, lack of family support, and costs.<sup>244</sup>

Illiteracy and lack of education, which typically result in lower self-esteem and self-confidence, are common hurdles to seeking remedies, given that justice systems are usually more accessible to the educated elite.<sup>245</sup> This reaffirms the importance of ensuring the right to education for people with albinism, as well as the interconnectedness of human rights generally.

Many attacks committed against people with albinism go unreported because of the victim’s fear of reprisals by the perpetrators<sup>246</sup> or because of the resulting stigmatization and discriminatory attitudes of family members and others in the community.<sup>247</sup> In Nepal, people with albinism will choose not to seek

justice because of a fear of speaking out against the community.<sup>248</sup> In Fiji, societal pressure to withdraw complaints is likely a factor in the reluctance to report cases.<sup>249</sup> Some people with albinism choose not to report crimes because of the embarrassment of having to recount the crime publicly; this is especially true when the perpetrator is a family member of the victim. In these cases, there is often indirect and direct pressure to settle the matter quietly, without the involvement of the formal justice system.<sup>250</sup>

Women “whose spouses were involved in attacks against their child with albinism often face actual and threats of reprisal after testifying against their husbands in investigations of cases of attacks. Reprisal often comes from both the family of her husband and the community at large.

*Respondent from Kenya*

Another reason why crimes against people with albinism are underreported is because victims do not trust the police or the justice system.<sup>251</sup> In Mozambique, when a crime is reported to the police, the police may disclose the complainant’s personal information to the accused.<sup>252</sup> This undermines the complainant’s trust in the legal system and deters people from reporting crimes in the first place.

The costs associated with legal proceedings—including transportation costs to court, lawyers’ fees, and filing fees—are prohibitive for many people with albinism.<sup>253</sup> In Uganda, the police charge a fee for making inquiries into an allegation, which is unaffordable for most people with albinism.<sup>254</sup> Although general legal aid schemes are available in many countries, these programmes are not typically inclusive enough to facilitate access to justice for people with albinism specifically.<sup>255</sup> States are responsible for ensuring that costs and other barriers to justice are eliminated or minimized for people with albinism.

## Endnotes

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238 Nigeria (TAF).

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## Chapter 4: Right to Education



“Children in school, South Africa” © UTSS

### i. Human Rights Overview

Education is both a human right in itself and an indispensable means of realizing other human rights.

*CESCR, General Comment 13 on the Right to Education*

The right to universal education without discrimination of any kind is recognized in numerous international and regional human rights instruments.<sup>256</sup> Education is an “empowerment right.” It promotes the full development of children’s abilities and potential<sup>257</sup> and allows otherwise marginalized individuals to participate fully in society.<sup>258</sup> The right to education encompasses (i) free, available, and compulsory primary education; (ii) generally available and accessible secondary education; and (iii) equitable access to higher education.<sup>259</sup> At all levels, education must exhibit four features:<sup>260</sup>

- 1. Availability:** There must be a sufficient school available throughout each state.<sup>261</sup>
- 2. Accessibility:** Schools must be accessible to all children. Accessibility includes buildings, playgrounds, hygiene and toilet facilities, educational materials, and support services.<sup>262</sup>

3. **Acceptability:** Education must be acceptable to the needs, cultures, and languages of all students.<sup>263</sup>
4. **Adaptability:** Education must be adaptable to the needs of all students, including those with different learning requirements.<sup>264</sup>

States must take all measures to the maximum extent of their available resources toward the progressive realization of the right to education. In other words, States have a continuing obligation to move as quickly and effectively as possible towards its full realization.<sup>265</sup>



“Young student, South Africa” © UTSS

People with albinism are consistently denied this right to education. “Discrimination, social stigma, superstitions and myths, violence, poverty, the absence of appropriate infrastructure, a lack of security and the absence of reasonable accommodation, learning material and methods, as well as a lack of sufficiently trained personnel,” significantly contribute to low school attendance and high dropout rates among people with albinism.<sup>266</sup> This lack of education, or adequate education, is a matter of life and death; it confines many people with albinism to poverty and dangerous jobs.<sup>267</sup>

The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.

*ICESCR, Article 13(1)*

Inclusive education, enshrined in Article 24 of the CRPD, is key to achieving the right to education for people with albinism.<sup>268</sup> Inclusive education recognizes that States must combat discrimination, recognize diversity, promote participation, and overcome barriers to learning and participation for all by focusing on the well-being and success of students with disabilities.<sup>269</sup> Achieving inclusive education involves:<sup>270</sup>

- 1. Reasonable accommodation:** States must provide “reasonable accommodations” for all students to have access to education on an equal basis with others.<sup>271</sup> Reasonable accommodations are adaptations that help combat discrimination in education and whose relevance and effectiveness outweigh expected costs.<sup>272</sup> They include, for instance, enlarging print, allowing students to use assistive technology, or allowing a student more time.<sup>273</sup> The failure to provide reasonable accommodation is discrimination.<sup>274</sup>

“Reasonable accommodation” means 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.

*CRPD, Article 2*

- 2. General and individual supports:** States must ensure that students have general and individual supports to ensure they are able to get the most out of their education. General supports include having enough trained teaching staff and ensuring access to financial resources, such

as scholarships.<sup>275</sup> Individual supports include individual education plans that set out what the student will need.<sup>276</sup> States must also provide specific support for people with certain impairments. Specific support includes, for example, orientation and mobility skills development for blind and partially sighted students.<sup>277</sup>

In realizing this right, States Parties shall ensure that:

- (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- (c) Reasonable accommodation of the individual's requirements is provided;
- (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

*CRPD, Article 24(2)*

**3. Trained teachers:** States must ensure that teachers are trained to effectively work in an inclusive environment. General Comment 4 encourages States to recruit and train teachers with disabilities to promote non-discrimination and equality, provide expertise in teaching students with disabilities, and serve as role models.<sup>278</sup>

Inclusive education recognizes that even though States are called on to progressively realize the full scope of the right to education, they do have certain immediate obligations. States have an immediate obligation to achieve non-discrimination, reasonable accommodation, and compulsory and free primary education for all.



## ii. Non-Discrimination

In most regions, people with albinism face discrimination inside and outside of the classroom, which interferes with their right to education. In many regions, parents do not send their children to school due to discriminatory beliefs. In some African countries, for instance, children with albinism are hidden at home and are not sent to school simply due to their albinism.<sup>279</sup> In some South American countries, parents withhold their children with albinism from school, based on the belief that their low vision and condition renders them incapable of succeeding in a school environment.<sup>280</sup> In Haiti, parents do not send their children with albinism to school because they believe that it is a waste of money given the perception that people with albinism have a shorter life expectancy.<sup>281</sup> In Colombia, girls and boys with albinism are withdrawn from school at a young age and confined at home or forced to support the family.<sup>282</sup> In parts of Asia, some families choose not to send their children with albinism to school because they see them as a burden.<sup>283</sup>

Since children with albinism cannot read on the board when the teacher writes, they must get up from their chair and this interferes with the non-albino classmates. Because of this, the child with albinism can be attacked with insults, teasing, criticism and any kind of psychological violence. This causes the child to think more than twice whether or not he or she will get up from his or her post to look and in the future will be a fearful adult who does not know how to ask for help or assert his or her rights.

Respondent from Colombia

Even when attempts are made to send children with albinism to school, children with albinism are sometimes unable to gain admission. In certain African countries, children with albinism are rejected by school authorities on the misconception that they are unable to learn or that they have 'special needs.'<sup>284</sup> In Colombia, some institutions refuse access to classrooms for people with visible differences.<sup>285</sup> In India, people with albinism sometimes have difficulty gaining admission to schools due to objections from other students' parents who believe that albinism is contagious.<sup>286</sup> Some people with albinism also face delays in their admission to school because of objections from teachers and discrimination based on physical appearance.<sup>287</sup>

Students with albinism who are able to access school face discrimination and

stigma in the classroom from peers, teachers, and members of the school's administration.<sup>288</sup> In Burundi and Côte d'Ivoire, there are reports that other students refuse to play with children with albinism, at times on the orders of their parents.<sup>289</sup> In Uganda, a survey revealed that pregnant teachers were afraid of students with albinism based on prevailing myths.<sup>290</sup> In Guatemala, children suffer physical violence at school.<sup>291</sup> In India, students face isolation from their peers and rude behavior from teachers and students alike.<sup>292</sup> In Japan, due to school regulations, students with albinism are forced to dye their hair black.<sup>293</sup> In Pakistan, people with albinism often face discrimination in education settings, from primary school through to university and college, due to their appearance and low vision.<sup>294</sup> In Europe, the Pacific, and the Middle East, there are reports that children with albinism experience name-calling,<sup>295</sup> physical violence and verbal abuse,<sup>296</sup> bullying, and stigma.<sup>297</sup>

### **iii. Reasonable Accommodation**

Around the world, there is little to no reasonable accommodation for students with albinism.<sup>298</sup> In many African countries, governments and schools do not provide adaptive devices to students, such as large print reading materials or glasses.<sup>299</sup> In Sierra Leone, for instance, 57% of school-age respondents said that their schools did not provide them with the necessary support and accommodation to enable them to access education on equal terms with others.<sup>300</sup> Reading materials are provided in inaccessible formats.<sup>301</sup> For example, books are printed in small font, which people with albinism have difficulty reading.<sup>302</sup> Students are not always given additional time during exams.<sup>303</sup>

In many South American countries, the lack of accommodation for low vision is considered the most significant barrier to education.<sup>304</sup> Even where services and accommodations are available, students with albinism do not always receive them. In some cases, students with albinism and their schools are unaware of the availability of such services.<sup>305</sup> For instance, in Zimbabwe, large print materials are available upon request, but students with albinism are not aware that they can access these materials; it falls on the teachers to request them.<sup>306</sup> Teachers are also sometimes unwilling to accommodate or they respond negatively to requests for accommodation.<sup>307</sup> In Colombia, there is no formal education protocol for persons with albinism; accommodation and inclusivity measures are at the discretion of each school.

This has resulted in both positive and negative experiences for students with albinism, depending on the school and the community.<sup>308</sup>

In many of these regions, teachers simply lack any knowledge or understanding of albinism, including the vision challenges<sup>309</sup> and the risks of sun exposure.<sup>310</sup> Teachers do not know how best to support students with albinism,<sup>311</sup> and do not invest time to help students with albinism succeed in the classroom.<sup>312</sup> In Zambia, due to the belief that people with albinism will eventually lose their vision fully, children with albinism are taught Braille in primary school and usually attend separate schools for people with visual impairment.<sup>313</sup> In Mozambique, children are required to participate in outdoor physical education, which exposes them to the sun.<sup>314</sup> In Uganda, students with albinism are not allowed to put on their wide-brimmed hats during outdoor classes,<sup>315</sup> and they are prevented from wearing long-sleeve shirts.<sup>316</sup> Similarly, in Argentina and Haiti, students with albinism are not accommodated in classes with outdoor activity.<sup>317</sup>

In much of Europe and Asia, reasonable accommodations and supports are guaranteed in law. However, in practice, students do not always receive these supports. In many European countries, for instance, accommodative devices and support are available for students with albinism through statute,<sup>318</sup> usually free of charge.<sup>319</sup> However, teachers are unaware of the needs of people with albinism as they relate to their visual impairments.<sup>320</sup> In Norway, the laws that ensure accommodation in school environments are difficult to navigate, and students struggle to obtain appropriate visual aids and other learning resources.<sup>321</sup> In Slovenia, the process to request adaptive devices can be lengthy.<sup>322</sup> In the United Kingdom and Ireland,



“Sisters, UK” © Rick Guidotti

parents are sometimes required to

proceed through the education tribunal system to guarantee support for their children.<sup>323</sup> In Turkey, there are legislative provisions for accommodation, but implementation of the legislation is not consistent.<sup>324</sup>

There is no specific consultancy available for the children with albinism at the schools, as a result the teachers/directors don't know and understand the requirements well enough to help to these children. Parents also don't have sufficient information on the requirements and most of them don't know information about their rights as well. As an example, the legislation allows children with disabilities in general to have an additional education hours after the school. The objective is to provide 1-1 education and to close the gap on the education if any. But most of the schools don't have enough capacity on personnel to execute it; most of the parents don't have knowledge about their rights.

*Respondent from Turkey*

In many Asian countries, accommodations and adaptive devices for students are available upon request.<sup>325</sup> However, there is a lack of specialists with knowledge of visual impairment in schools, and teachers are generally unaware of how to support students with low vision and photophobia.<sup>326</sup> Additionally, students are placed in classes with 50 students, which typically means teachers are not able to accommodate them.<sup>327</sup>

#### **iv. Primary education**

Partly due to the barriers detailed above, many countries are failing to provide free primary education to children with albinism. Discrimination leads to depression, demotivation, and isolation.<sup>328</sup> This contributes to a pattern of low school attendance and high dropout rates.<sup>329</sup> Similarly, a lack of accommodation leads to poor academic performance,<sup>330</sup> which contributes to low self-esteem and diminished ambition.<sup>331</sup> Ultimately, students with albinism drop out.<sup>332</sup>

In Africa, lack of financial support is another major barrier.<sup>333</sup> Children with albinism are often unable to pay tuition,<sup>334</sup> unable to afford uniforms and supplies to protect themselves from the sun,<sup>335</sup> and unable to afford eyewear, which leads to many dropping out of school.<sup>336</sup> Additionally, many children do not attend school because of risks to their health and safety.<sup>337</sup> Children

who have to travel long distances to school are often forced to drop out of school because of threat or fear of attacks,<sup>338</sup> or because of the risks of sun exposure while walking to school.<sup>339</sup> Many parents withhold their children, especially girls, from school or have them start at a later age because of fear of attacks or prejudice, or due to concerns about their children's learning ability.<sup>340</sup> In Malawi, most parents do not send their daughters with albinism to school.<sup>341</sup>

The challenges inside and outside of the classroom mean that children with albinism are unable to complete their schooling;<sup>342</sup> consequently, many have low levels of education.<sup>343</sup> In Burkina Faso, 30% of girls with albinism do not finish primary school.<sup>344</sup> In Burundi, 56% of people with albinism have not completed their schooling<sup>345</sup> and 20% of girls with albinism do not finish primary school.<sup>346</sup> In Zambia, people with albinism have a literacy rate of 66% compared to the national average of 92%,<sup>347</sup> and only half the population of people with albinism complete an education level greater than primary school.<sup>348</sup> In a small survey (n = 44) of children with albinism under 18 years old in Colombia, 17% of respondents neither studied nor worked.<sup>349</sup> In a census of people with albinism in Paraguay, 11% of the children did not attend school compared to the national average of 89%.<sup>350</sup>



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## Chapter 5: Right to Work and an Adequate Standard of Living



"Woman from USA" © Rick Guidotti

## **Article 6**

1. The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.

2. The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

## **Article 7**

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of just and favourable conditions of work which ensure, in particular:

(a) Remuneration which provides all workers, as a minimum, with:

(i) Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work;

(ii) A decent living for themselves and their families in accordance with the provisions of the present Covenant;

(b) Safe and healthy working conditions;

(c) Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than those of seniority and competence;

(d) Rest, leisure and reasonable limitation of working hours and periodic holidays with pay, as well as remuneration for public holidays

*International Covenant on Economic, Social and Cultural Rights*



## *i. Human Rights Overview*

**Right to work:** The right to work is guaranteed to people with albinism in various human rights treaties, most notably in Articles 6 and 7 of the ICESCR.<sup>351</sup> The right to work means the right to freely accept or choose work and the right not to be unfairly deprived of work.<sup>352</sup> Work must be “decent work,” meaning:

*“...[W]ork that respects the fundamental rights of the human person as well as the rights of workers in terms of conditions of work safety and remuneration. It also provides an income allowing workers to support themselves and their families... These fundamental rights also include respect for the physical and mental integrity of the worker in the exercise of his/her employment.”<sup>353</sup>*

Relatedly, everyone has the right to “just and favourable conditions of work,” such as fair pay and safe and healthy working conditions.<sup>354</sup> These rights apply to everyone and to all forms of work, including workers in the informal sector, unpaid workers, self-employed workers, domestic workers, and agricultural workers.<sup>355</sup>

People with albinism face many difficulties in accessing employment, including discrimination, unaccommodating work environments, fear of attacks, illiteracy, and lack of qualifications or education.<sup>356</sup> Due to these barriers, many people with albinism around the world are unemployed or precariously employed, with many forced to work low-paid, short-term jobs in the informal sector.<sup>357</sup> The informal sector consists of economic activities that are not regulated or protected by the government; this means that people employed within the informal sector do not have full access to laws and systems that protect workers’ rights. In the Brazilian state of Bahia, only 10% of people with albinism are employed in the formal sector.<sup>358</sup> In Ghana, many people with albinism work in agriculture or sell wares in the market.<sup>359</sup> In Zambia, 46% of working-age people with albinism are self-employed, and the majority of people with albinism (71% for males and 80% for females) are employed in the agriculture, forestry, and fishing sectors.<sup>360</sup> In India, a survey of people with albinism revealed that 22% of respondents were unemployed, 18% were daily-wage labourers, and 11% were employed part-time.<sup>361</sup>

Challenges faced in accessing education, lead to the myth that people with albinism are not intelligent. Hence, most companies are not keen to employ people with albinism. Couple that with the myths surrounding the whole condition in general, no one is willing to work side by side with a person with albinism.

