

**PROMOTING & PROTECTING
THE RIGHTS OF
PERSONS WITH ALBINISM
A MANUAL FOR NATIONAL
HUMAN RIGHTS INSTITUTIONS**



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First published in 2021
by Amnesty International Ltd
Peter Benenson House, 1 Easton Street
London WC1X 0DW, UK

Index: AFR 03/3879/2021
Original language: English

amnesty.org

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ACKNOWLEDGEMENTS

In July 2019, Amnesty International partnered with the South African Human Rights Commission to convene a SADC Regional Meeting of National Human Rights Institutions on Promoting and Protecting the Rights of Persons with Albinism in Southern Africa, in Johannesburg. Participants at the meeting called for practical tools to enhance the ability of NHRIs to promote and protect the human rights of persons with albinism in the region and beyond. This manual answers that call.

The manual could not have been realised without the support and commitment of many partners. Amnesty International is truly grateful to all those who contributed their time and expertise to its preparation.

In particular, Amnesty International acknowledges the work of Muluka Miti-Drummond, who drafted the manual. Amnesty International staff in the Southern Africa regional office conceptualised and managed production of the manual to its completion, with policy review from the Law and Policy team. A virtual pilot training on the manual was held in September 2020 and feedback from the training was incorporated into the final draft. Amnesty International would like to thank the participants at the pilot training, who included representatives of NHRIs from Eswatini, Malawi, Namibia, South Africa and Zimbabwe, for their important contributions. Amnesty International thanks Jane Waithera and Ms. Ikponwosa Ero, the UN Independent Expert on the enjoyment of human rights by persons with albinism for their timely and expert contributions during the compilation of the manual.

Amnesty International acknowledges the generous financial support and consistent partnership of the Open Society Initiative for Southern Africa. Last but not least, Amnesty International is truly grateful to all persons with albinism who were part of the many engagements that have led to the successful completion of the manual. Your courage and resolute stand in defense of the rights of all persons with albinism across Southern Africa, and globally, continues to inspire us all.

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LIST OF ABBREVIATIONS

ACERWC	African Committee of Experts on the Rights and Welfare of the Child
AU	African Union
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CED	Committee on Enforced Disappearances
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CERD	Committee on the Elimination of Racial Discrimination
CESCR	Committee on Economic, Social and Cultural Rights
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CSOs	Civil Society Organisations
ESC Rights	Economic, Social and Cultural Rights
FOCCISA	Fellowship of Christian Councils in Southern Africa
HP-AWRA	Harmful Practices related to Accusations of Witchcraft and Ritual Attacks
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICPPED	International Convention for the Protection of All Persons from Enforced Disappearance
ICRMW	International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families
IOM	International Organisation for Migration
MoUs	Memorandums of Understanding
NGOs	Non-Governmental Organisations
NHRIs	National Human Rights Institutions
OHCHR	Office of the High Commissioner for Human Rights
PAP	Pan African Parliament
PESTEL	Political, Economic, Social, Technological, Environmental and Legal
RAP	Regional Action Plan on Albinism in Africa
SADC	Southern African Development Community
SADC CNGO	SADC Council of NGOs
SADC-PF	SADC Parliamentary Forum
SARPCCO	Southern African Regional Police Chiefs Co-operation Organisation
SATUCC	Southern Africa Coordination Council
SNC	SADC National Committees (SNC)
SPF	Sun Protection Factor
UDHR	Universal Declaration on Human Rights
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children’s Emergency Fund
UPR	Universal Periodic Review

INTRODUCTION & TERMINOLOGY

This manual has been developed by Amnesty International and the Open Society Initiative for Southern Africa (OSISA) for the purposes of assisting National Human Rights Institutions (NHRIs) as they seek to carry out their functions in relation to the promotion and protection of the enjoyment of all human rights of persons with albinism. It is specifically designed for NHRIs based in the Southern Africa region, also known as Southern African Development Community (SADC), however, the principles contained herein are equally applicable to other regions.

The manual explains the role of NHRIs in protecting and promoting human rights in the context of albinism. It sets out the types of violations that prevent the full enjoyment of all human rights by persons with albinism and the obligations of States to protect these rights. It further seeks to provide tools to assist NHRIs in carrying out their human rights promotion and protection functions in relation to albinism. These include practical information on investigating violations of such rights through national inquiries and individual complaints, as well as developing and implementing promotion strategies, and carrying out advocacy at the national and international level. Lastly, it briefly provides information on monitoring, evaluation and learning to ensure continued progress in rights protection.

For the purposes of this manual, **NHRIs** are defined as, State bodies with a constitutional and/or legislative mandate set up, in accordance with the Principles relating to the Status of National Institutions (the Paris Principles)¹, to protect and promote human rights. They are part of the State apparatus, funded by the State, but independent and autonomous from government².

“**Albinism** is a relatively rare, non-contagious, genetically inherited condition resulting in little to no pigmentation in the skin, hair and eyes. The condition affects people worldwide regardless of ethnicity or gender. Persons with albinism are highly vulnerable to skin cancer and often have disabilities, mainly as a result of vision impairment and skin impairment.”³

The term “albino”, which has commonly been used in the past, is considered inappropriate and derogatory as it identifies the person on the basis of their condition rather than as a person first and foremost⁴. Many persons with albinism have also taken objection to the term ‘person living with albinism.’ They feel this implies their condition was acquired, rather than something they are born with. This report therefore uses, ‘**persons with albinism**’ as this is internationally accepted, including by the UN. For this reason, the report uses ‘**persons with disabilities**’, as opposed to other alternatives.

1 Principles relating to the Status of National Institutions (The Paris Principles), Adopted by General Assembly resolution 48/134 of 20 December 1993, www.ohchr.org (accessed 30 July 2020)

2 nhri.ohchr.org (accessed 07/07/2020)

3 For further information see for example: The report of the Independent Expert on the enjoyment of all rights by persons with albinism, Albinism Worldwide, A/74/190, 18 July 2019. Available at: undocs.org (accessed 14 July 2020)

4 Consider, for example, that persons with cancer are not called canceroids.

In addition, for the purposes of this manual, the below highlighted terms are defined as follows:

Discrimination – “any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.”⁵ Such discrimination includes failure to make reasonable accommodation for persons with albinism.

Harmful practices – values and beliefs held by members of a community for generations which are harmful to a specific group of people, usually women, children and the elderly. They prevent such groups from controlling and making their own choices, particularly in relation to their bodies. In the context of albinism, these include beliefs that rape of a woman or girl with albinism, or the mother of a child with albinism can cure HIV, use of body parts of persons with albinism for witchcraft, as well as social exclusion and abandonment of children with albinism and their mothers.

Intersectional discrimination – discrimination which takes place on the basis of two or more prohibited grounds which interact with each other at the same time and are inseparable and result in a greater disadvantage (e.g. a woman with albinism discriminated against because she is a woman and because she has albinism).

Reasonable accommodation – “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”.⁶

Stigma – a strong feeling of disgust which dehumanises, degrades, devalues and discredits people based on a particular circumstance, quality or characteristics of a person or group of persons that distinguishes them from others and is perceived as inferior or abnormal.

Systematic violation – a consistent pattern of human rights violations i.e. a situation where the same right appears to be violated regularly and not just an isolated case.

Systemic or structural violations – violations caused by laws, policies, and widespread practices, patterns of behaviour and ingrained attitudes. They are deeply ingrained in society, may be seen as normal and often serve to make the violation invisible.

⁵ General Comment No. 18, in United Nations Compilation of General Comments, p. 135, para. 7

⁶ Article 2 of the International Convention on the Rights of Persons with Disabilities

NHRIS & HUMAN RIGHTS

National Human Rights Institutions (NHRIs) play an important role in the promotion and protection of human rights at the national level. They may be known by a number of names including National Human Rights Commission, Ombudsman, and Public Protector (or *Provedor de Justiça* in Lusophone countries). However, regardless of their name, all NHRIs are set up by a constitutional or legislative act setting out their mandate, competencies, jurisdiction and structure. In addition, to be officially recognised internationally as an NHRI, these bodies must comply with the United Nations (UN) Paris Principles.⁷ The first of these principles – and the most important for the purposes of this manual - is that NHRIs must be vested with competence to promote and protect human rights.

The promotion of human rights involves increasing the public knowledge and awareness of human rights, the actions that constitute a violation of such rights, and mechanisms for redress in case of violations. The aim of such promotion is to build a culture of respect for human rights, leading to a decrease in the number of people intentionally or unintentionally violating rights.

The protection of human rights, on the other hand, goes further than knowledge dissemination. It is geared towards putting in place systems and mechanisms to ensure rights are not violated, and redress in cases where violations occur.

QUESTIONS

WHAT DO YOU UNDERSTAND BY HUMAN RIGHTS?

Think of the NHRI in your country:

- What law establishes it?
- What is it known as?
- Is it vested with competency to promote and protect human rights?
- How does it differ from Non-Governmental Organisations (NGOs) which seek to promote and protect human rights?

Review the Paris Principles. Does your NHRI meet the requirements of the Paris Principles? What needs to be changed to bring it in line with the Paris Principles?

⁷ Principles relating to the Status of National Institutions (The Paris Principles). Adopted by General Assembly resolution 48/134 of 20 December 1993

How an NHRI promotes and protects rights will be determined in part by the powers and functions given to it by its constitutive document. However, in the process of doing so, the Paris Principles endows them with, among others, the responsibilities of submitting opinions, recommendations, proposals and reports on human rights matters to the government, parliament and other competent bodies; contributing to State reports to international and regional human rights bodies; assisting in the development of human rights education programmes; and increasing public awareness of human rights by making use of the media.⁸

In order to effectively carry out these responsibilities and to ensure appropriate action targeted at protecting and promoting the enjoyment of rights by persons with albinism, NHRIs should have an understanding of the international human rights framework on albinism and a clear picture of the human rights situation in their country in relation to albinism. With the relevant information, NHRIs can then develop and implement protection and promotion strategies.

STEPS FOR WORKING ON RIGHTS OF PERSONS WITH ALBINISM



In addition, continuous monitoring, evaluation and learning is essential to ensuring promotion and protection activities are having the desired impact and making appropriate changes where required. Monitoring, evaluation and learning also helps in measuring government progress or retrogression. The successive sections will therefore provide a substantive understanding of the international human rights framework in relation to albinism before turning to a more practical look at methodologies and tools for understanding the national context; developing protection and promotion strategies; and carrying out monitoring, evaluation and learning.