*Respondent from Zimbabwe*

The right to work interacts with many other human rights. Barriers to other rights can hinder access to employment. For example, in many countries, people with albinism are unable to secure work in the formal sector because they lack the qualifications required for the job as a result of challenges they have faced in accessing education.<sup>362</sup>

**Right to adequate standard of living:** The right to an adequate standard of living is strongly linked to the fulfillment of the right to work—without decent employment, a person with albinism may be unable to achieve an adequate standard of living for themselves or their families.<sup>363</sup> Specifically, the right to just and favourable conditions of work requires that compensation provide a decent living for workers and their families.<sup>364</sup> The right to an adequate standard of living encompasses adequate food, clothing, housing, clean water, and other living conditions.<sup>365</sup>

1. The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international co-operation based on free consent.

*ICESCR, Article 11*

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

*CRPD, Article 28*

People with albinism often occupy the lowest socioeconomic level due to persistent marginalization and discrimination.<sup>366</sup> In Uganda, people with albinism in rural areas were found to be generally poorer than their immediate neighbours.<sup>367</sup> In Burkina Faso, 90% of women with albinism and 65% of mothers of children with albinism live in poverty,<sup>368</sup> while in Ecuador, the poverty rate for women with albinism and mothers of children with albinism is reported to be as high as 40%.<sup>369</sup> In some African countries, people with albinism are unable to access secure housing due to discrimination from landlords, family, and other members of the community.<sup>370</sup> This, in turn, increases their vulnerability to attacks.<sup>371</sup>

Ensuring the right to an adequate standard of living—and the interconnected right to work—is a fundamental obligation of the State. The following sections explore existing barriers to these rights, including discrimination, occupational health and safety, accommodation, and social security.

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions...

*CRPD, Article 27*



“Brothers and lawyers Dr. Abdallah Possi (L) and Dr. Ally Possi (R)”

## **ii. Non-Discrimination**

The biggest problem that we suffer people with albinism is discrimination in different areas, both socially, as in education, health and especially in the workplace; on this point, it is unavoidable the mistreatment and discrimination on the part of the eventual employers towards the albino people, which causes a very high rate of unemployment among this group; we believe that this situation is due to the lack of knowledge on the subject added to the beliefs based on myths about albinism. No less serious is the fact that, at an educational level, the lack of knowledge and lack of understanding is notorious, which leads to a poor adaptation of people with albinism to the school environment, which leads to an eventual school dropout and later incompetence.

Respondent from Argentina

Despite being prohibited by international law,<sup>372</sup> multiple and intersecting discrimination on the basis of colour and disability remains a barrier for people with albinism when trying to obtain and maintain employment. As a result of this discrimination, many qualified people with albinism are unemployed, often resulting in depression and self-esteem issues.<sup>373</sup>

During both the hiring process and the ongoing employment relationship, people with albinism experience discrimination, harassment, isolation,

and other mistreatment by employers and fellow employees alike, due to misconceptions and myths about albinism.<sup>374</sup> People with albinism are sometimes denied job opportunities on the basis of the colour of their skin and physical appearance.<sup>375</sup> In Japan, people with albinism have failed job interviews because of the colour of their hair and have been forced to dye their hair black by their employers.<sup>376</sup> In some countries in Africa, employers—particularly those in the food and hospitality industries<sup>377</sup>—do not hire people with albinism because they are concerned that they may “scare away” potential customers or create a perception of contagion.<sup>378</sup> People with albinism who operate their own businesses face similar discrimination from potential patrons, resulting in a loss of business.<sup>379</sup> In Eswatini, there is a myth that a person with albinism will disappear and not return the patron’s change.<sup>380</sup>

“My situation was not all that bad, there is no job I can’t do but some people on looking at our bodies, think we [persons with albinism] are too weak to work.”

*Respondent from Uganda*

Employers evaluate [people with albinism] as disabled people and do not want to work with or try to assign to unqualified jobs. Visual impairment is the biggest barrier in employment as none of the employers desire to provide additional contributions for [people with albinism].

*Respondent from Turkey*

Many employers shun from engaging PWAs to work in their company with the reason that they do not have the capacity to perform and also they may scare away potential customers.

*Respondent from Ghana*

Other times, employers refuse to hire people with albinism because of their disability.<sup>381</sup> Employers often conflate disability with inferiority or incompetency and make negative assumptions about people’s abilities in the workplace.<sup>382</sup> As well, people with albinism face difficulties securing a job because some employers are unwilling to provide accommodation.<sup>383</sup> The refusal to provide accommodation for a person with a disability is an act of discrimination according to the CRPD. In Colombia, some employers are unwilling to hire people with albinism because they do not want to be liable if the person suffers burns or other skin damage on the job.<sup>384</sup>



In some cases, particularly in private companies, employees with albinism in certain countries in Africa are vulnerable to sexual harassment and ritual rape by employers due to the belief that such acts bring wealth and good luck in business.<sup>385</sup>

### **iii. Occupational Health and Safety and Reasonable Accommodation**

People with albinism face challenges in obtaining and maintaining employment because of occupational health and safety hazards and because of a lack of accommodation by employers to minimize the risk of these hazards. Due to their vision impairments and increased susceptibility to skin cancer, people with albinism require work environments that are accessible and responsive to their health needs. For instance, people with albinism may require optical aids or sun protection gear to safely perform their work. A safe and healthy work environment is a fundamental aspect of the right to just and favourable conditions of work, and is closely connected to other rights, such as the right to health.<sup>386</sup> In order to fully enjoy their right to work on an equal basis with others, workers with disabilities, including people with albinism, require accessible workplaces; they should not be denied reasonable accommodation.<sup>387</sup>

Across the globe, the occupational health and safety of workers with albinism is threatened by a lack of reasonable accommodation for vision impairment and vulnerability to ultraviolet-induced skin damage.<sup>388</sup> Because of illiteracy and a lack of educational qualifications, people with albinism are often only qualified for jobs that involve working outdoors (such as peddling wares or agriculture) and for which they are not provided sun protection gear; as a result, working increases their risk of skin cancer.<sup>389</sup> In some countries, people with albinism cannot work early morning or night shifts because of fear or threat of attacks, thus limiting their income potential.<sup>390</sup> Without reasonable accommodations, people with albinism are forced to choose between unemployment or grave risks to their health and safety.

The low level of education of the PWAs in the large north, the prevailing poverty has made them assisted or living small jobs without real qualifications. In addition, there is also discrimination in hiring due to prejudices and also the need to adapt the workstation; a PWA that works on a computer needs to place the magnifying glass or zoom in strongly to see the writings that are displayed there.

*Respondent from Cameroon*

Refusal to adapt the workplace for people with albinism is a prohibited act of disability-based discrimination.<sup>391</sup> In many parts of the world, people with albinism are effectively barred from employment when prospective employers are unwilling to make accommodations for them.<sup>392</sup> In some European countries, employers are more hesitant to hire a person with albinism because of the perceived difficulties involved in accommodating an employee with a disability.<sup>393</sup> In Australia, people with albinism sometimes face the challenge of having to convince employers that they are indeed capable of working, as a result of the employer's misconceptions about albinism-related vision impairment.<sup>394</sup>

#### **iv. Economic Empowerment and Social Security**

The private sector is still reluctant to employ people with albinism on the pretext that they would not be effective because of their fragile condition. There are very few initiatives giving the opportunity for people with albinism to benefit from activities generating income.

*Respondent from Cote D'Ivoire*

In order for people with albinism to escape the cycle of poverty, resources must be invested in economic empowerment activities and social security programmes. Multiple and intersecting discrimination prevents people with albinism from pulling themselves out of poverty on their own. For example, people with albinism—particularly women with albinism—are sometimes unable to secure loans to start their own business because they do not have enough credit or assets required for the loan application as a result of subsisting poverty and unemployment.<sup>395</sup> In other cases, people with albinism miss out on economic opportunities when they are disinherited by family members because of their condition.<sup>396</sup>

Social security is an important element of the right to work and to an adequate standard of living because it compensates for a lack of work-related income.<sup>397</sup> According to the CRPD, States must ensure access to social protection and poverty reduction programmes for people with albinism.<sup>398</sup> In some parts of the world, social benefits are readily available to people with albinism.<sup>399</sup> In Denmark, for example, financial aid is provided to families until the child reaches the age of 18 in order to offset any costs arising from their condition.<sup>400</sup> The Ministry of Local Government, Housing and Environment in Fiji is involved in partially writing off loans for people with disabilities in dire financial situations.<sup>401</sup>

However, in many other countries, social assistance schemes are generally weak. In Nigeria, there is no inclusive financial benefit for people with albinism.<sup>402</sup> Even in countries where social security programmes do exist, people with albinism lack knowledge about how to access these benefits.<sup>403</sup> In Brazil, the social assistance program for people with disabilities who are unemployed, Benefício de Prestação Continuada (BPC), is relied on by many people with albinism. However, accessing the BPC program is difficult because people with albinism do not always meet the disability test. As a result, people with albinism often have to initiate a court process to receive the benefits.<sup>404</sup> In line with their responsibility to ensure the right to work and an adequate standard of living, governments have an obligation to ensure that social security programmes are robust and accessible to people with albinism.



“Twins with their big sister, Brazil” © annapmm

## Endotes

351 See also: ICCPR, Art. 8(3)(a); CRPD, Art. 27; ICERD, Art. 5(e)(i); CEDAW, Art. 11(1)(a); CRC, Art. 32; CRMW, Arts. 11, 25, 26, 40, 52, and 54. The right to work is also enshrined in various regional instruments including the European Social Charter (529 U.N.T.S. 89; E.T.S. No. 35 (October 18, 1961)) and the Revised European Social Charter (E.T.S. No. 163 (May 3, 1996)) (Part II, Art. 1), the African Charter on Human and Peoples' Rights (1520 U.N.T.S. 217; 21 I.L.M. 58 (June 27, 1981)) (Art. 15), and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (O.A.S.T.S. No. 69 (November 17, 1988)) (Art. 6).

352 UN Committee on Economic, Social and Cultural Rights. General Comment No. 18: The Right to Work. U.N. Doc. E/C.12/GC/18 (February 6, 2006), para. 6. Available from [undocs.org/en/E/C.12/GC/18](http://undocs.org/en/E/C.12/GC/18). [Hereinafter: OHCHR, General Comment No. 18]

353 *Ibid* at para. 7..

354 UN Committee on Economic, Social and Cultural Rights. General Comment No. 23 (2016) on the Right to Just and Favourable Conditions of Work (Article 7 of the International Covenant on Economic, Social and Cultural Rights). U.N. Doc. E/C.12/GC/23 (April 27, 2016), para 1. Available from [undocs.org/E/C.12/GC/23](http://undocs.org/E/C.12/GC/23). [Hereinafter: OHCHR, General Comment No. 23]

355 *Ibid* at para 5.

356 Angola (Movimento); Burundi (Femmes Albinos); Burundi (OPAB); Cameroon (Association); Côte d'Ivoire (APIFA); Côte d'Ivoire (BEDACI); Guinea (CNAG); Guinea (UBEAG); Malawi (MACOHA); Malawi & Tanzania (SV); Mali (CORPA); Mali (Traore); Mozambique (AAAM); Mozambique (Amor); Mozambique (Shade Tree); Niger (ANAN); Nigeria (OAM); Rwanda (OIPPA); Senegal (DIOP); Somalia (APHAD); Tanzania (Mesaki); Tanzania (UNICEF); Tanzania (UTSS); Togo (CAS); Uganda (AAAU); Uganda (DOTACM); Uganda (HUPA); Uganda (Lund & Goodman); Uganda (NCD); Uganda (SNUPA); Uganda (UAA); Zambia (DAZ); Zimbabwe (GAM); Argentina (Albinismo Argentina); Argentina (SA); Brazil (Albinal); Brazil (APALBA); Brazil (IE); Colombia (AdC); Colombia (FAC); Colombia (FVF); Ecuador (PdA); Fiji (MR); Guatemala (AdG); Haiti (ALBHA); Paraguay (AP); Venezuela (AG).

357 Brazil (APALBA); Brazil (IE); India (WPRA); Uganda (AAAU); Zambia (Albinism Foundation of Zambia).

358 Brazil (APALBA); Brazil (IE).

359 Ghana (NCPD).

360 Zambia (Albinism Foundation of Zambia).

361 India (WPRA).

362 Argentina (SA); Brazil (Albinal); Brazil (APALBA); Brazil (IE); Panama (GG); Paraguay (AP).

363 OHCHR, General Comment No. 23, *supra*, note 354 at para 1.

364 *Ibid* at para 18.

365 ICESCR, Art. 11; CRPD, Art. 28.

366 Brazil (IE); Colombia (FAC); Haiti (ALBHA); India (WPRA); Panama (GG); Burkina Faso (ABIPA 1); Burundi (Femmes Albinos); Cameroon (APAC); Côte d'Ivoire (APIFA); Eswatini (Minerva); Ghana (NCPD); Guinea (CNAG); Kenya (State); Mali (Traore); Mozambique (AAAM); Mozambique (Amor); Niger (ANAN); Sierra Leone (SLAFo); Tanzania (UTSS); Uganda (AAAU); Uganda (DOTACM); Uganda (HUPA); Uganda (Lund & Goodman); Uganda (SNUPA).

367 Uganda (AAAU).

368 Burkina Faso (ABIPA 1).

369 Ecuador (Comunidad).

370 Malawi & Tanzania (SV); Sierra Leone (SLAFo); Uganda (DOTACM); Uganda (UAA); Zambia (UNIE, Applicable International Human Rights Standards, *supra*, note 3 para. 60).

371 Malawi (MACOHA); Mozambique (Amor).

372 ICESCR, Arts. 2 and 3; CRPD, Art. 27; ICERD, Art. 5(e)(i).

373 Burkina Faso (ABIPA 1); Cameroon (Association); Côte d'Ivoire (BEDACI); Guinea (UBEAG); Rwanda (OIPPA); Uganda (AAAU).

374 Argentina (Albinismo Argentina); Argentina (SA); Brazil (APALBA); Brazil (IE); Colombia (AdC); Colombia (FAC); Colombia (FVF); Ecuador (PdA); Fiji (MR); France (Genespoir); Haiti (ALBHA); Paraguay (AP); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Cameroon (APAC); Cameroon (Association); Côte d'Ivoire (APIFA); Ghana (ENA); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Mali (Traore); Mozambique (AAAM); Mozambique (Shade Tree); Nigeria (OAM); Nigeria (TAF); Rwanda

(OIPPA); South Africa (Kromberg); Tanzania (UTSS); Uganda (AAAU); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zimbabwe (GAM); India (WPRA); India (JT); Japan (JAN); Malaysia (KLSAA); Nepal (NDAN).

375 Brazil (IE); Colombia (AdC); Ghana (ENA); Haiti (ALBHA); India (WPRA); Japan (JAN); Uganda (DOTACM); Uganda (Lund & Goodman); Uganda (UAA); UNIE, Applicable International Human Rights Standards, *supra*, note 3 at para. 62.

376 Japan (JAN).

377 UNIE, Applicable International Human Rights Standards, *supra*, note 3 at para. 62.

378 Ghana (ENA); Uganda (DOTACM); Uganda (Lund & Goodman); *Ibid* at para. 62.

379 Nigeria (TAF) [especially in the case of women with albinism]; Uganda (DOTACM); Uganda (SNUPA).

380 Eswatini (Albinism Society).

381 India (WPRA); India (JT); Japan (JAN); Malaysia (KLSAA); Nepal (NDAN); Brazil (APALBA); Mexico (FPLAM)

382 Brazil (APALBA); Colombia (FAC); Colombia (FVF); Mexico (FPLAM); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Cameroon (APAC); Cameroon (Association); Côte d'Ivoire (APIFA); Ghana (ENA); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Mali (Traore); Mozambique (AAAM); Mozambique (Shade Tree); Nigeria (OAM); Nigeria (TAF); Rwanda (OIPPA); South Africa (Kromberg); Tanzania (UTSS); Uganda (AAAU); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zimbabwe (GAM).

383 Denmark (ADK); Germany (NOAH); Turkey (AA).

384 Colombia (AdC); Colombia (FAC).

385 UNIE, Albinism Worldwide, *supra*, note 49 at para. 27.

386 ICESCR, Art. 7(b); OHCHR, General Comment No. 23, *supra*, note 354 at para 25.

387 CRPD, Art. 9 (1)(a); *Ibid* at para 47.

388 Burkina Faso (ABIPA 1); Côte D'Ivoire (BEDACI); Japan (JAN); Kenya (AFEA); Mozambique (AAAM); South Africa (Kromberg).

389 Cameroon (APAC); Kenya (KNCHR); Kenya (PE); Mali (Traore); Mozambique (AAAM); Uganda (UAA); Brazil (IE); Colombia (AdC); Haiti (ALBHA).

390 Eswatini (Minerva).

391 UN Committee on the Rights of Persons with Disabilities. General Comment No. 2 (2014): Article 9: Accessibility. U.N. Doc. CRPD/C/GC/2 (May 22, 2014), para 41. Available from [undocs.org/CRPD/C/GC/2](http://undocs.org/CRPD/C/GC/2).

392 Cameroon (APAC); Kenya (PE); Mozambique (Amor); Tanzania (UTSS); Turkey (AA).

393 Denmark (ADK); Germany (NOAH); Turkey (AA).

394 Australia (AFA).

395 Colombia (AdC); Eswatini (Minerva); Kenya (AFEA); Kenya (PE).

396 UNIE, Albinism Worldwide, *supra*, note 49 at para. 28.

397 ICESCR, Art. 9; OHCHR, General Comment No. 23, *supra*, note 354 at para 1.

398 CRPD, Art. 28(2)(b).

399 Denmark (ADK); France (Genespoir); Norway (NFFA); Spain (ALBA).

400 Denmark (ADK).

401 Fiji (MR).

402 Nigeria (TAF).

403 UNIE, Albinism Worldwide, *supra*, note 49 at para. 29.

404 Brazil (IE).



## Chapter 6: Right to Health

### i. Human Rights Overview

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

*International Covenant on Economic, Social and Cultural Rights,  
Article 12(1)*

International law guarantees people with albinism the right to the highest attainable standard of physical and mental health.<sup>405</sup> The right to health extends beyond just the right to health care and includes a variety of underlying socioeconomic factors that contribute to an individual's health, such as food, housing, water, working conditions, and the environment.<sup>406</sup> However, the right to health does not mean the right to be healthy—rather, it is the right to enjoyment of facilities, goods, services, and conditions that are necessary to achieve the highest attainable level of health.<sup>407</sup> This means that States have an obligation to provide health facilities, goods, and services that are available in sufficient quantity, accessible to everyone without discrimination, medically and culturally acceptable, and of good quality.<sup>408</sup> The right to health also includes the right to prevention and treatment of illnesses, the right to essential medicines, access to health-related education and information, and public participation in health-related decision-making at the national and community levels.<sup>409</sup>

The right to health is particularly important to people with albinism given the health complications they often experience. Insufficient pigment (melanin) in their eyes and skin can result in sensitivity to bright light, visual impairment, and increased susceptibility to ultraviolet-induced skin damage, including skin cancer.

Adequate health-related resources are essential not only to the right to health but to the enjoyment of many other rights as well. Without access to health-related resources for their conditions, people with albinism cannot fully enjoy the right to life, education, or work. For instance, without access to sun protection products, people with albinism may be unable to accept employment that takes place predominantly outdoors, thereby limiting their ability to achieve an adequate standard of living. Likewise, when their right

to education or their right to work is impeded or violated, their right to health will be challenged as well. In Kenya, due to discrimination and barriers to enjoying the right to work, people with albinism are often only able to secure outdoor work in the sun, which places them at a higher risk of skin cancer.<sup>410</sup>

“In the DRC, these challenges [to access to health] are compounded by many other problems, including instability armed conflicts, extreme poverty, displaced populations, the absence of specialists in dermatology and the lack of basic training in dermatology for dermatologists, health professionals in general, the lack of access to sun protection or dermatological drugs in the country, and lack of support organizations for the dermatology or albinism.

*Respondent from Democratic Republic of the Congo*

Unfortunately, across the globe, people with albinism continue to face a number of barriers to fully realizing the right to health. These challenges range from inaccessible health care, to a lack of knowledgeable health care practitioners, to inadequate government intervention. These barriers, outlined in the following sections, can have dire effects on the life expectancy and quality of life for people with albinism. In Brazil, for example, life expectancy for people with albinism is estimated to be as low as 33 years of age due to skin cancer.<sup>411</sup>

In the south, in the semi-arid region, the biggest problem is the burning sun, the desert, the lack of water, the painful life of the populations in which, on departure, the populations know beforehand that albinos have no chance of surviving to old age.

*Respondent from Angola*

## **ii. Accessibility**

The costs of health care services are very high for the people with albinism in our country. The cost of consultation, skin care products and other related care are inaccessible. There is no health insurance for the people with albinism. There are no early medical interventions. This is why many cases of skin cancer are detected every year. The situation in rural and remote areas is even more critical. Because the specialists (dermatologists and ophthalmologists) can only be found in some urban centers.

*Respondent from Burkina Faso*

Globally, many people with albinism are unable to access basic and necessary health care facilities, goods, and services.<sup>412</sup> Some of the barriers that impede access to health care include poverty,<sup>413</sup> prohibitive costs,<sup>414</sup> geography, bureaucracy and length of waiting times,<sup>415</sup> and social exclusion.<sup>416</sup> In some regions of the United Republic of Tanzania, only 43% of people with albinism have access to health services.<sup>417</sup> In Paraguay, only 5% of people with albinism reported that they had consulted a dermatologist at least once in their lives, and only 35% had visual aids.<sup>418</sup> Inaccessibility of health care can lead to serious consequences for people with albinism. In Haiti, for example, barriers to health care prevent people with albinism from accessing services until their cancer is very advanced.<sup>419</sup>

Accessibility is a foundational element of the right to health. It is composed of four overlapping components: non-discrimination, physical accessibility, economic accessibility, and information accessibility.<sup>420</sup>

**a. Non-discrimination**<sup>421</sup>

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

*Convention on the Rights of Persons with Disabilities, Article 25*

People with albinism face multiple and intersecting discrimination due to colour, disability, and gender, which prevents them from fully enjoying their right to health. The International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, and the International Convention on the Elimination of All Forms of Racial Discrimination all guarantee the right to health without discrimination.<sup>422</sup> Non-discrimination ensures that health facilities, goods, and services are available to everyone, especially vulnerable or marginalized groups, without discrimination based on one or more of the prohibited grounds, which include race, colour, sex, disability, and health status.<sup>423</sup> Discrimination can be overt—such as a doctor’s refusal to treat a person because of their albinism—or it can be covert. For instance, a lack of large-print health information or

medical forms may not be intended to discriminate against those with visual impairment, but may nevertheless have the effect of preventing people with albinism from accessing health care on an equal basis with others. For these reasons, States have a duty to provide reasonable accommodation with respect to the visual impairment of people with albinism.

In many regions of the world, colour- and disability-based discriminatory attitudes of health care professionals deter people with albinism from accessing health services.<sup>424</sup> Health professionals sometimes turn people with albinism away because of fear of contagion or bad luck, or because they find people with albinism visibly repugnant or undeserving of treatment.<sup>425</sup> In Colombia, health care professionals sometimes refuse to communicate with a patient with albinism directly and instead only address the person's companion, based on the belief that the person with albinism is a foreigner due to their skin colour; in other cases, health workers refuse to treat people with albinism altogether due to these misconceptions.<sup>426</sup> In some countries in Africa, people with albinism have reported that health care providers treat them inhumanly,<sup>427</sup> ignore them,<sup>428</sup> or are afraid to attend to them.<sup>429</sup> In India, people with albinism face discrimination from physicians and health care workers due to a lack of understanding of albinism and its cause.<sup>430</sup>

People with albinism who are living with HIV/AIDS face an additional layer of discrimination because of their health status. In some countries, the



“Boy from India” © Brent Stirton

rate of HIV/AIDS in people with albinism is disproportionately high because of prevailing myths that sexual intercourse with a woman with albinism can cure HIV/AIDS. However, people with albinism may be unable or unwilling to access treatment because of the stigma associated with HIV/AIDS or because they are excluded from mainstream HIV programmes.<sup>431</sup> States have an obligation to ensure health care is equally accessible to all people with albinism, including those living with HIV/AIDS.

## **b. Physical accessibility**

From Fiji to Haiti to Eswatini, people with albinism across the globe face physical and geographical barriers to health care, particularly in rural and remote areas.<sup>432</sup> Physical accessibility means that health facilities, goods, and services must be within safe physical reach for everyone, especially for vulnerable and marginalized groups.<sup>433</sup> States have a responsibility to ensure that health care is made available as close as possible to the communities in which people with albinism live. In countries across Africa, people with albinism face difficulties physically accessing skin care and sun damage prevention resources.<sup>434</sup> For instance, in Kenya, Malawi, and Tanzania, the distribution of sunscreen does not always reach people with albinism in remote areas.<sup>435</sup> The inaccessibility of sunscreen is exacerbated by a lack of availability of these products.<sup>436</sup> In Nepal, the geographical diversity of the country constitutes a significant barrier to accessing health care—many people with albinism have to travel miles in order to obtain any treatment.<sup>437</sup>

## **c. Economic accessibility (Affordability)**

A lack of economic accessibility is a common barrier faced by people with albinism around the world.<sup>438</sup> Economic accessibility means that health facilities, goods, and services, whether publicly or privately provided, must be affordable for all.<sup>439</sup> However, due to poverty and the high cost of products and services, health care remains inaccessible for people with albinism across the globe. Specifically, many people with albinism are unable to afford the costs of eyeglasses, contact lenses, optical aids, sunscreen and other sun protection, and screening services.<sup>440</sup> In the Bhatti tribe in Pakistan, people with albinism are exposed to high ultraviolet radiation but are unable to afford sunscreen or protective clothing, which leads to severe sunburns—a first step in the development of skin cancer.<sup>441</sup>



“Members of the Bhatti tribe, Pakistan” © Iranian Journal of Dermatology



States have a special obligation to provide health insurance to those who cannot afford health care.<sup>442</sup> However, in many countries, publicly provided health insurance for albinism-related conditions is unaffordable or offers inadequate coverage.<sup>443</sup> Services and products required by people with albinism are often excluded from free medical coverage and mandatory public health plans,<sup>444</sup> and sometimes even from private insurance plans.<sup>445</sup>

Often people with albinism are excluded from insurance coverage because they do not meet the required disability threshold.<sup>446</sup> In Japan, for example, people with albinism with high visual acuity are not always recognized as a person with a disability. —As a result, information has shown that approximately 60% of infants with albinism cannot obtain a Disability Certificate from the Japanese government, and so do not receive formal government support.<sup>447</sup> In Turkey, disability designation assessments, which determine the amount of support and coverage people with albinism receive, are often inconsistent and vary depending on the hospital and the knowledge of the medical professional carrying out the assessment.<sup>448</sup>

In other cases, medical insurance exists but is insufficient to meet the needs of people with albinism, in terms of both the availability and the quality of covered assistive devices and products.<sup>449</sup> Although people with albinism in Italy are eligible for additional health benefits, there are disparities between regions with respect to the accessibility and quality of sun protection products; as a result, people with albinism in some regions of the country receive much lower quality sunscreen than others.<sup>450</sup>

As well, sometimes discretionary coverage is denied because health care professionals lack an understanding of albinism. For instance, in Colombia, some dermatologists refuse to provide sunscreen for free because they consider it a “beauty product” and do not recognize the necessity of sunscreen for people with albinism.<sup>451</sup> In order to get coverage for these products and services, legal proceedings are required.<sup>452</sup> Similarly, in the United Kingdom and Northern Ireland, people with albinism are usually able to receive sunscreen free of charge through a prescription, but this can be sometimes difficult to obtain.<sup>453</sup>

#### **d. Information accessibility**

Many of the barriers to the right to health faced by people with albinism arise due to a lack of information accessibility. Information accessibility means the “right to seek, receive and impart information and ideas concerning health issues.”<sup>454</sup> This is a crucial source of empowerment for people with albinism because it empowers them to make informed decisions regarding their health and well-being.

In addition to a lack of information about where and how to access health care,<sup>455</sup> many people with albinism have a limited understanding of their condition and the associated health risks, including the damaging effects of the sun.<sup>456</sup> In Mozambique, there is a prevailing belief that albinism-related skin problems, including cancer, are due to allergies or a disease.<sup>457</sup> Similarly, in Haiti, some people with albinism believe that precancerous skin lesions are merely a superficial problem.<sup>458</sup> In a survey of people with albinism in India, a plurality of respondents (37%) were not aware of the reason for their physical appearance, while others believed that their condition was attributable to a skin disease (26%) or anemia (11%). Only 22% of respondents were aware that their condition was due to albinism or a “genetic disorder.”<sup>459</sup> For people with albinism in Belgium, the greatest barrier to health care is their own acceptance of their condition.<sup>460</sup> In Jordan, where many people with albinism can be unaware of how to best take care of their skin and vision, some people with albinism refuse to wear eyeglasses.<sup>461</sup>

Inaccessibility of information is integrally connected to the lack of effort by governments to raise awareness about albinism, as well as to the lack of knowledge about albinism on the part of health care workers. In order to achieve information accessibility, there must be a reliable and accurate source from which people with albinism can seek out information. In many countries, there is little to no awareness-raising effort by the State or medical community about albinism-related health information, such as skin cancer prevention.<sup>462</sup> This issue is further compounded by the medical community’s own lack of understanding of albinism, even though an adequate understanding is necessary to effectively assist patients.<sup>463</sup> For example, in Turkey, doctors erroneously informed parents that their child will be permanently blind and that they cannot leave the house because of potential sun damage.<sup>464</sup> In some European countries, such as Slovenia and Finland, people with albinism may

not receive a diagnosis of albinism until adulthood, as people with albinism are not as easily distinguishable from the generally fair-skinned and fair-haired population.<sup>465</sup> This means people with albinism may go decades without the support and resources they require.

Mainstream hospitals and clinics do not understand the condition. Often times people with albinism do not get adequate medical care due to the fact that the hospitals and clinics are not user-friendly. How can one serve a person they are afraid of because they think by just getting into close contact with them, they too will give birth to a child with albinism? The myths themselves hinders services.

*Respondent from Zimbabwe*

Information inaccessibility has significant negative effects on disease prognosis for people with albinism. In both Nepal and Brazil, many people with albinism do not know the severity of the associated health risks and only seek medical attention after their health concerns have progressed to a serious state.<sup>466</sup> Further, due to a lack of knowledge about their condition, some people with albinism in Panama are unaware of the importance of wearing protective clothing, and so they do not wear it.<sup>467</sup> In a study in the Democratic Republic of the Congo, 88% of patients with albinism surveyed reported not using sunscreen, with the most frequent reasons being inaccessibility and lack of education on the need to use sunscreen.<sup>468</sup> Without accurate and comprehensive information about albinism and its related health conditions, people with albinism cannot fully enjoy their right to health.