⁸ Principle 3 of the Paris Principles

UNDERSTANDING THE INTERNATIONAL HUMAN RIGHTS FRAMEWORK

OBJECTIVES OF PART 3:

By the end of Part 3, NHRIs should be able to:

- Explain what human rights are in general.
- Know the international bodies for the protection of human rights at the UN and African levels.
- Understand intersectional discrimination and how discrimination prevents persons with albinism from fully enjoying their rights to life and bodily integrity, health, education and work.
- Have an understanding of the rights violated in relation to attacks against persons with albinism and the duties of the State in relation to the protection of persons with albinism from attacks.
- Have an understanding of why albinism is considered a disability.
- Have an understanding of the specific obligations of States in relation to the protection of the rights to health, education and work of persons with albinism.

3.1 WHAT ARE HUMAN RIGHTS?

Human rights are the basic rights and freedoms (entitlements) that belong to everyone, regardless of race, sex, nationality, ethnicity, language, religion, or any other status.

They are:

- **Universal:** they belong to every single person
- **Inalienable:** they cannot be taken away from us
- **Indivisible and interdependent:** governments should not be able to pick and choose which rights are respected, protected and promoted.

Human rights are entitlements which States are obliged to:

- **Respect** – refrain from acts which violate these rights
- **Protect** – ensure others do not infringe these rights
- **Promote** – advance awareness of and respect for human rights
- **Fulfil** – take action to ensure all people are able to fully enjoy these rights

Human rights are mainly contained in agreements between States, the wording of which is negotiated by them and then voluntarily signed onto, which makes the agreements binding upon States Parties. These agreements are known as treaties, covenants or conventions. Other sources of human rights⁹ include:

- international custom,
- general principles of laws recognised by states (jus cogens),¹⁰ and as subsidiary means,
- judicial decisions (particularly of human rights courts and quasi-judicial bodies)¹¹, as well as
- the teachings of the most highly qualified publicists.¹²

The Universal Declaration on Human Rights (UDHR), considered by many as the primary source of human rights, is not a treaty. It is however, international customary law and therefore considered binding on all States. At national level, human rights are contained in the Bill of Rights in the constitutions of most countries. However, these must be in line with international human rights law.

QUESTIONS

1. What rights and treaties are you aware of?
2. Writings of highly qualified publicists are considered subsidiary sources of laws. Which writers would you consider as highly qualified and relevant for albinism?
3. Does your country have a bill of rights in its constitution? In any legislation? What rights are recognised in it?
4. What human rights do you see as relevant for work on albinism?

9 Article 38 of the International Court of Justice Statute

10 That is a principle of international law that is accepted by States as a norm from which no derogation is permitted i.e. which all States must respect. The prohibition against torture is an example of such a jus cogens.

11 For example, decisions of the African Court on Human and Peoples' Rights, as well as national courts in relation to that State.

12 Writings of Special Rapporteurs for example.

3.1.1 International human rights instruments

TOOL 1: LIST OF MAIN TREATIES SETTING OUT HUMAN RIGHTS APPLICABLE TO ALBINISM IN SADC REGION

TREATY	HOW IT RELATES TO ALBINISM
MAIN UN TREATIES	
International Convention on the Elimination of All Forms of Racial Discrimination of 1965 (ICRED)	Prohibits discrimination on the basis of colour. Persons with albinism are often discriminated against by people of the same race as them because of their fair complexion.
International Covenant on Civil and Political Rights of 1966 (ICCPR)	Provides for the rights to equality and non-discrimination, life, dignity, bodily integrity, liberty, not to be tortured and to redress. Physical attacks against persons with albinism often violate many of these rights (see 3.2.1)
International Covenant on Economic, Social and Cultural Rights of 1966 (ICESCR)	Provides for the rights to an adequate standard of living, education, health and work, as well as States obligations to ensure these rights. Persons with albinism are often prevented from fully enjoying these rights, particularly as States do not always take adequate steps to ensure they can. (see 3.2.2 – 3.2.5)
Convention on the Elimination of All Forms of Discrimination against Women of 1979 (CEDAW)	Requires States Parties to end discrimination against women. Harmful practices, such as rape of women and girls with albinism, exclusion of women with albinism and mothers of children with albinism, and accusation of mothers of children with albinism of being witches are all forms of discrimination against women (See 3.2.2)
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment of 1984 (CAT)	Involvement of State officials in attacks against persons with albinism; or the inability or unwillingness of States to adequately carry out investigations and prosecute such attacks may constitute torture (see 3.2.1)
Convention on the Rights of the Child of 1989 (CRC)	Guarantees the rights of children including those with albinism
International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families of 1990 (ICRMW)	Guarantees the rights of persons including those with albinism who are migrants

TREATY	HOW IT RELATES TO ALBINISM
MAIN UN TREATIES	
<p>Protocol to Prevent, Suppress and Punish Trafficking in Persons Especially Women and Children (2000)</p>	<p>Persons with albinism are sometimes taken from one place to another for the purposes of having body parts taken from them (i.e. for the purposes of exploitation) in a manner which amounts to trafficking. States are required to take steps to prevent and punish such trafficking, including working with CSOs and supporting victims of trafficking.</p>
<p>International Convention for the Protection of All Persons from Enforced Disappearance of 2006 (ICPPED)</p>	<p>Abductions of persons with albinism involving State agents may amount to enforced disappearances. States Parties have a duty to investigate all disappearances, including those not carried out by State agents. Inability or unwillingness of State to investigate disappearances of persons with albinism may amount to acquiescence by the State, therefore rendering such disappearance an enforced disappearance</p>
<p>Convention on the Rights of Persons with Disabilities of 2006 (CRPD)</p>	<p>Persons with albinism have low vision and are susceptible to skin cancer due to a lack of pigmentation. The low vision and susceptibility to skin cancer means that they fall within the framework of the CRPD (see 3.2.3)</p>
MAIN AFRICAN COMMISSION/ AU TREATIES	
<p>AU Convention Governing Specific Aspects of Refugee Problems in Africa of 1969 (African Convention on Refugees)</p>	<p>Persons with albinism fleeing widespread violence against persons with albinism in their countries may be entitled to refugee status</p>
<p>African Charter on Human and Peoples' Rights of 1981 (African Charter)</p>	<p>Like the ICCPR, it provides for the rights to equality and non-discrimination, life, dignity, bodily integrity, liberty, not to be tortured and to redress. Physical attacks against persons with albinism often violate many of these rights (see 3.2.1)</p> <p>It further provides for the rights to education, health and work, as well as States obligations to ensure these rights. Persons with albinism are often prevented from fully enjoying these rights, particularly as States do not always take adequate steps to ensure they can. (see 3.2.2 – 3.2.5)</p>
<p>African Charter on the Rights and Welfare of the Child of 1990 (African Charter on the Rights of the Child)</p>	<p>Guarantees the rights of children including those with albinism</p>

TREATY	HOW IT RELATES TO ALBINISM
MAIN AFRICAN COMMISSION/ AU TREATIES	
Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa of 2003 (the Maputo Protocol)	Like CEDAW, it requires States Parties to end discrimination against women and specifically mentions harmful practices (See 3.2.2)
African Charter on Democracy, Elections and Governance of 2011 (African Charter on Democracy)	States Parties to ensure non-discrimination for persons with albinism in relation to elections and governance
Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa of 2018 (African Protocol on older persons – not yet in force)	Applicable to older persons with albinism, particularly Article 13 on older persons with disabilities
Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa (not yet in force)	Specifically refers to albinism and raises concerns regarding attacks against persons with albinism in its preamble. Requires States Parties to take action for persons with albinism in situations of risk, as well as enshrining the rights to access to justice, equality, health, education, work and other rights for persons with disabilities, including albinism.
SADC TREATIES	
Protocol on Health (1999)	Requires States to cooperate in relation to research, as well as promotion of measures to prevent and manage disabilities, as well as to increase access to assistive devices. Relevant in relation to skin cancer prevention and assistive devices for persons with albinism, as well as research into albinism. (See 3.2.3)
The Revised Protocol on Gender and Development (SADC Gender Protocol)	Provides for measures to be adopted to end gender-based violence, equality in accessing justice and for measures to take into account the particular vulnerabilities of women with disabilities. (See 3.2.2)
Protocol on Employment and Labour (not yet in force)	Provides for measures to be adopted to end gender-based violence, equality in accessing justice and for measures to take into account the particular vulnerabilities of women with disabilities. (See 3.2.2)

*Tools 13 and 14 in section 6.4 provide further details on specific articles.

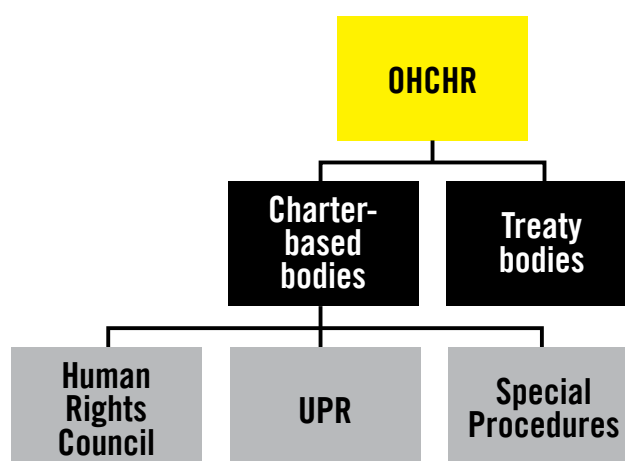
International bodies protecting human rights

A number of international and regional bodies have been set up to oversee the promotion and protection of human rights contained in human rights treaties, as well as to develop and clarify human rights standards.

At the international level, there are the UN Office of the High Commissioner for Human Rights (OHCHR), human rights treaty bodies and Charter-based bodies. Treaty bodies are groups of experts that monitor the implementation of the core international human rights treaties, such as the Committee on the Rights of Persons with Disabilities which monitors implementation of the CRPD. These bodies carry out regular reviews of member States' compliance with the relevant treaty and issue concluding observations, which are their assessments of the State's implementation, at the end of each review.

The Charter-bodies consist of the:

- Human Rights Council – an inter-governmental body within the United Nations system responsible for strengthening the promotion and protection of human rights around the globe and for addressing situations of human rights violations and making recommendations on them.
- Universal Periodic Review – a process involving the periodic review of the human rights record of all 193 UN member States by other States, and
- Special Procedures of the Human Rights Council – independent human rights experts with mandates to report and advise on human rights from a thematic or country-specific perspective. The most relevant special procedure for the purposes of this report is the Independent Expert on the enjoyment of all human rights by persons with albinism, as well as the Special Rapporteur on the rights of persons with disabilities.¹³



At the African regional level, the African Union (AU) has set up the African Commission on Human and Peoples' Rights (African Commission), as well as the African Committee of Experts on the Rights and Welfare of the Child (ACERWC). The African Commission also has individuals or groups of experts who report and advise on thematic and country human rights issues. The most relevant of these for albinism is the Working Group on rights of older persons and people with disabilities.