### **iii. Quality and Availability**

In addition to problems with accessibility, the right to health of people with albinism is also threatened by a lack of availability of quality health care. Health care facilities, goods, and services must be “scientifically and medically appropriate and of good quality” and must be available in sufficient quantity.<sup>469</sup> Availability will vary depending on the developmental level of the state, but generally requires the availability of safe drinking water, hospitals, clinics, essential medicines, and trained medical professionals.<sup>470</sup> Quality health care requires, among other things, medical professionals who are skilled, drugs and medical equipment that are scientifically approved and unexpired, and water that is safe and potable.<sup>471</sup> The quality and availability of

health care is strongly linked to accessibility—a limited availability of qualified health care workers will necessarily impede access to health services. For example, in Colombia, it can take up to two years to see a dermatologist or ophthalmologist due to a shortage of these types of doctors.<sup>472</sup>

There are three main issues related to quality and availability of health care for people with albinism: a lack of knowledgeable medical professionals, a lack of preventative and ongoing care, and a lack of psychosocial support.

Access to healthcare is very limited for [people with albinism]. There is only one dermatologist in the province of Nampula and he works only in the central hospital in the city of Nampula and the health professionals in other districts are under trained in albinism, its causes, and how to detect and treat skin problems due to sun exposure. When a [person with albinism] visits a health professional for reasons outside of the problems associated with albinism, most doctors do not address the issue and if they do often times are relating misinformation about the condition. We have found that many parents are afraid to take their child [with albinism] to the doctor because they feel they will be blamed for causing albinism.

*Respondent from Mozambique*

#### **a. Medical expertise**

An important aspect of quality medical care is the availability of skilled health professionals.<sup>473</sup> In many countries across the world, there is a lack of medical specialists who are knowledgeable about albinism-specific health issues; in particular, there is a lack of knowledgeable dermatologists and other skin care professionals, genetic counsellors, and ophthalmologists and eye specialists.<sup>474</sup> In Cameroon, there are only 20 dermatologists in a country of 26 million inhabitants.<sup>475</sup> In India, only 10-30% of medical professionals polled were knowledgeable about albinism.<sup>476</sup> In Central and South America, health professionals often misdiagnose patients with albinism, conduct unnecessary health examinations,<sup>477</sup> and provide incorrect information to people with albinism.<sup>478</sup> This issue is closely linked to information accessibility; unknowledgeable health workers may impart incorrect information to people with albinism, thereby limiting or even worsening their understanding of their condition.

When they lack the requisite knowledge to provide effective medical advice or services, health care professionals may convey incorrect information that can be harmful to the health of people with albinism. In Ghana, for example, some people with albinism are wrongly diagnosed, which leads to many preventable deaths.<sup>479</sup> In Eswatini, people with albinism who are dealing with complex health issues such as squamous cell carcinomas are turned away from further treatment because they are told by health care professionals that the sores are a normal part of their condition.<sup>480</sup> In Uganda, a patient with albinism received nothing more than a bandage when they sought treatment for serious skin cancer.<sup>481</sup> In Ecuador, health workers are not always informed about technical aids that could assist people with albinism with their vision.<sup>482</sup>

Uninformed and inaccurate decisions by medical professionals can have negative effects on other aspects of a person's life, as well. In Malaysia, for example, some jobs require people with disabilities to obtain a physician's approval to work. An assessing physician's lack of understanding regarding albinism can lead to erroneous decisions that prevent people with albinism from obtaining work.<sup>483</sup> In Colombia, some health professionals tell parents that their child with albinism is blind or will become blind, or that they will have a short life span and so it is not worth taking them to school.<sup>484</sup>



"Woman from Malaysia" © GAA

### **b. Prevention and treatment of skin cancer**

The right to health guarantees people with albinism the right to equal and timely access to basic prevention and treatment of health conditions and diseases, which must be tailored to the needs of people with albinism.<sup>485</sup> Despite this, around the world, publicly funded early medical prevention and detection resources for albinism-related health conditions are sorely lacking, particularly for dermatological care.<sup>486</sup> In Kenya, for instance, oftentimes, health facilities lack the capacity and financial resources to meet the demand for skin cancer care.<sup>487</sup> In Mozambique, many people with albinism do not seek out medical attention until their cancer has progressed to an advanced stage; this is particularly true in remote areas where there is a lack of specialists.<sup>488</sup> Additionally, there is a lack of monitoring and evaluation by governments to track the quality and effectiveness of skin cancer screening services.<sup>489</sup>



“The emphasis on curative approach to health has undermined early detection and preventive measures required of cancer especially through community health education and information. [People with albinism] therefore are denied the right to vital information that could keep them alive.”

*Respondent from Kenya*

Effective preventative and curative treatment for skin cancer can be the difference between life and death for people with albinism. Although it is a highly preventable form of cancer, skin cancer can be fatal without timely treatment and detection. In addition, disfigurement caused by precancerous and cancerous lesions leads to dehumanizing myths, which facilitate and justify attacks against people with albinism.<sup>490</sup> For these reasons, it is crucial that States invest in skin cancer treatment for people with albinism, particularly with respect to prevention and early-stage detection, since these are generally more widely accessible than curative treatment. Preventative care is closely linked to information accessibility—people with albinism who have access to information about skin cancer are better able to minimize the associated risks.

### **c. Psychosocial support**

In addition to physical health, people with albinism are guaranteed the right to the highest attainable standard of *mental* health. Unfortunately, there is a lack of psychosocial support for people with albinism who struggle with self-esteem and mental health issues arising from the widespread discrimination, exclusion, and bullying they endure.<sup>491</sup> In Mali, some people with albinism suffer from depression and alcoholism due to persistent marginalization.<sup>492</sup> In Fiji, there is an absence of specialized psychosocial support aimed at providing space for expression, building self-confidence, and empowering people with albinism.<sup>493</sup> In South Africa, frequent humiliation and discrimination along with difficulties in having normal, healthy and sustained personal and romantic relationships resulted in many psychosocial challenges for persons with albinism.<sup>494</sup> In Brazil, the cumulative effect of social exclusion can take a toll on persons with albinism and lead to low self-esteem and depression. Family members of persons with albinism also need psychosocial support and counselling as they also face stigma.<sup>495</sup>

## Endnotes

405 ICESCR, Art. 12(1); UDHR, Art. 25(1); CRPD, Art. 25; ICERD, Art. 5(e)(iv); CEDAW, Arts. 11(1)(f) and 12; CRC, Art. 24. Regional instruments that recognize the right to health include the European Social Charter (529 U.N.T.S. 89; E.T.S. No. 35 (October 18, 1961)) and the Revised European Social Charter (E.T.S. No. 163 (May 3, 1996)) (Part I, Art. 11), the African Charter on Human and Peoples' Rights (1520 U.N.T.S. 217; 21 I.L.M. 58 (June 27, 1981)) (Art. 16), and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (O.A.S.T.S. No. 69 (November 17, 1988)) (Art. 10).

406 UN Committee on Economic, Social and Cultural Rights. General Comment No. 14 (2000): The Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights). U.N. Doc. E/C.12/2000/4 (August 11, 2000), para. 4. Available from [undocs.org/E/C.12/2000/4](https://undocs.org/E/C.12/2000/4). [Hereinafter: OHCHR, General Comment No. 14]

407 Ibid at para. 9.

408 Ibid at para. 12.

409 Ibid at paras. 11, 16.

410 Kenya (PE).

411 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Visit to Brazil. U.N. Doc. A/HRC/46/32/Add. 2 (December 3, 2020) (by Ikponwosa Ero), para. 59. Available from <https://undocs.org/A/HRC/46/32/Add.1>

412 Angola (Movimento); Burkina Faso (ABIPA 1); Burundi (Femmes Albinos); Cameroon (APAC); Côte d'Ivoire (BEDACI); Guinea (UBEAG); Nigeria (TAF); Kenya (AFEA); Kenya (PE); Kenya (State); Malawi (MACOHA); Malawi & Tanzania (SV); Mozambique (AAAM); Mozambique (Shade Tree); Niger (ANAN); Sierra Leone (SLAFo); Somalia (APHAD); South Africa (Kromberg); Tanzania (KCBRP); Tanzania (UTSS); Uganda (AAAU); Uganda (DOTACM); Uganda (NCD); Uganda (SNUPA); Zimbabwe (GAM).

413 Burundi (OPAB); Cameroon (APAC); Côte D'Ivoire (BEDACI); Guinea (UBEAG); Kenya (AFEA); Mozambique (Amor); Mozambique (Shade Tree); Rwanda (OIPPA); Uganda (DOTACM); Uganda (NCD); Uganda (SNUPA).

414 Angola (Movimento); Burkina Faso (ABIPA 1); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Eswatini (Minerva); Ghana (NCPD); Guinea (UBEAG); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Mali (Traore); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (NHRC); Nigeria (TAF); Rwanda (OIPPA); Senegal (DIOP); Somalia (APHAD); Tanzania (KCBRP); Uganda (NCD); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).

415 Argentina (Albinismo Argentina); Brazil (IE); Colombia (FAC); Haiti (ALBHA).

416 Burundi (ASP); Malawi & Tanzania (SV).

417 This only applies to those living in the Buhangija and Mitindo centres [Tanzania (KCBRP)].

418 Paraguay (AP).

419 Haiti (ALBHA).

420 OHCHR, General Comment No. 14, *supra*, note 406 at para. 12.

421 For information on discrimination against women and children in the context of the right to health, see Chapter 7: Women and Children.

422 OHCHR, General Comment No. 14, *supra*, note 406 at para. 12; CRPD, Art. 25; ICERD, Art. 5(e)(iv).

423 Ibid at paras. 12, 18.

424 Burundi (Femmes Albinos); Kenya (AFEA); Kenya (PE); Kenya (State); Mozambique (Shade Tree); Nigeria (OAM); Nigeria (TAF); South Africa (Kromberg); Tanzania (UTSS); Uganda (DOTACM); Uganda (SNUPA); Uganda (UAA); Argentina (SA); Paraguay (AP); India (WPRA); India (JT).

425 UNIE, Applicable International Human Rights Standards, *supra*, note 3 at para. 55.

426 Colombia (AdC).

427 Nigeria (TAF); Rwanda (OIPPA).

428 Uganda (DOTACM).

429 Uganda (SNUPA).

430 India (WPRA); India (JT).

431 UNIE, Applicable International Human Rights Standards, *supra*, note 3 para. 55.

432 Colombia (AdC); Haiti (ALBHA); Guatemala (AdG); Burundi (ASP); Cameroon (APAC); Cameroon (Association); DRC (GI); Eswatini (Minerva); Kenya (AFEA); Mali (CORPA); Malawi (MACOHA);

Mozambique (Amor); Mozambique (Shade Tree); Niger (ANAN); Nigeria (NHRC); Nigeria (TAF); Somalia (APHAD); Tanzania (KCBRP); Tanzania (UTSS); Uganda (AAAU); Australia (AFA); Fiji (MR).

433 OHCHR, General Comment No. 14, supra, note 406 at para. 12.

434 Burundi (ASP); Cameroon (APAC); Cameroon (Association); DRC (GI); Eswatini (Minerva); Kenya (AFEA); Mali (CORPA); Malawi (MACOHA); Mozambique (Amor); Mozambique (Shade Tree); Niger (ANAN); Nigeria (NHRC); Nigeria (TAF); Somalia (APHAD); Tanzania (KCBRP); Tanzania (UTSS); Uganda (AAAU).

435 Kenya (AFEA); Kenya (PE); Malawi (MACOHA); Tanzania (KCBRP).

436 Kenya (PE); Mozambique (Shade Tree); South Africa (Kromberg); Uganda (DOTACM).

437 Nepal (NDAN).

438 Angola (Movimento); Burkina Faso (ABIPA 1); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Eswatini (Minerva); Ghana (NCPD); Guinea (UBEAG); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Mali (Traore); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (NHRC); Nigeria (TAF); Rwanda (OIPPA); Senegal (DIOP); Somalia (APHAD); Tanzania (KCBRP); Uganda (NCD); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).

439 OHCHR, General Comment No. 14, supra, note 406 at para. 12.

440 Burundi (OPAB); Cameroon (APAC); Côte d'Ivoire (BEDACI); Guinea (UBEAG); Kenya (AFEA); Mali (Traore); Mozambique (Amor); Mozambique (Shade Tree); Rwanda (OIPPA); Uganda (DOTACM); Uganda (NCD); Uganda (SNUPA); Angola (Movimento); Burkina Faso (ABIPA 1); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Eswatini (Minerva); Ghana (NCPD); Guinea (UBEAG); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Mali (Traore); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (NHRC); Nigeria (TAF); Rwanda (OIPPA); Senegal (DIOP); Somalia (APHAD); Tanzania (KCBRP); Uganda (NCD); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM); Jordan (Rasha); Argentina (Albinismo Argentina); Argentina (SA); Colombia (AdC); Colombia (FAC); Colombia (FVF); Haiti (ALBHA); Panama (OBSAP); Paraguay (AP); Burundi (Femmes Albinos); Cameroon (APAC); Côte d'Ivoire (APIFA); Eswatini (Minerva); Kenya (AFEA); Kenya (KNCHR); Guinea (UBEAG); Mozambique (Shade Tree); Uganda (DOTACM); Zimbabwe (GAM); India (JT); Slovenia (State); Australia (AFA).

441 Azam Jah Samdani, A. & Khan Khoso, B. (2009). A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: An epidemiological study. *Iranian Journal of Dermatology*, 12(2), 42-46. [iranjd.ir/article\\_101319\\_f1517fca34e8603f05897f35c93e6c5d.pdf](http://iranjd.ir/article_101319_f1517fca34e8603f05897f35c93e6c5d.pdf)

442 OHCHR, General Comment No. 14, supra, note 406 para. 19.

443 Burkina Faso (ABIPA 1); Cameroon (APAC); Cameroon (Association); Eswatini (Minerva); Ghana (NCPD); Kenya (PE); Mali (CORPA); Mozambique (Amor) [although health services are virtually free in the country, most of the specific drugs for PWA are not on the national health system's list of drugs and have to be purchased in private pharmacies]; Nigeria (TAF); Rwanda (OIPPA); South Africa (Kromberg); Tanzania (KCBRP); Uganda (NCD) [skin cancer is not one of the cancers treated free of charge]; Uganda (SNUPA) [sunscreen is not included in the national minimum healthcare package, and neither is treatment for sun cancer]; Uganda (UAA); Zimbabwe (GAM).

444 Argentina (Albinismo Argentina); Colombia (AdC); Colombia (FAC); Colombia (FVF); Turkey (AA).

445 Turkey (AA).

446 Japan (JAN); Slovenia (State); Turkey (AA).

447 Japan (JAN).

448 Turkey (AA).

449 Slovenia (State).

450 Italy (Albinit).

451 Colombia (AdC).

452 Colombia (FAC).

453 UK & Ireland (RP).

454 OHCHR, General Comment No. 14, supra, note 406 at para. 12.

455 Angola (Movimento); Kenya (AFEA); Nigeria (TAF); Sierra Leone (SLAFo).

456 Mozambique (Shade Tree); Somalia (APHAD); Uganda (AAAU); Zambia (DAZ); Colombia (FAC); Haiti (ALBHA); Brazil (APALBA); Guatemala (AdG); Fiji (MR); India (WPRA); Jordan (Rasha); Nepal (NDAN).