The AU has also established the African Court on Human and Peoples' Rights which hears cases related to the violation of human rights contained in the AU treaties against states parties to the African Charter on Human and Peoples' Rights and the protocol to the African Charter establishing the African Court on Human and Peoples' Rights allowing direct access of individuals and NGOs to the court. The African Commission also functions as a quasi-judicial body when it decides on human rights cases, referred to as communications.

In addition, sub-regional bodies have powers to determine human rights cases. The East African Court of Justice hears cases for countries based in East Africa, such as Tanzania and the SADC Tribunal should have power to determine cases in Southern Africa but is currently suspended.

¹³ See chapter 6 for further information on the treaty bodies and charter-based bodies.

TOOL 2: HUMAN RIGHTS BODIES*

UN CHARTER BODIES
Human Rights Council
Universal Periodic Review
Special Procedures of the Human Rights Council
Human Rights Council Complaint Procedure
UN TREATY BODIES
Committee on the Elimination of Racial Discrimination (CERD)
Committee on Economic, Social and Cultural Rights (CESCR)
Human Rights Committee (CCPR)
Committee on the Elimination of Discrimination against Women (CEDAW)
Committee Against Torture (CAT)
Committee on the Rights of the Child (CRC)
Committee on Migrant Workers (CMW)
Subcommittee on Prevention of Torture (SPT)
Committee on the Rights of Persons with Disabilities (CRPD)
Committee on Economic, Social and Cultural Rights (CESCR)
Committee on Enforced Disappearances (CED)
Committee on the Elimination of Discrimination against Women (CEDAW)

AU BODIES
The African Court on Human and Peoples' Rights
The African Committee of Experts on the Rights and Welfare of the Child (ACERWC)
African Commission on Human and Peoples' Rights, as well as its special mechanisms
<ul style="list-style-type: none"> ■ Special Rapporteur on Prisons, Conditions of Detention and Policing in Africa ■ Special Rapporteur on Rights of Women ■ Working Group on Indigenous Populations/Communities in Africa ■ Special Rapporteur on Freedom of Expression and Access to Information ■ Special Rapporteur on Human Rights Defenders and Focal Point on Reprisals in Africa ■ Special Rapporteur on Refugees, Asylum Seekers, Internally Displaced Persons and Migrant in Africa ■ Committee for The Prevention of Torture in Africa ■ Working Group on Economic, Social and Cultural Rights ■ Working Group on Death Penalty, Extra-Judicial, Summary or Arbitrary Killings and Enforced Disappearances in Africa ■ Working Group on Rights of Older Persons and People with Disabilities ■ Working Group on Extractive Industries, Environment and Human Rights Violations ■ Committee on The Protection of The Rights of People Living with HIV (PLHIV) and Those at Risk, Vulnerable to and Affected by HIV

* Section 6.4 provides further information on how NHRIs can engage with these bodies.

3.2 ALBINISM & HUMAN RIGHTS

3.2.1 What is albinism?

Albinism is a genetic condition resulting in little to no pigmentation in the skin, hair and eyes. Persons with albinism have a lighter complexion than others. This difference in appearance tends to be more exaggerated in places where the majority of the population has a darker complexion and may lead to discrimination based on colour, including from persons of the same race. The prevalence of persons with albinism varies from 1 person in 5,000 to 1 person in 15,000, with selected populations in Southern Africa having a prevalence of 1 person in 1,000.¹⁴

Some people wrongly believe that persons with albinism are lucky or unlucky, that their body parts can provide health, wealth or some other type of benefits. In some cultures, albinism is seen as a curse. Some believe the mother of a child or a child with albinism is cursed or a witch. Some believe that sex with a person with albinism or mother of a child with albinism can cure HIV/AIDS or grant some other type of supernatural benefit.

These erroneous beliefs, myths and superstitions have led to stigma and harmful practices related to accusations of witchcraft and ritual attacks (HP-AWRA). Such practices include abandonment and abuse of children with albinism and/or their mothers; rape of women and children with albinism or their mothers; as well as trafficking, mutilation and killing of persons with albinism by individuals seeking to use their body parts in ritual practices.

Due to a lack of skin pigmentation, persons with albinism are vulnerable to the sun and have an increased susceptibility to skin cancer. Albinism is often linked to photophobia (eye sensitivity to the sun), nystagmus (involuntary eye movement from side to side) and low vision. Due to their susceptibility to the sun and visual impairment, persons with albinism require changes (reasonable accommodation) to be made to enable them to enjoy their rights, including rights to health, education, work, an adequate standard of living, and access to justice on an equal basis with others. Under international human rights law they are considered persons with disabilities.

¹⁴ Report of the Independent Expert on Albinism, Albinism worldwide, A/74/190, 18 July 2019, para. 6. Available at undocs.org

3.2.2 Albinism, equality, non-discrimination and Economic, Social and Cultural Rights (ESC Rights)

How does equality and non-discrimination interact with albinism?

The right to equality is provided for in a number of international and regional human rights treaties. It goes hand-in-hand with the right to non-discrimination. Discrimination is any difference of treatment based on a prohibited ground that does not have an objective and reasonable justification and impairs the exercise of human rights on an equal footing with others. It can be direct, indirect or intersectional.

Direct discrimination is usually a clear distinction of treatment between people or groups of people, for example where medical professionals refuse to treat a person with albinism due to the stigma attached to albinism. Indirect discrimination is where a law, policy, procedure or practice appears to be neutral but has the effect of disproportionately disadvantaging a particular group. For example, where persons are required to wait in the sun for long hours to receive a service. Waiting in the sun increases the vulnerability of a person with albinism to skin cancer and therefore may be a barrier to that person accessing the relevant service.

The right to equality and non-discrimination does not mean that everyone should always be treated equally. In fact, to ensure enjoyment of rights at equal footing for all, distinctions may need to be made at times. This is the case where one group of people is, or has been, disadvantaged. The right to equality and non-discrimination therefore not only requires States to refrain from actions that disadvantage certain groups in favour of others,

but also to take positive steps to ensure that those not enjoying rights on an equal footing to others are able to do so. For example, due to their increased chances of contracting skin cancer, persons with albinism need to take precautions such as use of sunscreen. These can be financially out of reach for many people. The State therefore will need to provide free sunscreen for persons with albinism, but not necessarily for others.

Some groups may also be subjected to intersectional discrimination. This occurs when a particular group or groups of people are treated differently on the basis of two or more grounds without an objective and reasonable justification, which leaves them at a disadvantage. For example, where a woman with albinism is accused of being a witch and chased from her village, she is discriminated upon due to her albinism, gender and colour. This constitutes discrimination on the basis of gender as men are rarely accused of witchcraft and, in the rare occasions that they are, they are highly unlikely to be subjected to the forms of harmful practices women accused of witchcraft experience. It constitutes discrimination on the basis of colour as she is targeted on the basis of her much lighter complexion compared to the rest of the community.

International and regional human rights treaties such as the CRPD, CEDAW, ICERD, ICRMW, CRC, the Maputo Protocol, African Charter on the Rights of the Child and SADC Gender Protocol make provision for the type of positive steps States need to take to ensure equality and eliminate discrimination.

How do albinism, discrimination and Economic, Social and Cultural (ESC) rights interact?

Persons with albinism are often discriminated against directly and indirectly, particularly in the area of health, education and work. This includes where the State fails to take steps to ensure that persons with albinism are able to enjoy their rights on an equal footing to others.

International human rights law requires States to immediately take steps using their maximum available resources to ensure ESC rights for all. Such resources are not limited to financial resources available in the State, but also include what can be obtained through international assistance and cooperation. States must further ensure continuous progress in realising the rights and should not take any retrogressive steps.¹⁵ In addition, States are required to prioritise minimum core obligations relating to economic social and cultural rights, such as the right to health and education, particularly for marginalised groups in society.¹⁶ They must therefore prioritise these rights for persons with albinism who constitute a marginalised group in Africa.

The universality, inter-connectedness and inter-dependence of all human rights

The right to health is directly related to the right to life. The failure to prevent foreseeable deaths, including from skin cancer will not only constitute a violation of the right to health, but also the right to life. The right to health and life may also be violated where the State fails to put in place appropriate measures for persons with albinism to exercise other rights, such as the right to education and to work. Outdoor school and work activities and the potential walk to and from school or work, particularly if far, exposes persons with albinism to the sun thus increasing their vulnerability to skin cancer and negatively impacting their right to health. In addition, the threat of attack on the way to and at school or work may lead to a violation of the right to life. At the same time a lack of education impacts on job opportunities increasing the chances of only being able to obtain outdoor jobs in future and of contracting skin cancer.

The Protocol on the Rights of Persons with Disabilities in Africa will be an important step in recognising this as it includes, as part of the right to life, the duty of States to ensure “persons with disabilities have access to services, facilities and devices to enable them to live with dignity and to realise fully their right to life.”¹⁷ It will come into force 30 days after its formal ratification by 15 countries.¹⁸ However, at the time of writing only 2 countries had signed the protocol, but none had ratified it.

¹⁵ Report of the Independent Expert on Albinism, Albinism worldwide, A/74/190, 18 July 2019, para. 6. Available at undocs.org

¹⁶ CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), para. 43 and 44.

See also Articles 11 and 13 of the ICESCR

¹⁷ Article 8 (b) of the Protocol on the Rights of Persons with Disabilities in Africa

¹⁸ Article 38 of the Protocol on the Rights of Persons with Disabilities in Africa

3.2.3 Human rights and attacks on persons with albinism

CASE STUDY 1

On 24 March 2020, a man with albinism was dismembered and dumped in a maize field along the Lundazi/Chipata road in Zambia. The body was found without limbs and was not identified which led to the government and the local albinism organisation to bury the body. At the time of burial there was no report of a missing person, however 2 weeks after burial the family of the deceased approached the police to make a report. In their statement they mentioned that he was a renowned carpenter in his 40s, he had been called for a job far from his home and was told the job was a 2-week job. When the family heard of the attack, they never suspected it was him, as they expected he would be away for 2 weeks working.

CASE STUDY 2

Lucinda, a woman with albinism turns up at the police station and complains that a man took her hair and fingernails. She says she was not hurt, but surprised. Following the COVID-19 pandemic, she experiences further abuse from other members of the public who refer to her as corona. In stores everyone is required to use sanitiser before entering, however her skin reacts to it. She requests soap and water in her regular store instead and is denied this.

CASE STUDY 3

Joyce, a woman with albinism, walks in front of a pregnant woman. The woman shouts at her and asks if she wants to give her unborn child albinism as well. The pregnant woman then calls her an insulting name and spits at her.