457 Mozambique (Shade Tree).

458 Haiti (ALBHA).

459 India (WPRA).  
460 Belgium (Ecran Total).  
461 Jordan (Rasha).  
462 For example: Eswatini (Minerva); Jordan (Rasha); Mozambique (AAAM).  
463 France (Genespoir); Italy (Albinit); Norway (NFFA); Slovenia (State); Turkey (AA).  
464 Turkey (AA).  
465 Finland (FAA); Slovenia (State).  
466 Brazil (APALBA); Nepal (NDAN).  
467 Panama (GG).  
468 Study by the Cinquanteenaire Hospital of Kisangani and an NGO, Corbetta.  
469 OHCHR, General Comment No. 14, supra, note 406 at para. 2.  
470 Ibid.  
471 Ibid at para. 2.  
472 Colombia (AdC); Colombia (FAC).  
473 OHCHR, General Comment No. 14, supra, note 406 at para. 2.  
474 Burundi (ASP); Cameroon (APAC); Cameroon (Association); DRC (GI); Eswatini (Albinism Society); Eswatini (Minerva); Guinea (UBEAG); Kenya (AFEA); Kenya (PE); Mali (CORPA); Mozambique (Shade Tree); Rwanda (OIPPA); Senegal (DIOP); Sierra Leone (SLAFo); Uganda (AAAU); Uganda (SNUPA); Zimbabwe (GAM); India (WPRA); India (JT); Japan (JAN); Malaysia (KLSAA); Nepal (NDAN); Argentina (Albinismo Argentina); Argentina (SA); Colombia (AdC); Colombia (FAC); Ecuador (PdA); Mexico (FPLAM); Paraguay (AP); France (Genespoir); Italy (Albinit); Norway (NFFA); Slovenia (State); Turkey (AA); New Zealand (AT pdf); Fiji (MR).  
475 Cameroon (APAC).  
476 India (JT).  
477 Chile (ANGOC).  
478 Colombia (FAC); Mexico (FPLAM); Paraguay (AP).  
479 Ghana (ENA).  
480 Eswatini (Albinism Society).  
481 Uganda (SNUPA).  
482 Ecuador (PdA).  
483 Malaysia (KLSAA).  
484 Colombia (FAC); similar situations occur in Mexico (FPLAM).  
485 OHCHR, General Comment No. 14, supra, note 406 at paras. 16, 17.  
486 Angola (Movimento); Brazil (APALBA); Burkina Faso (ABIPA 1); Côte d'Ivoire (BEDACI); DRC (GI); Ghana (ENA); Ghana (NCPD); Jordan (Rasha); Kenya (AFEA); Kenya (PE); Mali (Traore); Mozambique (AAAM) [no awareness campaigns on skin cancer prevention]; Netherlands (AO); Niger (ANAN); Panama (GG); Slovenia (State); Uganda (SNUPA); Zimbabwe (GAM).  
487 Kenya (AFEA).  
488 Mozambique (Amor).  
489 Cameroon (APAC); Kenya (AFEA); Mali (CORPA).  
490 UNIE, Applicable International Human Rights Standards, supra, note 3 at para. 54.  
491 Colombia (FAC); Fiji (MR); Japan (JAN); Kenya (AFEA); Kenya (KNCHR); Kenya (State); Mali (Traore); Senegal (DIOP); Slovenia (State); Turkey (AA).  
492 Mali (Traore).  
493 Fiji (MR).  
494 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Visit to South Africa. U.N. Doc. A/HRC/43/42/Add.1 (January 9, 2020) (by Ikponwosa Ero), paras. 45, 51 Available from <https://undocs.org/A/HRC/43/42/Add.1>  
495 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Visit to Brazil. U.N. Doc. A/HRC/46/42/Add.1 (December 3, 2020) (by Ikponwosa Ero), paras. 82,82 Available from <https://undocs.org/A/HRC/46/32/Add.1>



## Chapter 7: Women and Children



“Mother and her baby, Tanzania” © UTSS

The weight of global suffering surrounding albinism is disproportionately borne by women with albinism and mothers of children with albinism.

*UNIE Ikponwosa Ero*

### *i.* **Human Rights Overview**

As discussed in Chapter 1, people with albinism face multiple and intersecting discrimination based on disability and colour. Gender and age often aggravate and compound that discrimination; this means that women and children with albinism are even more vulnerable to discrimination and exclusion. They are more likely to face violence, abuse, neglect, and various other human rights violations.<sup>496</sup> The Office of the High Commissioner for Human Rights has recognized the multiple and intersecting forms of discrimination that women and children face.<sup>497</sup>

**Prohibition of gender-based discrimination:** CEDAW provides the most comprehensive protection against gender-based discrimination. It defines



discrimination against women as any distinction, exclusion, or restriction that has the effect or purpose of impairing women's human rights on an equal basis with men.<sup>498</sup> Recognizing the unique challenges posed by intersectional discrimination, the CRPD specifically provides for substantive protection for women with disabilities, which encompasses the protection provided by CEDAW.

State Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard, shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

State Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

*Article 6, CRPD*

The Committee on the Elimination of Discrimination against Women and the Committee on the Rights of Persons with Disabilities have recognized the intersecting forms of discrimination that affect women with albinism, and have commented on the harmful practices that affect women with albinism, the low number of prosecutions for such harmful practices, and the multiple other barriers faced by women with albinism and mothers of children with albinism.<sup>499</sup>

Both the CEDAW and the CRPD require States to adopt laws to prohibit discrimination, establish institutions to ensure effective protection against discrimination, and ensure the elimination of all acts of discrimination. The CEDAW Committee has called on States to recognize intersecting forms of discrimination and their compounded negative impact on women, and to adopt policies and programmes to eliminate such discrimination.<sup>500</sup> Similarly, the CRPD Committee has emphasized the need for protective measures against multiple and intersecting forms of discrimination faced by women with albinism.<sup>501</sup>

**Prohibition of discrimination against children:** The CRC recognizes that children are human beings with their own rights. This is founded on the principles of non-discrimination; the best interest of the child; the right

to life, survival, and development; and respect for the views of the child.<sup>502</sup> Again, the CRPD supplements the protections of the CRC by recognizing the multiple and intersecting forms of discrimination experienced by children with disabilities.

State Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

*Article 7, CRPD*

The Committee on the Rights of the Child has expressed concern about the discrimination faced by and violence perpetrated against children with albinism, including ritual attacks and banishments, discrimination at school leading to dropout, family abandonment, and their limited access to remedies and protection.<sup>503</sup>

Under the CRPD, States must adopt measures that are in the best interests of the child, in order to ensure children with albinism are able to enjoy all of their rights on an equal basis with others.

## *ii.* **Human Rights Barriers**<sup>504</sup>

### **a. Stigma and exclusion**

Mothers of children with albinism in parts of Africa, the Caribbean, and South America are disproportionately impacted by a lack of understanding of albinism.<sup>505</sup> Often, they are viewed as being cursed<sup>506</sup> or unfaithful for giving birth to a child with albinism.<sup>507</sup> They are subjected to violence<sup>508</sup> and rejected or excommunicated by their husbands or families.<sup>509</sup> In Uganda, clan members encourage men to abandon their wives and children with albinism based on myths that their union will bring bad luck to the community.<sup>510</sup> In Gboko, Nigeria, a woman killed her baby with albinism after her husband's family threatened to excommunicate her if she did not.<sup>511</sup> Women who give birth to children with albinism are expelled from the community because of concerns that they may give birth to more children with albinism or will cause

other women in the community to have children with albinism.<sup>512</sup> There is no legal redress for these women as against their husbands.<sup>513</sup>



“Mother and child, DRC” © Patricia Willocq

Children with albinism face discrimination and bullying from parents, peers, and teachers.<sup>514</sup> In some cases, children with albinism are neglected or abandoned by their families<sup>515</sup> and are instead raised by grandparents or other guardians.<sup>516</sup> Parents of children with albinism have difficulty accepting or fully embracing their child<sup>517</sup> and may feel ashamed of their child.<sup>518</sup> In Uganda, some families hide their child with albinism from visitors because the parents do not want to be associated with them.<sup>519</sup> In Kenya, traditional rites of passage for boys require the participation of the boy’s father; boys with albinism who have been disowned by their fathers often suffer from low self-esteem and psychological trauma.<sup>520</sup>

Clan members usually influence the men to run away. Even if the man really wants to remain with his family, when the family members tell him “we shall all die if you remain with that woman”, they run away.

*Respondent from Uganda*

Children with albinism often have difficulty making friends and are excluded from social activities.<sup>521</sup> In school, other children refuse to sit next to or play with children with albinism.<sup>522</sup> Adults fuel the exclusion of children with albinism by warning their children not to interact with them.<sup>523</sup> In some countries, boys with albinism are expected to tolerate bullying and discrimination as ‘men.’<sup>524</sup>

### **b. Right to life**

Women and children with albinism are more susceptible to violence and ritual crimes.<sup>525</sup> As discussed in Chapter 2 (Right to Life), harmful practices related to accusations of witchcraft and ritual attacks most often affect women and children. Women experience the highest rates of witchcraft accusations, and accusations against children are on the rise. As a result, they are more frequently attacked, abandoned, or banished.<sup>526</sup> Additionally, women and girls with albinism are more often subject to ritual rape<sup>527</sup> based on erroneous beliefs that sexual intercourse with a person with albinism brings luck and cures diseases, including HIV. In addition to the trauma of unwanted sexual intercourse, victims of ritual rape can also experience unwanted pregnancy, infection, and disease.<sup>528</sup>



“Pregnant woman, DRC” © Patricia Willocq

### **c. Right to remedy and access to justice**

In South America, support for women and children with albinism who are victims of attacks or discrimination is largely provided by civil society, or otherwise is not available at all.<sup>529</sup> In many countries in Africa, there is little to no support for women and children with albinism who are victims of attacks or discrimination.<sup>530</sup> Women with albinism are deterred from seeking redress through the justice system because of the discriminatory attitudes and stigmatization they face in their attempts to seek justice, particularly in cases of sexual violence.<sup>531</sup>

#### **d. Right to education**

Although children with albinism are generally guaranteed access to education like any other children, there are multiple barriers to ensuring children with albinism can access education without discrimination. See Chapter 4 for a detailed description of the barriers to education faced by children with albinism.

#### **e. Right to work and an adequate standard of living**

Women with albinism and mothers of children with albinism are often impoverished because of the discrimination and isolation they face.<sup>532</sup> In Burkina Faso, 90% of women with albinism and 65% of mothers of children with albinism live in poverty.<sup>533</sup> In Burundi, it is estimated that around 99% of women with albinism and over 85% of mothers of children with albinism live in poverty.<sup>534</sup> In Senegal, children with albinism are forced to beg, exposing them to the sun all day.<sup>535</sup>

Mothers of children with albinism are unable to work full time because they bear a disproportionate burden of child care—which includes taking their children to school to ensure they are safe from attacks<sup>536</sup>—due to abandonment by spouses.<sup>537</sup> In Haiti, women who are reportedly abandoned by the father of their baby upon the birth of a child with albinism often have meagre means and are forced to beg on the street to support their families.<sup>538</sup> Women are sometimes discriminated against and denied work when an employer learns that they have given birth to a child with albinism.<sup>539</sup>

In addition, there are limited or no economic empowerment opportunities for women with albinism and mothers of children with albinism.<sup>540</sup> Limited access to information about their rights to social benefit schemes and other programmes prevents women with albinism and mothers of children with albinism from benefiting from these initiatives.<sup>541</sup>

#### **f. Right to health**

Women and girls with albinism have limited or no access to reproductive or sexual health care,<sup>542</sup> often as a result of stigma and discrimination.<sup>543</sup> For women who give birth to a child with albinism, there is no active support



or accurate education about their child's diagnosis or health needs at the time of birth.<sup>544</sup> In Turkey, doctors erroneously tell parents that their child will never be able to see and that they cannot leave the house because of potential sun damage.<sup>545</sup> From the moment a child with albinism is born, their mothers are ignored, neglected, or treated with less dignity by health care professionals than other mothers.<sup>546</sup> In Colombia, women with albinism who become pregnant are encouraged to abort the baby, without first being able to access genetic counselling, on the ground that the baby will be born with albinism as well.<sup>547</sup>

“...mothers [suffer] post-natal depression after giving birth to a child with Albinism as they do not know how to raise the child who is different from other children and even members of the family, especially since even at governmental level nothing has been done to create awareness on Albinism. For example during pregnancy, the mother is only prepared to expect a regular child and hence when she gives birth to such a child with albinism she faces a lot of stress as she was not prepared, and even post birth there is not much support received from health on how to take care of the child.”

*Respondent from Eswatini*

### *iii.* **Disproportionate Impact**<sup>548</sup>

The additional barriers to the full enjoyment of their human rights faced by women and children constitute disproportionate impact. Reports from parts of Africa, South America, South Asia, among other regions have identified the following elements as illustrative of disproportionate impact.

**Blame and abandonment:** After having a child with albinism, women frequently face blame and abandonment. This is often due to a lack of awareness about albinism and the fact that it is a genetic condition inherited from both parents. Women are often accused of having caused their child's pale colouring—some are accused of infidelity, while others are accused of having a curse that manifested in their child's appearance. Consequently, many mothers of children with albinism are abandoned by their partners or spouses.

**Isolation and expulsion:** Women are often isolated or expelled from their communities after having a child with albinism. This is a consequence of the belief in certain regions that a child with albinism is a curse on the community. In some cases, mothers of children with albinism remove themselves (and their children) from their communities in order to avoid hostility and exclusion from community members.

**Poverty:** Due to abandonment by their spouses or partners upon the birth of a child with albinism, and the ensuing situation of being a single parent, mothers of children with albinism often face abject poverty. This exposes children with albinism to continuous poverty, especially since children with albinism are generally unable to receive a proper education or, thereafter, opportunities for gainful employment.

**Health risk:** Due to a general lack of education with respect to obtaining adequate work, including indoor employment, women and girls with albinism often take on various types of menial work outdoors. Long-term work outdoors in the sun creates a high risk of contracting skin cancer. Moreover, due to their hypervisibility and experiences of constant discrimination in nearly all spheres of their lives, women and children with albinism are at a high risk of facing psychosocial challenges, which often negatively impact their social relationships and aggravate their social exclusion.

**Sexual violence:** Women with albinism are often targets of sexual harassment and violence. This is frequently due to fetishes, myths, and misbeliefs that result in rape and sexual assault. In some countries, it is also due to the prevalent myths that sexual intercourse with women with albinism can cure HIV and can confer good luck. These myths continuously expose women with albinism to violence and increase their vulnerability to unwanted pregnancies and sexually transmitted infections.

**Heightened vulnerability to attacks:** In places where attacks against people with albinism have been reported, poverty, expulsion, and isolation often leave mothers and their children with albinism vulnerable to attacks. A significant number of attacks have taken place against those who have been removed or isolated from their community and against the poorest families of children with albinism. In this context, poverty can also mean that women are unable to afford safe and secure housing, which is a necessary protection against attacks.

**Victims of impunity:** Women have been recognized by both the CEDAW Committee and the African Committee of Experts on the Rights and Welfare of the Child as being particularly at risk in conflict situations and disasters, and as being affected by violence more frequently and severely than others, often falling victim to violent acts committed clandestinely and with impunity. In this context, women with albinism are at extreme risk of violence, particularly in regions where attacks occur due to myths and misconceptions about albinism.

**Reprisals:** Women whose spouses, partners, or family members were involved in attacks against their child with albinism often face threats of reprisal after testifying against their relatives during investigations and the prosecution process. The threats of reprisal reportedly come both from relatives and the community at large.

**Displacement:** Both women with albinism and mothers of children with albinism have been displaced in the wake of physical attacks against people with albinism in general. Many have gone to shelters set aside for them by governments to provide temporary safety. Some enter the shelters voluntarily while others enter through government and community intervention. Women and children with albinism constitute a significant number of the residents at these shelters, where often only minimal care is provided to them, particularly in the areas of psychosocial support, education, health treatment to prevent skin cancer, and low-vision support to enable education.

## Endnotes

496 UNIE, *Women and Children Impacted by Albinism*, supra, note 165.

497 Ibid.

498 CEDAW, Art. 1.

499 UNIE, *Applicable International Human Rights Standards*, supra, note 3 at para. 26.

500 Ibid.

501 Ibid.

502 CRC, Art. 2 (non-discrimination); Arts. 3(1), 9(1) and (3), 18(1), 20(1), 21, 37(c), and 40(2)(iii) (best interests of the child); Art. 6(a) (right to life); Art. 6(b) (survival and development); and Art. 12(1) (views of the child).

503 UNIE, *Applicable International Human Rights Standards*, supra, note 3.

504 UNIE, *Women and Children Impacted by Albinism*, supra, note 165.

505 Burundi (Femmes Albinos); Cameroon (ANAPRODH); Kenya (KNCHR); Kenya (PE); Malawi & Tanzania (SV); Nigeria (OAM); Rwanda (OIPPA); South Africa (Kromberg); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM); Haiti (ALBHA); Colombia (AdC); Colombia (FAC).

506 Eswatini (Albinism Society); Kenya (PE); Mozambique (AAAM); Mozambique (Amor); Uganda (SNUPA); Uganda (UAA); Zimbabwe (GAM).

507 Eswatini (Minerva); Ghana (ENA); Kenya (PE); Mozambique (AAAM); Mozambique (Amor); Uganda (SNUPA); Uganda (UAA); Zimbabwe (GAM).

508 Uganda (DOTACM).

509 Burundi (Femmes Albinos); Eswatini (Albinism Society); Ghana (ENA); Kenya (KNCHR); Kenya (PE); Rwanda (OIPPA); Nigeria (NHRC); Nigeria (TAF); Zimbabwe (GAM); Angola (Movimento); Burundi (Femmes Albinos); Cameroon (ANAPRODH); Cameroon (APAC); Côte D'Ivoire (BEDACI); DRC (GI); Eswatini (Albinism Society); Guinea (CNAG); Guinea (UBEAG); Malawi & Tanzania (SV); Mali (Traore); Nigeria (NHRC); Nigeria (TAF); Kenya (AFEA); Kenya (PE); Senegal (DIOP); Tanzania (UTSS); Uganda (Albinism Umbrella); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).

510 Uganda (Lund & Goodman).

511 Nigeria (TAF).

512 Côte d'Ivoire (BEDACI); Eswatini (Albinism Society); Zimbabwe (GAM).

513 DRC (GI).

514 Angola (Movimento); Burundi (Femmes Albinos); Cameroon (APAC); DRC (AF); Eswatini (Minerva); Eswatini (Albinism Society); Nigeria (NHRC); Nigeria (OAM); Nigeria (TAF); Senegal (DIOP); South Africa (Kromberg); Zimbabwe (GAM).

515 Uganda (DOTACM); Uganda (Lund & Goodman); Uganda (SNUPA); Uganda (UAA); Zambia (Albinism Foundation of Zambia); Zimbabwe (GAM).

516 Burundi (Femmes Albinos); Cameroon (APAC); Kenya (PE).

517 Burundi (OPAB); Cameroon (APAC); Congo (AF); Eswatini (Minerva); Senegal (DIOP); Togo (CAS); Uganda (UAA).

518 Kenya (KNCHR); Senegal (DIOP).

519 Uganda (UAA).

520 Kenya (AFEA).

521 Cameroon (ANAPRODH); Côte d'Ivoire (BEDACI); Guinea (UBEAG); Kenya (AFEA); Sierra Leone (SLAFo); South Africa (Kromberg); Zambia (Albinism Foundation of Zambia).

522 Burundi (ASP).

523 Zimbabwe (GAM).

524 Kenya (AFEA); Kenya (PE).

525 Burundi (ASP); Kenya (PE); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (OAM); Tanzania (UNICEF).

526 Witchcraft allegation, refugee protection and human rights, Schnoebelen, supra, note 169; BBC, Whitaker, supra, note 177; UNIE, *Women and Children Impacted by Albinism*, supra, note 165.

527 Burkina Faso (ABIPA 1); Burundi (ASP); Burundi (Femmes Albinos); Burundi (OPAB); Cameroon (Association); Côte d'Ivoire (APIFA); Côte d'Ivoire (BEDACI); DRC (GI); Eswatini (Minerva); Ghana (NCPD); Guinea (UBEAG); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Malawi & Tanzania (SV); Mozambique

(AAAM); Mozambique (Amor); Nigeria (NHRC); Nigeria (OAM); Senegal (DIOP); Sierra Leone (SLAFo); Uganda (NCD); Uganda (SNUPA); Zimbabwe (GAM).

528 Burundi (Femmes Albinos); Burundi (OPAB); Cameroon (APAC); Côte d'Ivoire (APIFA); Côte d'Ivoire (BEDACI); Eswatini (Albinism Society); Eswatini (Minerva); Guinea (CNAG); Kenya (PE); Malawi & Tanzania (SV); Mali (Traore); Mozambique (AAAM); Nigeria (OAM); Senegal (DIOP); South Africa (Kromberg); Tanzania (KCBRP); Tanzania (UTSS); Tanzania (UNICEF); Uganda (DOTACM); Uganda (Lund & Goodman); Uganda (NCD); Uganda (SNUPA); Zimbabwe (GAM).

529 Colombia (AdC); Guatemala (AdG); Panama (OBSAP); Venezuela (AG).

530 Angola (Movimento); Burkina Faso (ABIPA 1); Eswatini (Albinism Society); Ghana (NCPD); Nigeria (TAF); Somalia (APHAD); Uganda (NCD); Zambia (DAZ).

531 Côte d'Ivoire (APIFA); Eswatini (Albinism Society); Kenya (AFEA); Kenya (PE); Zambia (DAZ); Zimbabwe (GAM).

532 Burkina Faso (ABIPA 1); Burundi (OPAB); Cameroon (APAC); Côte d'Ivoire (APIFA); DRC (GI); Guinea (UBEAG); Kenya (PE); Mali (Traore); Nigeria (TAF); Uganda (Albinism Umbrella); Uganda (DOTACM); Uganda (SNUPA); Zimbabwe (GAM).

533 Burkina Faso (ABIPA 1).

534 Burundi (ASP); Burundi (OPAB).

535 Senegal (DIOP).

536 Eswatini (Minerva); Uganda (DOTACM).

537 Côte d'Ivoire (BEDACI); Kenya (PE); Mozambique (Shade Tree); Uganda (SNUPA).

538 Haiti (FA).

539 Uganda (DOTACM).

540 Mozambique (AAAM); Sierra Leone (SLAFo); Somalia (APHAD); Uganda (NCD); Zambia (DAZ).

541 Kenya (PE); Uganda (SNUPA).

542 Angola (Movimento); Burundi (Femmes Albinos); Côte d'Ivoire (BEDACI); Eswatini (Albinism Society); Japan (JAN); Kenya (AFEA); Kenya (KNCHR); Mali (Traore); Mozambique (Amor); Mozambique (Shade Tree); Nigeria (NHRC); Somalia (APHAD); Togo (CAS).

543 Ghana (NCPD); Kenya (AFEA); Kenya (KNCHR); Kenya (PE); Mali (Traore); Tanzania (UTSS); Uganda (HUPA); Zimbabwe (GAM).

544 Eswatini (Minerva); Kenya (PE); Mozambique (Shade Tree); Nigeria (OAM); Somalia (APHAD); Tanzania (KCBRP); Brazil (APALBA); Colombia (AdC); Colombia (FVF); Jordan (Rasha); Venezuela (AG); Finland (FAA); Turkey (AA).

545 Turkey (AA).

546 Kenya (PE).

547 Colombia (AdC).

548 UNIE, Women and Children Impacted by Albinism, supra, note 165.



# PART III: STATE ACCOUNTABILITY



"Man from DRC" © Patricia Willocq

## 1. Overview

Part I of this report introduced the human rights-based approach to advocating for and empowering people with albinism.<sup>549</sup> This approach underscores that people with albinism are rights-holders and States are primary duty-bearers. From a human rights perspective, “accountability” refers to the relationship between rights-holders and duty-bearers.

By becoming parties to international human rights treaties, States assume certain duties, which include the duty to protect human rights and to ensure that rights are not violated, either by themselves or by non-state actors. Because States have these duties, they are responsible for human rights violations both by action, when state actors commit human rights violations themselves, and by omission, when they fail to act to prevent violations caused by non-state actors.

The duty to prevent human rights violations is both direct and indirect. States must take direct action to mitigate or eliminate risk factors and establish a legal, administrative, and policy framework that works to prevent violations. States are also required to take indirect measures to protect human rights and to prevent the recurrence of violations by identifying and addressing the root causes of these violations.

Accountability has three dimensions: responsibility, answerability, and enforceability.<sup>550</sup>

**Responsibility** requires that those in positions of authority have clearly defined duties and performance standards, enabling the objective and transparent assessment of their conduct.

**Answerability** refers to the obligation of those in authority to explain and justify their actions to the people affected by their decisions (the rights-holders), to oversight bodies, and to the public at large.

**Enforceability** requires the establishment of mechanisms that monitor the authorities’ compliance with performance standards; these mechanisms should also ensure appropriate corrective and remedial action is taken when state conduct flouts or falls below established standards. In other words, those in authority must be sanctioned if they fail to fulfil their duties to the people affected by their actions.

State accountability has two main functions: a backward-looking corrective function and a forward-looking preventive function. The corrective function of accountability makes it possible to address the complaints and concerns of rights-holders and to condemn or punish wrongdoing by duty-bearers. The preventive function helps to determine which aspects of policy or service delivery are working, so they can be built on, and which aspects need to be adjusted, so they can be made more effective and responsive to the demands of rights-holders.

The human rights standards explained in Part II of this report define the scope of State accountability. Under international human rights law, States have a duty to respect, protect, and fulfil the rights of those within their jurisdiction, as well as to provide effective remedies when those rights are infringed—this is the “what” of state accountability. The “how” is an array of national and international human rights mechanisms that exist to assess the claims and grievances of those who have suffered unjust treatment, to determine responsibility through fair and transparent processes, and to provide appropriate remedies, such as compensation and rehabilitation.

Accountability is primarily ensured at the national level. Relevant mechanisms include a broad range of political, administrative, legislative, judicial, quasi-judicial, and social accountability mechanisms. These mechanisms can be and have been used to hold State decision-makers accountable for their commitments under international human rights treaties, including by enabling rights-holders to enforce their claims against those in authority and to seek appropriate redress if their rights have been violated. Examples include parliamentary committees (political accountability), charters and codes of conduct for public servants (administrative accountability), litigation (judicial accountability), and independent oversight bodies, such as human rights commissions and ombudsperson offices (quasi-judicial accountability).

At the international level, accountability mechanisms encompass various monitoring and review processes, including the universal periodic review of the Human Rights Council, the United Nations treaty-monitoring bodies, and the Special Procedures. International accountability mechanisms typically have a supervisory or oversight role rather than an enforcement function. However, they can play an important role in fostering responsibility among States, including by setting targets, benchmarks, and minimum performance

standards. They can also strengthen accountability, for example, by investigating and considering whether existing national mechanisms for redress are sufficient. They offer additional forums for raising grievances, which is particularly important for individuals and groups who are disregarded by their own governments.

## **2. States' core obligations to people with albinism**

States who are parties to international human rights treaties are legally bound to international obligations to respect, protect, and fulfil all human rights. States must act in good faith to give effect to these obligations. All branches of the State, including local authorities, must comply with the State's obligations.

In undertaking to respect, protect, and fulfil human rights, States have a duty to take positive action, including legal and other measures.

### **i. Obligations to prevent human rights violations and protect persons with albinism against attacks**

Physical attacks against persons with albinism constitute a violation of multiple human rights, including the right to life and security of the person, and the right to be free from torture. In some cases, attacks may also violate the right to be free from trafficking and exploitation, as people with albinism are sometimes trafficked to other areas where their body parts are used for ritual practices. The right to life and the right to be protected from torture may not be derogated from under any circumstance.<sup>551</sup>

Considering the principle of the interdependence and indivisibility of human rights, the right to life functions as an enabling and protective right that is necessary for the enjoyment of all other human rights. At the same time, the right to life also depends on the enjoyment of other human rights. In this regard, States have a core obligation to ensure the satisfaction of, at the very least, minimum essential levels of economic and social rights for people with albinism.<sup>552</sup> States also have a core obligation to guarantee the right to equality and non-discrimination, including reasonable accommodation, to people with albinism.

Concerns about the lack of accountability for violations of the rights to life, security, and physical integrity against people with albinism have been raised by the Independent Expert, United Nations treaty bodies, and the special rapporteurs.

**States have a duty to take legal and other measures.** In order to protect people with albinism, States must adopt legislation to criminalize attacks against people with albinism, as well as crimes related to attacks, such as trafficking in persons. States should also adopt legislative measures that criminalize harmful practices against people with albinism, and clarify ambiguities (where they exist) in legislation related to witchcraft and traditional health practices.

Laws to protect people with albinism from attacks and prevent these violations should be accompanied by concrete measures to facilitate their implementation, such as advocacy and the training of law enforcement personnel and judicial authorities.<sup>553</sup>

States must also seek better understanding of the root causes and the specific nature of attacks against people with albinism—for example, attacks carried out for the purpose of trafficking in body parts. This knowledge can facilitate the work of law enforcement agencies in protecting life and preventing torture. Similarly, a thorough understanding of root causes enables state actors to adequately address those causes. Equipped with this knowledge, States can proactively combat the superstitions and stigma surrounding albinism, including through education and awareness-raising campaigns.

The duty of States to protect the right to life and prevent torture also requires the systematic recording of attacks. States must circulate this information to promote awareness among law enforcement and to ensure that appropriate measures are developed where necessary. Furthermore, to facilitate the development of strategies and measures to prevent crimes relating to attacks against persons with albinism, States must undertake and support research, systemic collection of data, and thorough analysis of risk factors.



## ii. **Obligations to ensure equality and non-discrimination**

Similar to the right to life, the right to equality and non-discrimination can be considered an enabling right that is necessary for the enjoyment of all other human rights. Violations of the right to equality and non-discrimination may prevent people with albinism 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.

The obligation to protect the right to equality and non-discrimination requires States to take concrete, deliberate, and targeted measures. Such measures should include legislation prohibiting discrimination on any grounds, as well as policies, plans, and strategies to ensure that formal and substantive discrimination, by both State and non-state actors, is eliminated. These measures should be selected and implemented on the basis of close consultation with and involvement of representative groups of the persons concerned.

The Human Rights Council's Advisory Committee has indicated that States should launch and sustain education and awareness-raising campaigns aimed at combating the underlying causes of discrimination, which include prejudice, superstition, misconception, and stigma against people with albinism. The Committee has suggested the gradual targeting of key groups, such as law enforcement officers, judges, teachers, social workers, health care workers, and the families and communities of people with albinism.<sup>554</sup>

Measures to achieve equality may include affirmative action measures.<sup>555</sup> These measures aim to secure the advancement of certain groups or individuals who require specific protection if they are to fully enjoy their human rights. In essence, these measures are used to mitigate conditions that perpetuate discrimination. Special measures are typically temporary, until such time substantive equality is achieved, but they may also be permanent in exceptional circumstances.

The Framework of international human rights obligations that applies to people with albinism includes the obligation to adopt, firstly, temporary special measures aimed at redressing discrimination and accelerating equality; and secondly, permanent special measures such as reasonable accommodation for visual impairment and vulnerability to skin cancer. States must take all appropriate steps to ensure that such reasonable accommodation is provided.<sup>556</sup>

States have an obligation to promote a positive perception of people with albinism, including by combating stereotyping, stigmatization, and discrimination. Albinism is deeply misunderstood, and long-term ignorance about the condition has given rise to myths that are often extremely concerning. Many such myths have a dehumanizing effect on people with albinism, which paves the way for exclusion and attacks. Misunderstanding and ignorance of albinism has also led to name-calling, verbal abuse, and discrimination for school-aged children with albinism throughout the world.

### iii. **Progressive realization and immediate obligations**

States have an obligation to *progressively* achieve the full realization of economic, social and cultural rights. This obligation is closely related to the obligation of States to take appropriate measures toward the full realization of these rights, taking into account each state's maximum available resources. The obligation of progressive realization therefore recognizes the cost of fully implementing appropriate measures, and understands that they might be achieved only over a period of time.

When taking measures toward the progressive realization of economic, social, and cultural rights—in particular the right to health, education, work, and housing—States are required to prioritize access for the most vulnerable or marginalized.<sup>557</sup>

States have an *immediate* obligation to take appropriate steps toward the realization of economic, social and cultural rights. A lack of resources cannot justify inaction; however, resource constraints should be taken into account when evaluating the efforts taken by a state to implement these rights.

Certain economic, social, and cultural rights are *not* subject to progressive realization, based on the nature of these rights, while others have strict time-bound limits. Examples of the former include the right to participate in cultural life and the right to form trade unions. An example of a time-bound obligation is an obligation to develop a plan of action to ensure the provision of free and compulsory primary education for all within two years.

Non-discrimination is an immediate obligation. Similarly, the obligation to provide reasonable accommodation applies immediately to all rights.

#### **iv. Obligations to respect, protect and fulfil all human rights**

The obligation to respect, protect and fulfil human rights is at the heart of state accountability.

**The obligation to respect** requires States to refrain from taking any discriminatory action or any measure infringing the exercise of human rights. This includes measures that limit or deny access to goods and services (including reasonable accommodation) for persons with albinism, and ultimately limit the enjoyment of economic and social rights, such as the right to food, housing, or health.

**The obligation to protect** is especially important in the context of attacks against people with albinism. States tend to fail to protect people with albinism against acts committed by private persons or entities. States must also protect people with albinism from discrimination by private persons or entities. In this context, the duty of due diligence requires States to take appropriate measures to prevent, punish, investigate, or redress the harm caused by the actions of private persons or entities.<sup>558</sup> Because such measures may have a deterrent effect, due diligence can be considered a measure of protection.