CASE STUDY 4

A 17-year-old boy with albinism, Davis, left his home in Malawi on 24 April 2016 to watch a soccer game with a friend and never returned. He was abducted by about four men who took him to Mozambique and killed him. The men chopped off both his arms and legs and removed the bones. They then buried the rest of his body in a shallow grave. Davis's remains were found in Mozambique on 1 May.

QUESTIONS

- Which of these cases are violations of human rights?
- What rights are/potentially violated?
- What further information is required to make a determination?
- What would you expect the state to do in relation to such cases?

What rights are violated?

Attacks against persons with albinism range from verbal to physical. They may include:

- insults, intimidation and threats
- cutting and taking of hair or nails
- spitting, pushing, slapping and other acts of aggression/assault
- kidnapping, rape, mutilation and killing

Such acts may constitute a violation of the following rights of individuals:

RIGHTS TO LIFE AND SECURITY OF PERSON¹⁹

The right to life refers to the “*entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy life with dignity.*”²⁰ An act may constitute a violation of the right to life even where there is no loss of life, if the act was intended, or could have been expected, to kill someone. Closely related to this is the right to security of person, which refers to freedom from intentional injury to the body and the mind. This right applies to all and not just to detained and imprisoned persons. It is sometimes referred to as the right to bodily integrity.

The rights to life and security of person are the most evident human rights violations connected with attacks against persons with albinism. They are violated by the State where it actively engages in the unlawful attacks. They may also be violated where the State fails to take steps, such as the enactment of laws, to prevent private individuals from violating them; or where a State fails to take action after a private individual has unlawfully killed or attacked a person with albinism.

RIGHT TO BE FREE FROM TORTURE AND CRUEL, INHUMAN AND DEGRADING TREATMENT

International human rights bodies have stated that attacks against persons with albinism may fall within the definition of torture where they involve (i) the infliction of pain or suffering (ii) for any reason based on any discrimination and (iii) they are carried out with the involvement or acquiescence of the state.²¹ These requirements are clearly met in cases where attacks have been shown to involve state officials. However, even when state officials are not directly implicated, there can still be torture on the basis of state acquiescence.

19 Article 6(1) of the ICCPR and the CRC; Articles 10 and 17 of the CRPD; Article 4 of the African Charter; and Article 4 of the Maputo Protocol all enshrine the right to life and security of person. Also Article 8 and 9 of the Protocol of the Rights of Persons with Disabilities in Africa, which was not in force at the time of writing.

20 General comment No. 36 (2018) on article 6 of the International Covenant on Civil and Political Rights, on the right to life, CCPR/C/GC/36, para. 3, available at: tbinternet.ohchr.org (accessed 26/03/20). This General comment specifically mentions persons with albinism and alleged witches as, “persons in vulnerable situations whose lives have been placed at particular risk because of specific threats or pre-existing patterns of violence” and requires states to take special measures to protect them. See para. 25

21 Report of the Independent Expert on Albinism, Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism, A/72/131, para. 33 -36

State acquiescence occurs where the State:

- fails to take adequate steps in response to attacks, including the lack of investigation, even when no complaints have been filed by the family of the victim;
- fails to prosecute, or pronounce a sentence commensurate with the gravity of the crime;
- is “unable or unwilling” to provide effective protection from attacks.²²

Physical attacks may therefore constitute a violation of the duty of the State to prevent and protect individuals from torture contained in the CAT, as well as the right to be free from torture contained in several international and regional human rights treaties.²³

The Protocol on the Rights of Persons with Disabilities in Africa will further specifically require States to protect persons with disabilities from all forms of violence, exploitation and abuse both within and outside the home as part of the right to freedom from torture.²⁴ Failure of States to prevent attacks against persons with albinism will therefore violate the right to be free from torture contained in this protocol.

RIGHT TO LIBERTY AND TO BE FREE FROM TRAFFICKING AND EXPLOITATION

Persons with albinism are sometimes forcibly taken from one area to another within or outside a country for the purposes of having their body parts taken for exploitation. This can be done through kidnapping, deceit or false promises. In the process of being transported, they are held captive against their will. Such acts constitute a violation of the right to liberty²⁵ and to be free from trafficking and exploitation.²⁶ International and regional human rights treaties place a high level of attention on the trafficking of women and children. However, men can also be trafficked.

RIGHT TO EQUALITY AND NON-DISCRIMINATION

When carried out for the purposes of witchcraft or ritual practices, or because the person believes a person with albinism poses some type of threat or benefit, such attacks also constitute a violation of the right to equality and non-discrimination; as well as the duty of states to prevent discrimination contained particularly in CEDAW, ICERD, CRPD, CRC, the Maputo Protocol, the African Charter on the rights of the Child and the SADC Gender Protocol, as well as the Protocol on the Rights of Persons with Disabilities in Africa once it comes into force.

Discrimination can be on the basis of more than one ground. For example, a girl child with albinism can be discriminated against on the basis of gender, race, including race on the grounds of colour, disability and age. Discrimination on the basis of colour and gender are manifested through harmful cultural practices such as use of body parts of persons with albinism or

22 The African Commission in *Zimbabwe Human Rights NGO Forum v Zimbabwe* stated “human rights law imposes obligations on States to protect citizens or individuals under their jurisdiction from the harmful acts of others. Thus, an act by a private individual and therefore not directly imputable to a State can generate responsibility of the State, not because of the act itself, but because of the lack of due diligence to prevent the violation or for not taking the necessary steps to provide the victims with reparation.” [*Zimbabwe Human Rights NGO Forum v Zimbabwe* (2006), Communication 245/02, para. 143. See also the Report of the Independent Expert on Albinism, Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism, A/72/131, para. 33 -36

23 Articles 7 of the ICCPR; 37(a) of the CRC; 15(1) of the CRPD; 5 of the African Charter; and 16 of the African Charter on the rights of the child

24 Article 10(2)(d)

25 Articles 9 of the ICCPR; 37 of the CRC; 6 of the African Charter; and 14 of the CRPD

26 Protocol to Prevent, Suppress and Punish Trafficking in Persons Especially Women and Children, supplementing the United Nations Convention against Transnational Organised Crime Adopted and opened for signature, ratification and accession by General Assembly resolution 55/25 of 15 November 2000. See also Articles 6 of CEDAW; 35 of the CRC; 4 of the Maputo Protocol; and 29 of the African Charter on the rights of the child. Also Article 28(4)(e) of the Protocol on the Rights of Persons with Disabilities, which was yet to come into force at the time of writing

abandonment, rape, abuse of children with albinism or their mothers. In some cases, persons with albinism are believed to be witches and subjected to harmful practices related to accusation of witchcraft. Women are often the main targets of HP-AWRA. Consequently, these are prohibited under the CEDAW.

RIGHT TO REMEDY FOR VIOLATION OF RIGHTS (ACCESS TO JUSTICE)

All individuals have the right of access to justice, which means they should be able to obtain effective remedy and reparations for the violation of their rights.²⁷ The right of access to justice is violated in situations where attacks happen, but there are no prompt, impartial and credible investigations or prosecutions into the attacks, or where perpetrators are given sentences that are not commensurate to the offence.

The right of access to justice can also be violated where States fail to ensure persons with albinism are able to access justice on an equal footing to others. For example, due to poor vision, persons with albinism may not be able to read posters, pamphlets or other written material setting out their rights or relevant procedures for criminal or other cases. They may also encounter other barriers to accessing legal representation.

States should ensure that measures are taken to eliminate or minimise these barriers, including through requiring the criminal justice sector to make “necessary and appropriate modification and adjustments, such as printing documents in accessible format for persons with albinism i.e. make reasonable accommodations.”²⁸

How should States respond in relation to attacks?

First and foremost, States are obliged to respect the rights of persons with albinism and should never be involved in attacks, whether verbal or physical. They also have the general duty to promote, protect and fulfil rights, including through adopting legal and other measures as required by international treaties. They further have specific duties spelt out in international treaties to:

- protect the right to life through law;²⁹
- protect vulnerable groups from discrimination, trafficking, exploitation and harmful practices;³⁰
- ensure equal protection of the law; and
- guarantee an effective remedy³¹ and adequate reparations.³²

The Independent Expert on albinism has further produced a report which sets out specific measures to be taken by States to ensure protection of rights.³³

27 Articles 8 of the UDHR; 2(3) of the ICCPR; 4,6,7 and 13 of the CAT; 6 of the ICERD; and 2(c) of CEDAW. Also Article 13 of the Protocol on the Rights of Persons with Disabilities in Africa once it comes into force.

28 Article 13(1) of the Protocol on the Rights of Persons with Disabilities will specifically require this once it comes into force.

29 Article 6(1) of the ICCPR

30 Article 20 and 26 of the ICCPR; Article 10 (3) of the ICESCR; most of the articles of CEDAW; Article 2, 35, and 36 of the CRC; Article 4, 16, and 8 of the CRPD; Article 18 and 5 of the African Charter; Article 2, 8, 12, 22, 23, 4(g), 3, 11, 13, and 5 of the Maputo Protocol; and Article 21, 29, and 15 of the African Protocol on the rights of the child

31 Articles 8 of the UDHR; 2(3) of the ICCPR; 4,6,7 and 13 of the CAT; 6 of the ICERD; and 2(c) of CEDAW

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

33 Report of the Independent Expert on albinism, Protection of Persons with Albinism, A/75/170, 17 July 2020, undocs.org. See also: Best Practices in the protection of human rights of persons with albinism, Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (Presented to the 75th session of the General Assembly, A/75/50343), 17 July 2020, www.ohchr.org

TOOL 3: MEASURES TO BE TAKEN BY STATES IN RELATION TO PROTECTION OF PERSONS WITH ALBINISM FROM ATTACKS

Such measures include, but are not limited to:

- carrying out education and awareness-raising campaigns to address myths and superstitions that perpetuate attacks;
- monitoring and carrying out research, including data collection, into cases of attacks with the view to developing strategies to address the attacks, as well as monitoring and evaluating impact of interventions;
- adopting specific measures to protect persons with albinism from attacks, particularly in areas of high incidence of attacks;
- adopting and revising relevant laws, including in relation to trafficking, accusations of witchcraft and harmful traditional practices;
- strengthening capacity of law enforcement officers to carry out investigations into cases of attacks;
- strengthening the capacity of the justice sector to hold perpetrators accountable for attacks, including through appropriate witness protection and victim assistance; and ensuring victims of attacks are provided adequate reparations.³⁴

International human rights law³⁵ and the Sustainable Development Goals (SDGs)³⁶ also require and empower States to seek international cooperation and assistance in combatting attacks against persons with albinism. Such cooperation and assistance can extend to:

- capacity building and information exchange;
- law enforcement and other cooperation in relation to trafficking of, and prosecution of cases of attack against, persons with albinism; and
- data collection, research and investigations into root causes.

QUESTIONS

- What are the ways in which the state can fail to respect rights?
- How do states fail to protect rights?
- Revisit the case studies above.
Are your responses any different now you have more information on rights and duties in relation to attacks?

³⁴ See reports on the Independent Expert on albinism on applicable international human rights standards and related obligations addressing the issues faced by persons with albinism [\[A/72/131\]](#), witchcraft and the human rights of persons with albinism [\[A/HRC/34/59\]](#), access to justice [\[A/HRC/40/62\]](#), women and children impacted by albinism [\[A/HRC/43/42\]](#), and albinism worldwide [\[A/74/190\]](#)

³⁵ UDHR Arts 22 and 28; ICESCR Arts 2(1), 11(1), 11(2), 15(4), 22 and 23; Trafficking Protocol Art 9; and CRC Art 25

³⁶ SDG 17 calls for global partnerships in implementation of the SDGs, including capacity-building for developing states.

3.2.4 Health & Albinism

Why is albinism considered a disability?

Persons with albinism often have low vision, nystagmus and photophobia. In addition, their lack of pigmentation makes them vulnerable to the sun and more susceptible to skin cancer. The CRPD does not define disability, but sees it as resulting from “the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”³⁷ Persons with albinism are unable to fully enjoy rights (such as the right to education, access to information, participation in public affairs, etc), for example, where the State fails to put in place facilities and policies which will enable them to access information contained in written literature. In addition, they are unable to enjoy rights on an equal basis with others when they are treated differently due to their lack of pigmentation or nystagmus; or when they are unable to attend rallies or other community events held outdoors in the sun because of lack of appropriate shelter and high cost of sunscreen. The visual impairment and high susceptibility to skin cancer, therefore constitute impairments requiring barriers to be removed.

The Protocol on the Rights of Persons with Disabilities in Africa specifically mentions albinism in its preamble indicating that it recognises albinism as a disability. However, this Protocol is yet to come into force.

What are the specific health concerns of persons with albinism?

Persons with albinism are highly susceptible to skin cancer. The risk can be reduced through the use of skincare products such as sunscreen and after sun, as well as wearing protective clothing, such as long sleeves and hats. They also experience photophobia i.e. their eyes are sensitive to sunlight and they need to wear appropriate sunglasses to protect their eyes. However, they may not be aware of the risk of skin cancer. Furthermore, some of these products are expensive and out of the reach of many persons with albinism.

In addition to sensitivity to the sun, persons with albinism often have visual impairments. Glasses can assist minimise visual impairment, although they cannot completely correct their sight. Large print materials and use of other assistive devices, such as monoculars and magnifying glasses, can also minimise the barriers for persons with albinism.

Furthermore, they may not be able to enjoy their right to health due to barriers to accessing healthcare services. Such barriers include:

- stigma resulting in discriminatory treatment,
- physical distance requiring them to walk long distances in the sun, as well as
- inappropriate services, infrastructure or products that do not take into account their visual impairment or susceptibility to the sun (e.g. informative pamphlets only provided in small print or having to wait outside in the sun for services).

³⁷ See part (e) of the Preamble

What are the duties of the State in relation to right to health for persons with albinism?

The right health is recognised in a number of international instruments.³⁸ The State has a duty to ensure this right, including through ensuring healthcare services are:

- Available:** functioning public healthcare facilities, services, goods and practitioners in the right quantity;
- Accessible:** physically and financially accessible, without discrimination and accessibility of information on health
- Acceptable:** ethical and respectful of cultural, gender, age and other differences; and
- Quality:** scientifically and medically appropriate and of good quality.³⁹

The CRPD further elaborates on the elements of this right for persons with disabilities, including albinism. Article 25 requires States to:

- a. provide free or affordable health care and programmes for persons with albinism on an equal footing with others;⁴⁰
- b. ensure equality of treatment by healthcare professionals, including on the basis of free and informed consent;⁴¹
- c. ensure training and promulgation of ethical standards for public and private health care;⁴²
- d. provide health services as close as possible to people's own communities, including in rural areas (accessible health services);⁴³

- e. prohibit discrimination against persons with albinism in the provision of health insurance, and life insurance;⁴⁴
- f. prevent discriminatory denial of health care or health services or food and fluids on the basis of disability/albinism;⁴⁵
- g. provide early identification of disability/albinism and conditions related to it such as visual impairment and skin cancer;
- h. provide early intervention in respect of skin cancer and visual impairment
- i. provide services designed to minimize and prevent further disabilities, such as deteriorating eyesight and cancer.⁴⁶

The Protocol on the Rights of Persons with Disabilities in Africa will place similar duties on States Parties once it comes into force. In addition, it will specifically require States to ensure that:

- a. "...health care services are provided using accessible formats and that communication between service providers and persons with disabilities is effective";
- b. "...persons with disabilities are provided with support in making health decisions, when needed"; and
- c. "... health campaigns include disability specific needs, but in a manner which does not stigmatise persons with disabilities."⁴⁷

38 Article 25.1 of the UDHR, Article 12 of the ICESCR, Article 5 (e) (iv) of the ICERD, Articles 11.1 (f) and 12 of CEDAW, Article 24 of the CRC, Article 25 of the CRPD, Article 16 of the African Charter, Article 14 of the Maputo Protocol and Article 14 on the African Charter on the Rights of the Child

39 CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12) Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000 (Contained in Document E/C.12/2000/4)

40 Article 17(2)(a) of the Protocol on the Rights of Persons with Disabilities in Africa

41 Article 17(2)(d) Ibid

42 Article 17(2)(i)

43 Article 17(2)(e) Ibid

44 Article 17(2)(c) Ibid

45 In Africa identification of albinism tends to done by sight i.e. noticing lighter complexion, colour of hair and eyebrows and eye movements. However, genetic testing might be required to identify the specific type of albinism, particularly to rule out the rarer forms of albinism which have more health complications, such as Hermansky–Pudlak syndrome (HPS), and ensure early intervention for complications related to these forms.

46 See also Article 17(2)(b) of the Protocol on the Rights of Persons with Disabilities in Africa which requires States to provide, "those health services needed by persons with disabilities specifically because of their disabilities or health services designed to minimise or prevent further disability, the provision of medicines including pain relieving drugs."

47 Article 17(2)(f)-(h) of the Protocol on the Rights of Persons with Disabilities in Africa

CASE STUDY 5

Sangwani is an 11-year-old boy with albinism living in a remote rural area. His parents carry the gene for albinism, but neither of them has it and they have never heard of the condition before. They own a number of cattle and it is Sangwani's responsibility to herd them. His parents have attached bells to all the cattle to help him prevent them getting lost. While looking after the cattle, he wears mainly short sleeves, shorts and other light clothes to keep cool. He has developed spots on his skin and his mum is concerned that they look unpleasant and might make him unattractive.

- Given the above information on the right to health, what are the potential health concerns related to Sangwani?
- What are the potential failings of the State in relation to Sangwani's case and other similar cases?
- What further information would you need to make a determination?

TOOL 4: ASSESSING POTENTIAL VIOLATIONS OF THE RIGHT TO HEALTH OF PERSONS WITH ALBINISM*

AVAILABILITY

Functioning public healthcare facilities, services, goods and practitioners in the right quantity

- Are there functioning public healthcare facilities near the community?
- Are there services specifically related to albinism including skin cancer screening and treatment, as well as clinical assessments by ophthalmologists and optometrists?
- Are there practitioners with knowledge of albinism and related conditions to provide services or necessary referrals?
- Are services and products necessary for the prevention and treatment of skin cancer and minimisation of visual impairments available?

ACCESSIBLE

Physically and financially accessible, without discrimination and accessibility of information on health

- Are the products and services (e.g. suncare products, eye test and assistive devices, cancer tests and treatment) within financial reach of persons with albinism?
- Are health services within reasonable distance for persons with albinism i.e. as close as possible to the communities?
- Are there any barriers which may stop persons with albinism, but not others, from accessing the services (e.g. need to walk long distances in the sun due to inability to pay transport fees, fear for personal safety during the commute, excessive exposure to the sun, etc)?
- Have steps been taken to remove the physical barriers to accessing the services for persons with albinism, including those caused by the need to reduce exposure to the sun?
- Have steps been taken to reduce superstitions and misconceptions around albinism that can lead to discriminatory practices?
- Is there enough information on albinism available to persons with albinism and is it provided in an accessible format technically and linguistically?

ACCEPTABLE

Ethical and respectful of cultural, gender, age and other differences; and...

- Do the services provided take into account the need to minimise exposure to the sun?
- Do the services and products provided take into account visual impairment of persons with albinism?
- Are there appropriate policies and practices in place for the treatment and provision of services by professional to persons with albinism?
- Are health practitioners respectful of persons with albinism and do they respect ethical standards in relation to persons with albinism?

QUALITY

Scientifically and medically appropriate and of good quality

- Are the goods and products provided of good and appropriate quality for persons with albinism (e.g. sunscreen of appropriate SPF and quality)?

SPECIAL MEASURES

Provision for early identification, intervention and services designed to minimize and prevent further disabilities

- Are services provided for the identification of albinism and the type of albinism?
- What information and support, including counselling, is provided for parents of children with albinism?
- What services and products are provided for the prevention, identification and treatment of skin cancer (i.e. suncare products, skin cancer screening and treatment)?
- What services and products are provided with regard to visual impairment (e.g. clinical assessments by ophthalmologists and optometrists, glasses, magnifying glasses, monoculars, etc)?
- Who bears the cost for such services and products?
- Are these services and products within financial reach of persons with albinism or their families?

*This is not an exhaustive list. NHRIs may seek to add, remove or adapt the questions for their purposes.

3.2.5 Education & Albinism

The right to education is contained in several human rights instruments.⁴⁸ Components of this right include the right to:

- a. free and compulsory primary education;
- b. available and accessible secondary education, including technical and vocational secondary education, which the State should progressively make freely available;
- c. equal access to higher education on the basis of capacity, with the progressive introduction of free education;
- d. fundamental education for those who have not received or completed primary education; and
- e. freedom of parents and, when applicable, legal guardians to choose for their children schools which conform with their religious and moral convictions and meet minimum educational standards laid down or approved by the State.

States are also required to take steps to encourage regular attendance and reduce drop-out rates.

What are the specific educational concerns of persons with albinism?