Victims of human rights violations have a right to receive fair and adequate reparation for the damage suffered.<sup>559</sup> In the context of rising cases of attacks against people with albinism, States have an obligation to provide effective redress or remedy. Persistent impunity surrounding such attacks obliges States to adopt provisional or interim measures to avoid continuing violations, and to endeavour to repair any harm caused by such violations at the earliest

possible opportunity.<sup>560</sup> States have a related obligation to take appropriate measures to guarantee the safety and wellbeing of victims, their relatives, and witnesses during and after judicial, administrative, or other proceedings.

**The obligation to fulfil** human rights requires States to take all necessary steps to create an environment that is conducive to the full enjoyment of human rights. In the context of civil and political rights, States must take steps to ensure the necessary legal framework, institutions, and resources are in place for the enjoyment of these rights.

In the context of economic, social, and cultural rights, States are obliged to fulfil these rights in situations where a person or a group is unable, for reasons beyond their control, to enjoy them. States have a core obligation to ensure non-discriminatory access to the rights to health, education, work, and an adequate standard of living, especially for vulnerable or marginalized groups such as people with albinism.<sup>561</sup> Furthermore, as set out in the Convention on the Rights of Persons with Disabilities, States have a duty to consult and involve persons with disabilities, including persons with albinism, regarding all laws, policies, and measures concerning them.<sup>562</sup> In particular, educational, informational, and training programs should be planned and implemented with the full involvement of people with albinism and their representatives.

#### **a. Right to education**

States have a core obligation to ensure the satisfaction of, at the very least, the most basic forms of education.<sup>563</sup> States must avoid measures that hinder or prevent the enjoyment of the right to education and take measures that prevent third parties from interfering with such enjoyment, such as discrimination and stigma from the community, family members, teachers, and perpetrators of attacks against children with albinism. States must also take positive measures that enable and assist individuals to enjoy the right to education, particularly through measures that implement reasonable accommodations.

In guaranteeing the right to education, States have an obligation to address the special needs of people with albinism due to their vision impairments in the context of education. In this regard, States must:

- provide the necessary resources for special needs educators to regularly access all schools attended by children with albinism;
- ensure the availability of large-print materials, low-vision devices, and adaptive devices as measures of reasonable accommodation; and
- take measures to train teachers with respect to the particular needs of children with albinism, including their need to be seated in the front row of classrooms and be provided with teachers' notes.

**b. Right to work and an adequate standard of living**

States have a core obligation to ensure non-discrimination and equal protection of employment, especially for marginalized individuals and groups, to enable them to live a life of dignity.<sup>564</sup> States must not deny or limit equal access to decent work for all people, especially historically and currently disadvantaged and marginalized individuals and groups. States must also adopt legislation or other measures to ensure that people with disabilities, including people with albinism, have equal access to work and adequate vocational training in safe and healthy working conditions.<sup>565</sup> Finally, States are obliged to provide for the right to work when individuals or groups are unable, for reasons beyond their control, to realize that right themselves using the means at their disposal.

The right to work is particularly important for people with albinism, not only in terms of access to an adequate standard of living, but also because of the implications for their health. People with albinism who work outdoors, such as farmers or traders, face a particularly high risk of developing skin cancer.<sup>566</sup> States therefore have an obligation to develop policies that promote and regulate flexible and alternative work arrangements, and that reasonably accommodate the needs of workers with disabilities.<sup>567</sup> For people with albinism, these policies should include provisions allowing them to carry out work indoors.

With respect to the right to an adequate standard of living, States must ensure that people with disabilities have equal access to adequate food, accessible housing, and other basic material needs. For people with albinism, this should include access to adaptive devices as well as access to adequate clothing for people with albinism to protect themselves from the sun, and thereby reduce the risk of skin cancer.



### **c. Right to health**

In guaranteeing the right to health, States have an immediate obligation to ensure that health facilities, goods, and services—as well as information about them—are accessible to everyone without discrimination, especially those most vulnerable and marginalized. Non-discriminatory accessibility requires both physical accessibility (within safe physical reach for all, including for people in rural areas and for people with disabilities) and economic accessibility (affordability).

People with albinism have special health needs, owing to the vision impairments and vulnerability to skin cancer associated with the condition. In this regard, to ensure access to the right to health for people with albinism, States have an obligation to ensure access to suitable skin cancer prevention such as sunscreen and sun protective clothing, access to information on skin cancer prevention, access to affordable skin cancer treatments, and access to glasses and other visual aids and adaptive devices, such as magnifying glasses.

States have an obligation to respect traditional preventive care, healing practices, and medicines. At the same time, States are obliged to ensure that harmful practices do not interfere with the right to life, physical integrity, and health. In this regard, the right to health requires States to circulate appropriate information relating to albinism and harmful practices.

### **3. Best practices by governments**

People with albinism have specific needs that engage multiple intersections of human rights. In addition to the right to life and security of the person and related harmful practices, it is necessary to address their needs in terms of education due to their vision impairments, and in terms of health, particularly in the area of skin cancer prevention. Governments should therefore be encouraged to address the human rights situation of people with albinism in a holistic manner. The following three key principles should guide decision-makers in government action on albinism:<sup>568</sup>

- 1) Multisectoral approach.** Multiple state agencies and sectors must participate in order to ensure appropriate measures are implemented to protect people with albinism including from attacks where they occur, and ensure their enjoyment of the rights to health, education, and work. Accordingly, States should implement a method to ensure multisectoral coordination and cooperation in the development, implementation, and evaluation of their national plans.
  
- 2) International cooperation.** States should provide technical and financial assistance to other States seeking to strengthen their services and build capacity related to the need of people with albinism. Further, States should cooperate to develop action plans and working groups to facilitate regional coordination and collaboration around human rights issues related to albinism. For example, between January 2016 and April 2017, the Independent Expert and more than 200 stakeholders from Africa worked together to develop a regional action plan on albinism in Africa in order to address attacks and related violations against people with albinism in the region. The plan covers the period of 2017–2021 and was endorsed by the African Commission on Human and Peoples’ Rights in its resolution 373 (LX) in 2017.

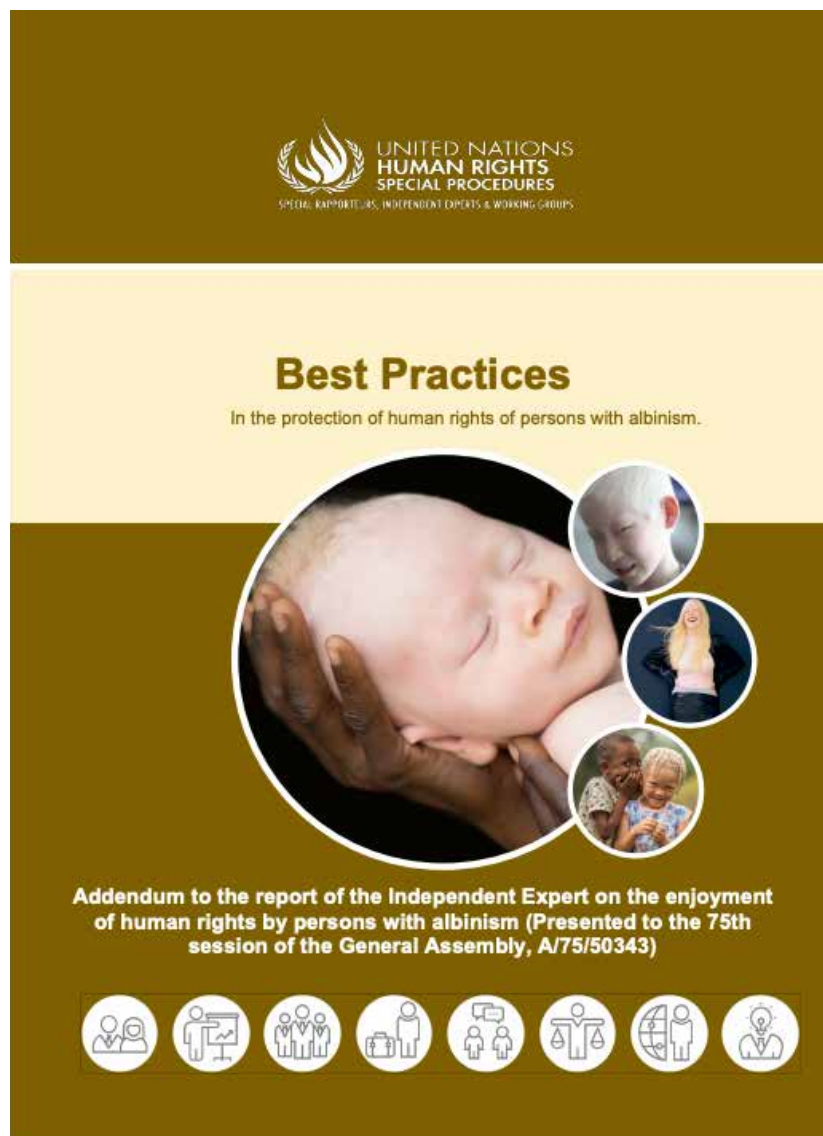
The regional action plan consists of recommendations made by United Nations and African Union human rights bodies and mechanisms. The recommendations were distilled into specific emergency measures, as an immediate response to attacks, and long-term initiatives, to address the underlying causes of attacks. The resulting measures are divided into four clusters:

- (1) prevention (public education campaigns, data collection, research on root causes);
- (2) protection (law enforcement, legislative framework, health, social welfare);
- (3) accountability (combating impunity, victim support); and
- (4) equality and non-discrimination (reasonable accommodation, intersectionality).

- 3) Budget for rights.** States should prioritize marginalized groups—including people with albinism—in national budgets, in accordance with

international human rights standards and the Sustainable Development Goals. States should immediately enact measures that do not require much funding and actively mobilize resources for the implementation of other, more expensive measures. People with albinism should have opportunities to actively participate in resource mobilization, allocation, and expenditure including through National Councils or Commissions on Disabilities.

Best practices including exemplary measures and interventions to promote the enjoyment of human rights by persons with albinism have been catalogued by the UN Independent Expert.<sup>569</sup>



"Front cover of report by UNIE" © UNIE

## Endnotes

549 See Part I.3.ii of this report, “Why a human rights approach?”

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558 UN Human Rights Committee. General Comment No. 31: The Nature of the General Legal Obligation Imposed on States Parties to the Covenant. U.N. Doc. CCPR/C/21/Rev.1/Add.13 (May 26, 2004). Available from [undocs.org/en/CCPR/C/21/Rev.1/Add.13](http://undocs.org/en/CCPR/C/21/Rev.1/Add.13).

559 See for example: CAT, Art. 14. See also 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, December 16, 2005, U.N. Doc. A/RES/60/147, Annex I. Available from [undocs.org/en/A/RES/60/147](http://undocs.org/en/A/RES/60/147) [UN Basic Principles].

560 UN Basic Principles, para. 19.

561 OHCHR, General Comment No. 14, *supra*, note 406.

562 CRPD, Art. 4(3).

563 OHCHR, General Comment No. 3, *supra*, note 551.

564 OHCHR, General Comment No. 18, *supra*, note 352 at para. 31.

565 CRPD, Art. 27.

566 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. U.N. Doc. A/HRC/31/63 (January 18, 2016) (by Ikponwosa Ero), para. 38. Available from [undocs.org/A/HRC/31/63](http://undocs.org/A/HRC/31/63).

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568 UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. (2020). Best Practices in the Protection of Human Rights of Persons with Albinism. [ohchr.org/Documents/Issues/Albinism/A-75-170-Addendum.pdf](http://ohchr.org/Documents/Issues/Albinism/A-75-170-Addendum.pdf) [Hereinafter: UNIE, Best Practices in the Protection of Human Rights of Persons with Albinism]

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# PART IV: HUMAN RIGHTS ADVOCACY



"Representatives from across Africa, Action on Albinism Forum, Dar es Salaam, 2016" © UTSS



## 1. Definition

Strong advocacy for the rights of people with albinism is necessary to achieve concrete results at all levels—local, national, regional, and international.

Advocacy is a set of organized activities undertaken for the purpose of influencing government and other institutional policies and practices. Advocacy calls for reform in institutions, power relations, and attitudes and behaviours, directed towards positive, lasting social change.

Human rights advocates use multiple methods, tools, and tactics to achieve their objectives. While they vary considerably, human rights advocacy methods, tools, and tactics tend to have the following characteristics in common:

- Methods and tactics are *planned*, and tools are used with *intentionality*;
- They are used and applied in a *targeted* manner;
- They are used in a manner that is *strategically complementary* to other methods, tools, and tactics;
- Methods and tactics have *clear objectives*; and
- They are based on *strong evidence*.

There are four key steps in human rights advocacy. Advocates must answer the following:

- 1) What is the problem, and what are the solutions?
- 2) What do we want to change?
- 3) Who will be our target?
- 4) How are we going to do it?

## 2. Methods

Historically, advocates have used any or a combination of the following methods:

**Monitor:** Be a human rights witness. Document the problems you see in your community and categorize them as human rights violations.

**Educate:** Raise awareness of human rights violations and educate others about human rights and responsibilities.

**Strengthen government:** Strengthen human rights laws and systems at the national level.

**Name and shame:** Pressure governments to stop violations and change policies through protests, letter-writing, and media campaigns.

**Empower:** Build the capacity of others to claim their rights, participate, have their voices heard, and create change.

**Lobby:** Use human rights standards to make recommendations and pressure government officials to change budgets, policies, and laws.

**Legally enforce:** Bring violations to justice and use international human rights legal arguments to support cases in domestic courts.

**Fulfill rights:** Provide direct services that fulfill the immediate human rights needs of others.

### 3. Building a Movement

Over the past twenty years, albinism groups have increased about ten-fold worldwide. A majority formed in the wake of the internet and the social connections enabled by that media. Others formed in the wake of attacks against people with albinism in Africa and the consequent need to protect themselves, and carry out advocacy. Others formed in response to the international attention on albinism in wake of the attacks, seizing the momentum to highlight their situation around the world. Regional albinism groups, registered and unregistered consortiums have also been formed in Africa, North America, South America and Europe.



“Second European Days of Albinism Meeting” © EDA

In January, 2020, civil society groups representing people with albinism from six continents assembled in Paris, France, to lay the foundation for an international coalition to combat the attacks, stigmatization, and discrimination faced by people with albinism worldwide. By unanimous vote, these groups formed the first-ever Global Albinism Alliance.

#### **4. Best Practices in Human Rights Advocacy**

The following best practices represent only a small sample of the extensive efforts undertaken by civil society and human rights institutions worldwide. For more examples, see the Addendum to the report of the Independent Expert on the protection of human rights of persons with albinism.<sup>570</sup>

##### **i. Monitoring, naming and shaming, and educating**

Civil society groups have used traditional and social media to draw attention to the issues faced by people with albinism, including marginalization, stigma, and discrimination. They have also engaged artists, actors, celebrities and other people of influence in the fight to protect human rights.

Active public education and awareness-raising campaigns have a powerful potential to dispel superstition and misinformation about albinism. These campaigns should aim at combating prejudice, superstition, misconception, and stigma, with a view to diminishing the multiple and intersecting forms of discrimination affecting people with albinism. In many parts of Africa, successful awareness-raising at the national level, including through the platform of International Albinism Awareness Day (June 13), has facilitated public education worldwide.

**Innovative approaches to awareness-raising.** In Kenya, Positive Exposure Kenya has developed an app that is designed to educate the public on albinism.<sup>571</sup> In Nigeria, The Albinism Foundation (TAF) airs a 15-minute weekly radio program across the country that features discussions on issues facing persons with albinism.<sup>572</sup> Under the Same Sun has developed an “Understanding Albinism” seminar, which is delivered through publications, media (e.g., social media, radio, TV), and public meetings.<sup>573</sup> Large international albinism conferences are held periodically in the USA and in Europe.