Due to visual impairment, persons with albinism often face barriers in education. They may be unable to read text written or projected in the front of the class or in printed in small, or otherwise inappropriate text. They may also be seated in direct sunlight making it difficult for them to read text. These barriers often lead to the misconception that persons with albinism have intellectual disabilities. This misconception, as well as superstitions and wrong beliefs associated with albinism may lead to stigma and

discrimination against students with albinism. They may also be adversely impacted by being required to carry out activities which unduly expose them to sunlight and thus the possibility of contracting skin cancer. The failure to make reasonable accommodation for students with albinism at schools, for example allowing them to remain indoors, also constitutes a violation of the right to education. In addition, parents may be unwilling to allow their children to go to school, particularly if they have to walk to and from school, for fear that they will be abducted or attacked along the way. Long walks to school also further expose them to the risk of skin cancer.

What are the duties of the State in relation to the right to education for persons with albinism?

Article 24 of the CRPD provides for the right to education specifically for persons with disability, including albinism. In addition to the general content of the right to education, States must ensure the following:

- a. right to education without discrimination and on an equal basis with others – i.e. that persons with albinism are not excluded from free and compulsory primary education, or from secondary education on the basis of disability;
- b. (an inclusive education system at all levels – i.e. that persons with albinism are not excluded from the general education system on the basis of their disability, but are able to access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

⁴⁸ Article 26 of the UDHR, Article 13 of the ICESCR, Article 28 of the CRC, Article 24 of the CRPD, Article 10 of CEDAW, Article 17 of the African Charter, Article 12 of the Maputo Protocol, and Article 11 of the African Charter on the rights of the child. It is also included in Article 16 of the Protocol on the Rights of Persons with Disabilities in Africa which is yet to come into force

- c. reasonable accommodation of the individual's requirements in places of learning and support for persons with albinism, within the general education system, to facilitate their effective education; and
- d. training of teachers incorporating albinism awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

While some parents may elect to have their child with albinism at schools for persons with visual impairments or other specialised schools, children with albinism (and indeed all children) should have access to inclusive education i.e. education in the general educational system. All schools, whether within the general educational system or specialised schools, must make reasonable accommodations specifically for the need of persons with albinism. The State must ensure inclusive education policies include the need for reasonable accommodation. Schools and teachers must also be targets of public awareness campaigns to tackle stigma and superstition around albinism which lead to discrimination, in turn contributing to drop-out rates of persons with albinism.

Although not yet in force at the time of writing, Article 16 of the African Protocol on the Rights of Persons with Disabilities in Africa contains similar provisions. It further requires States to ensure that:

- "...persons with disabilities learn life and social development skills to facilitate their full and equal participation in education and as members of the community;
- ...multi-disciplinary assessments are undertaken to determine appropriate reasonable accommodation and support measures for learners with disabilities, early intervention, regular assessments and certification for learners are undertaken regardless of their disabilities; [and]
- ...educational institutions are equipped with the teaching aids, materials and equipment to support the education of students with disabilities and their specific needs."⁴⁹

⁴⁹ Article 16(3)(f)-(h) of the Protocol on the Rights of Persons with Disabilities in Africa

TOOL 5: REASONABLE ACCOMMODATION FOR SCHOOLS CHECKLIST

PROVISION OF INFORMATION

- Information projected or written on board in front of the class provided orally as well
- Handouts provided in addition to information projected
- Written material in appropriate text format, colour and size
- Information on albinism and reasonable accommodation provided to teachers
- Information of albinism and services for persons with albinism provided to family of children with albinism by the school

CLASS SET-UP

- Person with albinism seated away from direct sunlight
- Person with albinism permitted to sit near the front of the class
- Class with appropriate shelter from sunlight (i.e. not outside without roof)

EXTRA-CURRICULAR ACTIVITIES

- Person with albinism exempted from outdoor activities exposing them to the sun
- Person with albinism permitted hats, sunglasses, long sleeves and other protective gear, even if not part of the school uniform

ASSISTIVE & ADAPTIVE DEVICES

- Person with albinism exempted from outdoor activities exposing them to the sun
- Person with albinism permitted hats, sunglasses, long sleeves and other protective gear, even if not part of the school uniform

*This list is not exhaustive. Other sources on reasonable accommodation for persons with albinism are available online.⁵⁰

⁵⁰ See for example Federal Republic of Nigeria, Core Messages on Albinism Education, albinofoundation.org; National Organisation for Albinism and Hypopigmentation (NOAH), Information Bulletin – Assisting Students with Albinism, www.albinism.org

CASE STUDY 6

Chikondi Zomba is a child with albinism. She does not like going to school because the other students tease her constantly about her complexion, hair and eyes. Chikondi tells her parents about the teasing and they tell her to stand up for herself. When it's hot, she burns easily in the playground and has asked the teacher if she can stay inside, but her request has been refused because there is no one to watch her while she is inside at break time. She also can't see anything on the board and once asked her teacher if she could sit near the front, but the teacher insisted they all sit in alphabetical order according to their surname.

One day, she hits a child who constantly teases her. The headteacher calls both children and tells them off for fighting. Later Chikondi overhears her teacher telling the headteacher that she does not trust Chikondi because she has dishonest eyes and is always seeking attention, like asking to sit in front or stay indoors during hot days.

The constant teasing and lack of support from teachers affects her self-esteem. She is unable to concentrate and does badly in school. At 15 years she meets someone who wants to marry her. At 16 years she fails her school leavers exam. Her parents encourage her to get married rather than try to continue her studies.

- What are the human rights issues?
- What treaties apply?
- What should the state be doing to ensure other children do not experience the same situation as Chikondi?

3.2.6 Work & Albinism

Everyone has the right to work, including the right to an opportunity to make a living through work they freely choose or accept.⁵¹ To ensure protection and fulfilment of this right States are required to:

- a. ensure non-discrimination in access to work and pay;⁵²
- b. put in place technical and vocational guidance and training programmes; and
- c. ensure policies and techniques to achieve full and productive employment under conditions safeguarding the rights of individuals.⁵³

What are the specific work concerns of persons with albinism?

Discriminatory treatment, fear of attacks and abductions, lack of reasonable accommodation at learning institutions and other barriers to education, often lead to persons with albinism not being able to access the best education and consequently poor access to jobs for them. Many have no option, but to work in informal or other outdoor jobs further exposing them to the sun and the risk of skin cancer.

Even those with a good level of education may not be able to access work due to discriminatory treatment with:

- employers not wanting to have an employee with albinism due to superstition,
- the misconception that they are unable to perform their work adequately and
- inability or unwillingness to make reasonable accommodation to enable persons with albinism to enjoy the right to work on an equal footing with others.

What are the elements of the right to work for persons with albinism?

To protect the right to work of persons with disabilities, including albinism, Article 27 of the CRPD requires States Parties to pass legislation to:

- a. prohibit discrimination and protect rights related to work;
- b. ensure access to technical and vocational guidance programmes;
- c. promote and ensure access to work in the public and private sector, as well as self-employment opportunities;
- d. put in place appropriate policies and measures to promote employment of persons with albinism, including affirmative action and incentives; and
- e. ensure reasonable accommodation is made for persons with albinism in the workplace.

Similar provisions are included in the Protocol on the Rights of Persons with Disabilities in Africa, which will be binding on States once it comes into force.

Reasonable accommodation at work is essential to ensuring persons with albinism are able to enjoy this right on equal basis with others. Examples of reasonable accommodation include provision of large computer screens or double screens, as well as other assistive devices and technology; ensuring persons with albinism are not seated in direct sunlight; as well as ensuring appropriate and flexible working hours and arrangements to reduce exposure to the sun for persons with albinism.

51 Article 23(1) of the UDHR, Article 6 of ICESCR, Article 11 of CEDAW, Article 27 of the CRPD, Article 5(e)(i) of the ICERD, for migrants in the ICRMW, Article 15 of the African Charter, Article 13 of the Maputo Protocol, and Article 6 of the African Protocol on older persons. Also included in Article 19 of the Protocol on the Rights of Persons with Disabilities in Africa, which was not in force at the time of writing.

52 CEDAW, ICERD, ICRMW, CRPD, and Maputo Protocol elaborate on steps to be taken to ensure non-discrimination in work for the respective categories of groups.

53 Article 6 of ICESCR, Article 15 of the African Charter

QUESTIONS

- What percentage of persons with albinism, as a general percentage of the population, are employed in formal employment in your country?
Is this a concern?
- What further information would you need to answer the question?
- Is this information available with regard to your country?
- What human rights violations may occur due to inability to obtain this information? Assuming that the percentage of persons with albinism employed in formal employment, as a percentage of the population, is only 1% and bearing in mind that the overall percentage of persons with albinism is 13%, what are the concerns and measures that could be taken in relation to this?
- What laws are in place to ensure non-discrimination and access to work for persons with albinism in your country?
- What is the content of these laws?
- What is the extent of implementation of these laws?

TOOL 6: SUMMARY TABLE: CONCERNS, RIGHTS AND DUTIES

CONCERNS	RIGHTS VIOLATED	DUTY OF STATE
<p>Attacks, including verbal and physical abuse, abandonment, social exclusion, cutting off body parts, abductions, killings, accusation of witchcraft and ritual attacks of persons with albinism</p>	<ul style="list-style-type: none"> ■ Rights to life and security of person ■ Right to dignity ■ Right to be free from torture and cruel, inhuman and degrading treatment ■ Right to liberty and to be free from trafficking and exploitation ■ Right to equality and non-discrimination 	<ul style="list-style-type: none"> ■ Respect the rights of persons with albinism and refrain from involvement in attacks against persons with albinism, whether verbal or physical. ■ Take steps to prevent the arbitrary deprivation of life, including through appropriate laws. ■ Protect vulnerable groups from discrimination, trafficking, exploitation and harmful practices, through laws and other measures, including social protection measures. ■ Ensure equal protection of the law; and guarantee an effective remedy and adequate reparations. ■ Protect, fulfil and promote rights, including through measures, such as: <ul style="list-style-type: none"> - Carrying out education and awareness-raising campaigns to address myths and superstitions that perpetuate attacks; - Monitoring and carrying out research, including data collection, into cases of attacks with the view to developing strategies to address the attacks, and for monitoring progress of interventions; - Adopting specific measures to protect persons with albinism from attacks, particularly in areas of high incidence of attacks; - Strengthening capacity of law enforcement officers to carry out investigations into cases of attacks; - Strengthening the capacity of the justice sector to hold perpetrators accountable, including through witness protection and victim assistance; and - Ensuring victims of attacks are provided adequate reparations.

CONCERNS	RIGHTS VIOLATED	DUTY OF STATE
<p>Health, including discrimination in health services, failure to provide adequate health services in relation to skin cancer and low vision</p>	<ul style="list-style-type: none"> ■ Right to highest attainable standard of health ■ Right to life ■ Right to dignity ■ Right to equality and non-discrimination ■ Right of access to justice and redress 	<ul style="list-style-type: none"> ■ Provide free or affordable health care and programmes for persons with albinism on an equal footing with others. ■ Provide healthcare and services that are accessible and appropriate for persons with albinism and of appropriate quality. ■ Ensure equality of treatment of persons with albinism by healthcare professionals, including on the basis of free and informed consent. ■ Ensure training and promulgation of ethical standards for public and private health care in relation to albinism. ■ Provide health services as close as possible to people's own communities, including in rural areas (accessible health services). ■ Prohibit discrimination against persons with albinism in the provision of health insurance, and life insurance. ■ Provide early identification of albinism and conditions related to it such as visual impairment and skin cancer. ■ Prevent foreseeable and preventable deaths, particularly through providing early intervention in respect of skin cancer and visual impairment. ■ Provide services designed to minimize and prevent further disabilities, such as deteriorating eyesight and cancer, including sun care products, protective clothing, assistive devices like binoculars.

CONCERNS	RIGHTS VIOLATED	DUTY OF STATE
<p>Education, including abuse in schools leading to high dropout rates, failure of schools to make reasonable accommodation, lack of inclusive education options</p>	<ul style="list-style-type: none"> ■ Right to education ■ Right to work ■ Right to an adequate standard of living ■ Right to health ■ Right of access to information ■ Right to equality and non-discrimination 	<ul style="list-style-type: none"> ■ Put in legal and other measures to ensure: ■ Right to education without discrimination and on an equal basis with others – i.e. that persons with albinism are not excluded from free and compulsory primary education, or from secondary education on the basis of disability; ■ An inclusive education system at all levels - i.e. that persons with albinism are not excluded from the general education system on the basis of their disability, but are able to access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live; ■ Reasonable accommodation of the individual’s requirements in places of learning and support for persons with albinism, within the general education system, to facilitate their effective education; and ■ Training of teachers incorporating albinism awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities. ■ While some parents may elect to have their child with albinism at schools for persons with visual impairments or other specialised schools, children with albinism (and indeed all children) should have access to inclusive education.

CONCERNS	RIGHTS VIOLATED	DUTY OF STATE
<p>Work, including denial of work and refusal to put in place reasonable accommodation measures</p>	<ul style="list-style-type: none"> ■ Right to work ■ Right to an adequate standard of living ■ Right to health ■ Right to equality and non-discrimination 	<ul style="list-style-type: none"> ■ Prohibit discrimination and protect rights related to work. ■ Ensure access to technical and vocational guidance programmes. ■ Promote and ensure access to work in the public and private sector, as well as self-employment opportunities. ■ Put in place appropriate policies and measures to fulfil the right to employment of persons with albinism, including affirmative action and incentives. ■ Ensure reasonable accommodation is made for persons with albinism in the workplace.

3.3 FURTHER READING

For further information on specific obligations of the State in relation to albinism see:

- The Independent Expert’s recently published report on the protection of the rights of persons with albinism.⁵⁴
- Best Practices in the protection of human rights of persons with albinism, Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism.⁵⁵
- Other country and thematic reports of the Independent Expert.⁵⁶
- The UN Independent Expert’s Regional Action Plan on Albinism for 2017 – 2021 (the RAP).⁵⁷
- “We Are Not Animals to Be Hunted or Sold”: Violence and Discrimination Against People with Albinism in Malawi, AFR 36/4126/2016, Amnesty International, 2016.⁵⁸
- ‘Waiting to disappear’ International and Regional Standards for the Protection of the Human Rights of Persons with Albinism, International Bar Association’s Human Rights Institute (IBAHRI), June 2017.⁵⁹

⁵⁴ Report of the Independent Expert on albinism, Protection of Persons with Albinism, A/75/170, 17 July 2020, undocs.org

⁵⁵ Best Practices in the protection of human rights of persons with albinism, Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (Presented to the 75th session of the General Assembly, A/75/50343), 17 July 2020, www.ohchr.org

⁵⁶ All available at: www.ohchr.org

⁵⁷ ap.ohchr.org

⁵⁸ www.amnesty.org

⁵⁹ Available for download at www.ibanet.org

UNDERSTANDING THE NATIONAL CONTEXT

OBJECTIVES OF PART 4

This part sets out the steps for understanding violations of the rights of persons with albinism at the national level. It provides methodologies and tools for collecting information and assessing the human rights situation in the countries where NHRIs are based.

By the end of Part 4, NHRIs should:

- have an understanding of how to go about carrying out an assessment of the challenges persons with albinism encounter in their respective countries and how these impact on the full enjoyment of their rights
- understand how to go about developing indicators for their assessments
- understand how to identify duty-bearers in relation to the rights of persons with albinism
- know the sources for information on the situation of persons with albinism and obligations of the authorities in relation to their country
- understand the processes and tools available to NHRIs for obtaining information on the rights of persons with albinism in their country, as well as the factors that should be taken into account when using these tools in relation to albinism
- This section ultimately helps in carrying out research, developing reports and producing recommendations.

4.1 PRELIMINARY CONSIDERATIONS

Violations of the rights of persons with albinism occur in all countries to varying degrees. In some countries certain violations may be more prevalent or of a more urgent nature than others. Where there has been little work done on albinism, the extent of the problem may not be understood. For example, in some countries the killing of persons with albinism may not be a concern or it may be hidden due to underreporting, a lack of disaggregated data in relation to homicide cases and insufficient research into the area. The same applies to concerns related to health, education and work for persons with albinism, which may be hidden due to absence of any reporting or research on the matter and lack of disaggregated data.

As a first step therefore, NHRIs will need to obtain accurate information, including statistical and research data, on the extent to which persons with albinism are able to enjoy their rights in their country. This inevitably involves an analysis of the extent to which the State is meeting its obligations to ensure the full enjoyment of all rights by persons with albinism. In so doing, they will need to decide, prior to carrying out any research:

- The scope of the research to be carried out (e.g. will it cover all rights or only focus on certain areas, such as attacks or education?),
- The type of information, including indicators, that will need to be gathered (i.e. what type of information could be useful in understanding whether persons with albinism are able to fully enjoy the rights being assessed?),
- The amount of information that will need to be collected,
- How the information will be collected (e.g. desk research, public inquiry, etc),
- How the information will be stored and managed,
- How it will be analyzed (i.e. what the analysis will seek to ascertain from the information, what certain information is likely to indicate in respect of state compliance with rights obligations),⁶⁰ as well as
- How the information will be used following the assessment.

4.1.1. Ethical principles

In seeking to promote and protect the rights of persons with albinism, NHRIs should adhere to the following principles in all processes that assess, plan, design, implement, monitor or evaluate protection measures:

- **Do no harm** – ensuring that any actions taken do not expose persons with albinism to additional risks or harm. This requires that due consideration is given to the broader context and how to mitigate any potential negative effects.
- **Inclusion and meaningful participation** – In line with international standards, persons with albinism should be closely consulted and actively included in the development and implementation of all strategies related to them.⁶¹
- **Empowerment** – the development and implementation of all strategies should seek to increase the understanding and knowledge of persons with albinism regarding their rights,

as well as to increase their capacity, self-

autonomy and independence in demanding such rights.

- **Equality and non-discrimination** – ensuring that development and implementation of strategies does not unfairly discriminate against certain groups or individuals. This requires ensuring that special attention is paid to marginalised groups within the broader context of albinism e.g. women and children with albinism, those who live in rural areas, those with a low level of literacy, etc.
- **Accuracy and objectivity** – information obtained and used in the process must be objective, thorough and accurate. NHRIs should ensure information is accurate through seeking direct evidence and corroboration from other sources.
- **Accountability** – ensuring transparency and accountability throughout the process, including being able to defend and provide information on how findings and conclusions were reached if necessary.

⁶⁰ UNFPA, A Guide in Support of National Human Rights Institutions: Country Assessments and National Inquiries on Human Rights in the Context of Sexual and Reproductive Health and Well-being, New York. March 2019, page 24

⁶¹ Article 4(3) of the CRPD

4.1.2 Indicators

To assess if States are meeting their obligations in relation to persons with albinism, NHRIs will need to analyse **signs or markers that point to the status of the enjoyment of certain rights (or lack thereof)** in this regard. These signs or markers are referred to as indicators. Types of indicators include:

- **Quantitative indicators** - information that can be quantified or that relates to number. For example, the number of received cases of killings of persons with albinism or the number of successfully prosecuted cases of attacks against persons with albinism. Such an indicator can give an idea or indication of the enjoyment of the right to life for persons with albinism.
- **Qualitative indicators** - relate to words and is often about individual perception or views. For example, the experience of persons with albinism in accessing healthcare services and their perception of their treatment.

Such an indicator can provide an indication of the enjoyment of the right to equality and non-discrimination.

They can further be categorised as follows:

- **Structural indicators** – steps being taken by States with regard to acknowledgement of their obligations e.g. acceptance of international standards and international commitments
- **Process indicators** – steps being taken to fulfil those obligations
- **Outcome indicators** – results of those efforts

One indicator is unlikely to provide a clear enough picture of the enjoyment of rights. NHRIs will therefore need to use or develop several. Indicators need to be relevant to the national context. For this reason, there are no set human rights indicators. NHRIs can use and adapt a number of pre-existing indicators, or can develop their own.

Potential sources of indicators for assessing rights

NHRIs may already have relevant indicators developed by them, for example, in respect of other rights. They may also seek to use other relevant indicators such as:

- illustrative human rights indicators produced by the OHCHR;⁶²
- indicators produced by the Bridging the Gap project, in relation to the rights of persons with disabilities in line with the articles of the CRPD.⁶³
- those in national human rights plans or commitments related to disability, equality and non-discrimination, the right to life, health and education;
- socio-economic indicators developed by the UNDP or the World Bank for example on literacy, life expectancy or employment levels, particularly where these are disaggregated by disability;
- gender equality indicators;
- global goals, such as those for the Sustainable Development Goals;⁶⁴ and
- guidelines from specialised UN agencies.⁶⁵

62 Human Rights Indicators Tables: Updated with the Sustainable Development Goals (SDG) Indicators. Available at: www.ohchr.org (accessed 12 August 2020)

63 EU-OHCHR Bridging the Gap I: Human Rights indicators for the Convention on the Rights of Persons with Disabilities in support of a disability inclusive 2030 Agenda for Sustainable Development. Available at: bridgingthegap-project.eu (accessed 21 August 2020)

64 See SDG indicators database: unstats.un.org (accessed 27 September 2020)

65 Defending Dignity: A Manual for National Human Rights Institutions on Monitoring Economic, Social and Cultural Rights, Asia Pacific Forum of National Human Rights Institutions and the Center for Economic and Social Rights January 2015 (updated August 2018), page 49.