**Artistic approaches and beauty pageants.** In Malawi, awareness about albinism is fostered using drama, poems, and songs by local leaders.<sup>574</sup> Kenya hosts a beauty pageant for Mr. and Ms. Albinism East Africa. Likewise, in Zimbabwe, Miss Zimbabwe Albinism Trust (MZAT) holds a beauty pageant every year to build self-confidence in persons with albinism and raise awareness of the condition.<sup>575</sup>

**Training for stakeholders.** In Burundi, ASP and Femmes Albinos are engaged in disseminating information about the needs of children with albinism to teachers and students. For instance, they are instructing teachers to seat children with albinism with visual impairments closer to the blackboard.<sup>576</sup>

In Tanzania, Standing Voice has developed a Vision Ambassador Training Scheme, through which 105 teachers have been trained to defend the rights of students with albinism and facilitate academic success for these students. Standing Voice has also developed a booklet on albinism and vision to help all teachers.<sup>577</sup>



“Advocates at AU headquarters in Ethiopia”



## ii. Strengthening government

Some civil society organizations have played active and instrumental roles in the design, development, and implementation of laws, policies, and services aimed at addressing the needs of people with albinism.

In Nigeria, The Albinism Foundation (TAF) collaborated with the government to develop the National Inclusive Education Policy; however, it has yet to be implemented.<sup>578</sup> In addition, the Ministry of Health has partnered with the National Hospital in Abuja and the Albino Foundation to coordinate a project on free skin cancer treatment.

In Fiji, the government developed a national response to the needs of people with albinism in close collaboration with civil society, and in particular with the Fiji Albinism Project. The Fiji Albinism Project emerged from the first Fiji Albinism Workshop, which was held at the Fiji School for the Blind in 2014.<sup>579</sup> The project's steering committee was formed within the Ministry of Health. The project went on to organize the first Fiji Albinism Awareness Symposium in 2015, during which several barriers affecting the lives of people with albinism in Fiji were identified. The symposium led to the implementation of various measures to address the health issues of people with albinism, including awareness-raising at the community level, among provincial service officers, and at the educational level.

The Fiji Albinism Project is governed through multisectoral coordination among civil society and the government ministries responsible for health, education, and women's issues. While the Ministry of Health provides skin and eye clinics, civil society provides free sunscreens and eyeglasses, and the Ministry of Education shares information on albinism.



"Woman holding baby, Fiji" © Rick Guidotti



In the United Republic of Tanzania, the government collaborates with civil society groups to run a sunscreen production and distribution program. The Regional Dermatology Training Centre at the Kilimanjaro Christian Medical Centre has developed a comprehensive care programme for people with albinism. In conjunction with Kilimanjaro Sunscreen (KiliSun) and Standing Voice, the programme covers ten regions and reaches approximately 2,000 people with albinism. The programme includes:

- the registration and periodical health inspection of people with albinism in different regions of the country;
- the provision of free skin health services;
- education and awareness-raising on the importance of sun protection; and
- distribution of sun protection materials.

### iii. Empowering people with albinism

Civil societies are developing forums and structures (e.g., need analysis forums, focus group discussions) that provide space for persons with albinism, specifically for women and mothers of children with albinism, to participate in decision-making that concerns them.<sup>580</sup>

**Facilitating connection and network-building.** Led by Kenya, the Climb for Albinism brought together six women with albinism from different African countries to climb Mt. Kilimanjaro, in order to amplify the voices of persons with albinism.<sup>581</sup> In Nigeria, TAF hosts support meetings for persons with albinism once a month across all States; the state chapters report the outcome of the meetings to the Foundation head office for action if needed.<sup>582</sup> Thanks to awareness campaigns like IAAD, people with albinism in Uganda have been able to meet and connect with each other, which has greatly improved their self-esteem.<sup>583</sup> Through advocacy and support by the Albinism Umbrella of Uganda, the first person with albinism was employed by the Parliament of Uganda.<sup>584</sup>

**Facilitating participation in decision-making.** In Burkina Faso, ABIPA organized Fédération Burkinabè des Associations pour la Promotion des Personnes Handicapées (FEBAH), through which people with albinism can participate in the decisions that affect them.<sup>585</sup>

**Building capacity.** Under the Same Sun has developed an education sponsorship program for persons with albinism in Tanzania.<sup>586</sup>

## Endnotes

570 Ibid.

571 Kenya (PE).

572 Nigeria (TAF).

573 Tanzania (UTSS).

574 Malawi (MACOHA).

575 Zimbabwe (GAM).

576 Burundi (ASP); Burundi (Femmes Albinos).

577 Malawi & Tanzania (SV).

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579 UNIE, *Enjoyment of Human Rights by Persons with Albinism*, supra, note 39.

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584 Uganda (AAAU).

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# PART V: SUBSISTING CHALLENGES AND RECOMMENDATIONS



"Connie Chiu, Hong Kong" © Ellis Parrinder

## **1. Subsisting Challenges**

### **i. Awareness-Raising**

In the last decade, information about albinism has increased manifold with special features on major news media such as the BBC, CNN, Aljazeera, among others. However, the ongoing challenges highlighted in this report indicate that there remains work to be done in promoting understanding of the condition in both the public at large and also in particular sectors that are most relevant to the enjoyment of human rights by persons with albinism such as in the family setting, health and education sectors, as well as in the public at large.

### **ii. Insufficient and inaccessible social protection measures**

Social protection programmes for people with disabilities are often designed in such a way that people with albinism only benefit from them in relation to their visual impairment. Even for measures related to visual impairment, the application procedures can be confusing and often depend on a medical assessment. Social protection measures need to extend beyond recognizing visual impairment to include other barriers to interaction, such as susceptibility to skin cancer. They should ensure increased social and economic participation in order to reduce poverty.

Measures specifically for people with albinism include the provision of free sunscreen, lip care, after-sun products, and protective clothing; free screening, detection, and treatment of cancer; free optometric and ophthalmological tests; and ready access to visual aids and other adaptive devices, such as eyeglasses and monocular.

### **iii. Lack of data collection**

The lack of data on people with albinism, particularly women and children with albinism, has been cited by many civil society organizations over the years as a key challenge in designing, developing, and implementing initiatives to support people with albinism. Insufficient data collection and analysis contributes to the marginalization of those whose specific needs are poorly understood or ignored, including people with albinism.

There is an urgent need for capacity-building related to data collection, which should in any context follow a human rights-based approach and include the appropriate participation of the relevant population and their representatives. Confidentiality and data privacy are particularly important in countries where attacks occur.

National censuses offer an opportunity to collect data on people with albinism, but only a few instances have been documented to date. The national censuses of Namibia and the United Republic of Tanzania are two examples of good practices of collective data on people with albinism.<sup>587</sup>

#### **iv. Addressing harmful practices related to accusations of witchcraft and ritual attacks (HPAWR)**

Challenges in conceptualizing HPAWR and developing effective specific measures have impeded attempts to establish clear legal boundaries around such practices. Fortunately, the African Union Disability Protocol and the Plan of Action on Albinism, indicate a legal approach and several measures respectively, which when implemented are likely to be transformative in the protection of people with albinism at risk of physical violence.

## **2. Recommendations**

The following recommendations are directed to States where attacks against people with albinism occur:

### **SPECIFIC**

In countries where attacks occur, relevant States, Civil Society, National Human Rights Institutions and International Development Partners should support the implementation of the Plan of Action on Albinism (2021-2031).



## **GENERAL**

### **Regarding data collection and research:**

- Adopt a human rights-based approach to data collection, and build national capacity to disaggregate data that capture the situation of people with albinism. Such data should be disaggregated at minimum by gender, age, health status, and rural-urban prevalence;
- In data collection, apply the methodology in Best Practices, including but not limited to Washington Group on Disability Statistics, and include a specific question in censuses aimed at identifying people with albinism.

### **With respect to social and economic rights:**

- Continue to adopt measures to address poverty, in light of the 2030 Agenda for Sustainable Development, which pledges to leave no one behind, including persons with albinism;
- Provide reasonable accommodation for visual impairment as well as adequate protective measures against attacks on persons with albinism in schools and at places of work;
- Improve access to health care for persons with albinism, with particular focus on affordable or free sun protection products and skin cancer treatment. Such a health programme ought to be accessible to persons in rural or remote areas at little or no cost to them. The training of community health nurses and the use of mobile clinics have been identified as best practices in this regard.

### **With respect to public education:**

- Ensure sustained and uninterrupted multi-year-long efforts in public education on albinism, particularly in rural and remote areas, as well as border communities, to provide relevant information about albinism, including the scientific reasons behind albinism, as well as on the human rights of persons with albinism;

## **With respect to research and data collection:**

The following recommendations are directed to all States:

- Collect data on people with albinism – through censuses and surveys
- Formulate and implement specific, concrete, and time-bound national action plans;
- Incorporate a method of ensuring multisectoral coordination and cooperation in the development, implementation, and evaluation of the national plan of action, for instance by setting up an inter-agency coordination mechanism or by designating focal entities within a relevant state agency, such as an agency working on health and disabilities, to facilitate cooperation;
- Combat the stigmatization of and discrimination against persons with albinism through the wide range of methods, including through the promotion of positive information about persons with albinism, role models, and continued awareness-raising campaigns;
- Publicly condemn, at every opportunity (including on International Albinism Awareness Day every June 13), all forms of bullying, exclusion, discrimination, and stigmatization against persons with albinism;
- Support, both financially and technically, civil society organizations representing persons with albinism in their efforts to increase public awareness about albinism, including public education targeting key domains such as education and health, and in the provision of various forms of support to persons with albinism and their family members;
- Ensure full and meaningful participation of persons with albinism in the design, development, and implementation of all measures concerning them, and in particular national action plans and legislation;
- Ensure that social services are accessible to persons with albinism without discrimination, with reasonable accommodation, and in a manner that does not subject them to further stigmatization or require them to be exposed to the sun in order to receive support from social services;

- Include information on persons with albinism and their rights in training curricula generally, and particularly in the training of specialists in all relevant sectors, including disability, education, health, employment, justice and law enforcement, racial discrimination, diversity, and statistics;
- Deliberately seek out and include qualified persons with albinism in significant government and public offices;
- Prioritize marginalized groups or people with rare conditions, including persons with albinism, in national budgetary allocations;
- Continually monitor and evaluate the impact of measures adopted and adapt such measures as required;
- Cooperate with other States, including through research, capacity-building, information exchange, sharing of best practices, and technical and financial assistance, for the purposes of increasing the knowledge base and capacity to carry out and improve protection measures.

### **Regarding access to justice:**

- Undertake a justice needs assessment that captures the lived experiences of persons with albinism in order to improve their access to justice;
- Incorporate in the training of actors in the justice system—including police, courts, tribunals, national human rights institutions, ombudspersons, forensic investigations, and other mechanisms—modules on all barriers to the enjoyment of human rights by persons with albinism and measures to remove them that facilitate justice and human rights protection.
- Train and raise awareness among justice system personnel regarding the multiple forms of discrimination faced by women, as well as the principle of equality, including measures to:
  - Create supportive environments that encourage women to claim

their rights, report crimes committed against them, and actively participate in criminal proceedings;

- Protect women against secondary victimization in their interactions with law enforcement and judicial authorities;
- Provide competent and affordable legal representation and effective legal aid to persons with albinism, and waive legal fees if necessary;
- Establish a sufficient number of mobile courts and legal aid clinics with experienced legal representatives specifically for rural settings;
- Ensure equal access for persons with albinism by providing them with reliable legal information in accessible formats and at various points of entry into the legal system, including at police stations, court clerks, and registries;
- Train community leaders, including community police and traditional and religious leaders, on the justice system, including where to refer and how to initially address a diversity of cases, including those concerning persons with albinism. Incorporate into existing training or create specific training on the human rights of persons with albinism, including the particular threats they face at home and in community environments;
- Support persons with albinism and organizations serving them in availing themselves of legal remedies and exercising influence upon law-making and implementation processes and institutions;
- Review and clarify referral pathways for accessing justice for persons with albinism in order to remove protracted and bureaucratic barriers, including by training organizations of persons with albinism;
- Involve persons with albinism in the design and delivery of community education programmes to increase awareness of their rights and legal remedies;
- Engage diverse stakeholders, including persons with albinism, in developing national indicators and tracking national data on the functionality and efficacy of access to justice for persons with albinism.

## Regarding the right to health:

- Address health-related aspects of albinism as a public health concern;
- Incorporate albinism into existing public health initiatives, including through maternal and family support policies; cancer prevention policies; rare condition policies; and genetic counselling policies, particularly in communities with consanguineous marriage practices;
- Ensure the adoption of special measures on persons with albinism in policies governing health and disabilities, as well as the training curricula of health-related professions;
- Include specific services for persons with albinism in existing health centres;
- Provide guidance for health professionals on the support needed by persons with albinism and ensure that the training of health workers, including ophthalmologists, dermatologists and nurses, includes topics on the condition of albinism and protection measures;
- Ensure that albinism is included in early intervention programmes on health, including dissemination of detailed health-care information and advice;
- Ensure that the right to the highest attainable standard of health is exercised without discrimination of any kind, in particular against persons with albinism;
- Include sunscreen on the list of essential medicines without further delay, and ensure that quality sunscreen is accessible, available, and affordable in both rural and urban areas;
- Ensure the availability, accessibility, affordability and quality of treatment for skin cancer without discrimination. Such treatment should include curative measures, as well as cosmetic treatment to restore or improve appearance to avoid further discrimination based on appearance;



- Deliver accessible and culturally appropriate rehabilitation programmes, particularly concerning skin cancer and visual impairment;
- Support or initiate the production and distribution of locally produced sunscreen, such as KiliSun. Distribution should include health education on the use of such a product;
- Support best practices such as mobile clinics where they exist, or initiate such measures;
- Ensure that specific measures for persons with albinism are integrated into disability-related programmes, including the distribution of adaptive devices as a means of reasonable accommodation;
- Facilitate the importation of glasses and gadgets as a measure of reasonable accommodation, for example, by removing taxes and administrative costs associated with the importation of these goods;
- In collaboration with civil society:
  - Continue to conduct quality research to shape public policy and effectively implement sun protections strategies;
  - Support prevalence and epidemiological studies as a basis for developing effective measures;
  - Publish data acquired in the course of research to inform collaborative work and develop policies;
- In collaboration with civil society, continue to raise awareness to:
  - Include specific information about albinism, in particular about the associated susceptibility to skin cancer, in training for health professionals;
  - Ensure that there is no barrier to the recognition of persons with albinism as persons with disabilities;
  - Use International Albinism Awareness Day as an opportunity to inform the general public about albinism and, where appropriate, engage in media campaigns to this effect.

## Regarding education:

- Ensure that reasonable accommodation is provided to persons with albinism in the school system.

The following recommendations are directed to civil society and national human rights institutions:

- Incorporate and centralize the human rights approach in advocacy, public education, research and all other domains of work, to mitigate the negative consequences of the medical or charity approach to persons with disabilities;
- Continue monitoring the implementation of the rights of persons with albinism and report regularly to international mechanisms such as treaty bodies or the Universal Periodic Review;
- Monitor national data collection on albinism and ensure it follows a human rights-based approach;
- Take an active role in the implementation and promotion of action plans on the rights of persons with albinism and the inclusion of relevant action in existing programmes and strategies;
- Ensure that in all albinism-related programming, a gender perspective forms an integral part of the design, implementation, monitoring, and evaluation of all interventions;
- Collaborate with key actors, advocates, experts, and researchers in relevant domains, including disability, health, education and rare conditions;
- Develop national, regional, and global collaboration platforms, including through networks and action plans, to promote and replicate best practices and to include the human rights situation of persons with albinism in various national, regional, and international human rights and development forums in a coherent, strategic, and effective manner.

**The following recommendations are directed to the international community, including international organizations:**

- Deliberately seek out and include persons with albinism in all public discussions on human rights, including relevant national and international mechanisms and processes, as well as in particular discussions, such as in regional forums tasked by the United Nations to follow up on the implementation of the Sustainable Development Goals;
- Continue to support States and civil society working on the human rights of persons with albinism, including through capacity-building, particularly in the area of investigative research and forensic science, as well as in the area of implementation of protective measures;
- Support efforts for the realization of the right to health of persons with albinism, such as the scaling-up of best practices and by ensuring its insertion into existing health projects;
- Support epidemiological studies on albinism in order to gather the data necessary to develop public health policies;
- Assist States and other stakeholders in ensuring data collection on people with albinism nationally, regionally, and globally, in line with human rights approaches and principles.

Endnotes

587 UNIE, Best Practices in the Protection of Human Rights of Persons with Albinism, *supra*, note 568.