Below is an example of indicators related to equality and non-discrimination for persons with disabilities, developed by the Bridging the gap project:

- National constitutional provisions adopted and legislation enacted Recognising the right to equality and non-discrimination of persons with disabilities, including the right to be provided with reasonable accommodation and the duty to adopt specific measures to achieve de facto equality for persons with albinism.
- Adoption of a national strategy and/or plan for equality of all persons with disabilities, in particular the groups more at risk of discrimination, such as persons with albinism.
- Legal or statutory requirement to collect and publish data disaggregated by disability across all sectors (health, employment, education, violence, access to justice, political participation, among others), including enrolment rate, employment rate, access to health services, victims of violence, complaints on discrimination lodged, etc.)⁶⁶
- Legal requirement to establish a marker on all public spending to promote and protect the rights of persons with albinism.

*Extract and adaptation from EU-OHCHR Indicators on Article 5 of the CRPD⁶⁷

Developing Indicators

The OHCHR has developed a tool to assist States, NHRIs and Civil Society Organisations (CSOs) in the development of human rights indicators. The tool recommends the development of structural, process and outcome indicators. It further suggests that in order to develop indicators for specific human rights, it is first necessary to identify the attributes of the right i.e. what that right entails or legally requires a State to do in order to fulfil it. Indicators should then be developed to assess the extent to which the State has carried out steps to fulfil these attributes. For example, in relation to the right to life, the ICCPR requires that no one is arbitrarily deprived of life. No arbitrary deprivation of life may therefore be seen as an attribute of the right to life. An indicator in relation to this could therefore be a measurement of arbitrary deprivation of life or steps taken to prevent arbitrary deprivation of life (e.g. number of victims of homicide or Proportion of received complaints on the right to life investigated and adjudicated). In addition, the Human Rights Committee in General Comment No. 36 on the right to life stated that the right to life included freedom to be free from acts or omission that are intended or could be expected to cause unnatural or premature death.⁶⁸ The prevention of premature and unnatural deaths can therefore be identified as an attribute of the right to life. Relevant indicators would relate to steps taken to prevent such deaths (e.g. Proportion of the target population covered by all vaccines included in their national programme).

Tool 6 on the summary table of concerns, rights and duties in this manual provides examples of attributes of rights which can be used to assist NHRIs in developing indicators. In addition, attributes of rights developed by other bodies, which are similar to those in Tool 6, are given below.⁶⁹

⁶⁶ Publication of data must respect the right to privacy of individuals and data protection standards. See OHCHR, [A human rights based approach to data](#) (2018).

⁶⁷ Available at: bridgingthegap-project.eu

⁶⁸ Human Rights Committee, General comment No. 36, Article 6: right to life, CCPR/C/GC/36, 3 September 2019

⁶⁹ See the Bridging the gap project specifically in relation to attributes for CRPD rights, bridgingthegap-project.eu; as well as the OHCHR attributes in its illustrative indicators, www.ohchr.org

RIGHT	ATTRIBUTES
Right to life	<ul style="list-style-type: none"> ■ No arbitrary deprivation of life ■ Prevention of premature and unnatural deaths ■ No disappearances of individuals ■ Provision of basic health and nutrition
Freedom from torture, cruel, inhuman and degrading treatment	<ul style="list-style-type: none"> ■ Prevention of torture, ill-treatment and other violations to physical and mental integrity through acts not specifically related to albinism ■ Prevention of torture, ill-treatment and other violations to physical and mental integrity through non-consensual treatments and other practices related to albinism ■ Prohibition of medical experimentation on persons with albinism without their free and informed consent ■ Prevention of Community and domestic violence
Liberty and security of person	<ul style="list-style-type: none"> ■ Absolute ban on deprivation of liberty on the basis of actual or perceived impairment, including albinism ■ Non-disability specific forms of detention: criminal and administrative detention
Equality and non-discrimination	<ul style="list-style-type: none"> ■ Equality and protection from discrimination (disability based and others) ■ Provision of reasonable accommodation ■ Specific measures to achieve de facto equality
Access to justice	<ul style="list-style-type: none"> ■ Equal access to and equality before the justice system ■ Participation of persons with albinism in the justice system
Right to health	<ul style="list-style-type: none"> ■ Equal access to mainstream and specific services within general health services ■ Inclusive health Insurance ■ Free and informed consent ■ Prevention, treatment and control of diseases (particularly skin cancer in relation to albinism)
Right to education	<ul style="list-style-type: none"> ■ Inclusive education system ■ Quality and free primary and secondary education ■ Access to tertiary, vocational training and lifelong learning ■ Inclusive teaching
Right to work	<ul style="list-style-type: none"> ■ Access to decent work and employment ■ Just and safe working conditions ■ Equal opportunities in the workplace, including training, skill upgrading and professional development ■ Protection from forced or compulsory labour

CASE STUDY 7

Example of use of indicators - South African Human Rights Commission inquiry into discrimination in the workplace.

In carrying out its analysis on equality and non-discrimination, the Commission made use of a number of already existing indicators and sources of information from national programmes and institutions, such as Statistics South Africa, the South African Institute for Race Relations, the Commission for Employment Equality, and data from individual complaints brought before the Human Right Commission itself. Indicators used included:

- the number of complaints received by the Commission raising allegations of a violation of the right to equality as a proportion of the total number of complaints received by the commission
- the annual increase of the number of equality related complaints disaggregated by grounds of unfair discrimination
- the number of number and proportion of persons from different racial and gender groups in the employment market as compared to the number of Economically Active Population in those groups
- the compliance of the public and private sector in meeting targets for equitable representation in employment of disadvantaged groups
- the rate of increase in the proportion of disadvantaged groups in employment disaggregated by groups including race, gender, and disability
- the percentage of senior management positions held by disadvantaged groups
- the provision of reasonable accommodation and assistive devices within the public service on an annual basis

The Commission acknowledge the shortcomings of the indicators in providing a complete picture of the situation. Quantitative information obtained was supplemented with qualitative information from public hearings.

4.2 STEPS IN UNDERSTANDING HUMAN RIGHTS CONCERNS RELATED TO ALBINISM IN A COUNTRY

The United Nations Population Fund (UNFPA) suggests that an appropriate process for understanding the national context would be to i) define the problem and those affected by it, ii) understand the causes of the problem, iii) identify those responsible for addressing the problems and causes, as well as what they should do, and iv) examining the level of compliance with human rights obligations.⁷⁰



4.2.1 Defining the problem

In the context of albinism, NHRIs should seek to understand:

- the challenges persons with albinism face in the country and how these impact on their full enjoyment of rights. (For example, threats, killings and other attacks resulting in inability to enjoy the right to life, bodily integrity, health, etc. Or fewer persons with albinism in schools resulting in their inability to enjoy right to education and consequently right to work, food, or health.)
- the extent and gravity of the problem (i.e. has there been a number of cases of attacks against persons with albinism? Is it a relatively high number of children with albinism in the country who are not in school? Is the literacy level generally lower in persons with albinism than in their counterparts?)
- Which sections of persons with albinism are most affected (e.g. women and children with albinism, persons with albinism living in rural areas, those with a low literacy level, etc)

⁷⁰ UNFPA, A Guide in Support of National Human Rights Institutions: Country Assessments and National Inquiries on Human Rights in the Context of Sexual and Reproductive Health and Well-being, New York. March 2019, page 35

4.2.2 Understanding the causes of the problem

Understanding the causes of the problem will help NHRIs in identifying the potential violation and failure by specific institution to prevent or address the violation. Such an understanding will further help in the development of relevant recommendations and in targeting the recommendations to the relevant institution. Causes of the problem can be multifaceted. They can include:

Political – government and government policy impact (e.g. political involvement in killings or lack of political will to address the killings or put in place strategies to increase school attendance of children with albinism)

Economic – financial incentives or disincentives leading to the particular action (e.g. high cost of body parts of persons with albinism, financial incentives for involvement in attacks and poverty of persons involved in attacks; or lack of money to send children to school)

Social – cultural, religious and other practices and beliefs (e.g. belief that person with albinism has supernatural powers or is cursed which dehumanise persons with albinism and contribute to attacks or stigma in school)

Technological – the impact of technology or lack thereof (e.g. forensic and other technological advances to help with investigations into killings, availability of assistive devices to assist with learning)

Environmental – the impact of surrounding environment (e.g. lack of street lights, police patrols and other security facilities in certain areas, including on the way to school which increase the likelihood of attacks and may impact on ability to attend schools, having to walk long distance in the sun thus increasing the risk of skin cancer)

Legal – existence of or lack thereof an enabling legal or policy framework (e.g. laws criminalising all acts associated with attacks against persons with albinism, laws and policies providing for inclusive education and reasonable accommodation)

NHRIs should carry out an analysis of the underlying causes by taking into account all these factors (i.e. carry out a PESTEL analysis). In addition, it is essential to also consider the rights that need to be fulfilled in order for other rights to be enjoyed. For example, education is essential to obtain work and in turn, work impacts on the ability to obtain money for food, housing, health requirements and increasing protection against attacks through being able to drive to places or put up walls around homes.

4.2.3 Identifying who is responsible for addressing the problems and causes, as well as what they are supposed to do

Although individuals or non-State actors often carry out the acts which lead to violations of the rights of persons with albinism, the State holds the primary responsibility for the protection and fulfilment of rights. This responsibility means that the State is required to take measures to ensure such violations do not occur, including addressing the root causes. They must further ensure redress where such violations occur. For example, individuals or organised crime groups carry out abductions and killings because of perceived economic benefits, but the State needs

to ensure measure to prevent such attacks are in place (e.g. police patrols in hotspots, awareness raising campaigns). In the same way, schools may in some cases refuse to enrol a student, but the State needs to put in place laws and policies to ensure they are held accountable if they do and disincentivise such denial of school enrolment. To ensure recommendations, promotion and protection activities are appropriately targeted, NHRIs should seek to identify which specific State institution has the responsibility to take action and what they are required to do.

EXERCISE

Refer to the attributes of rights and summary table of rights and duties (tool 6) to identify what the State needs to do to address problems and root causes. Which ministry/government department is responsible for tackling the root causes and implementing the relevant action(s)?

TOOL 7: RELEVANT QUESTIONS IN MAKING AN ASSESSMENT OF DUTY BEARERS

- Who are the people/institutions carrying out the acts of concern? (identify perpetrators)
- Why are they carrying out these acts? (root causes)
- Who can stop them from doing so? How? (prevention and protection)
- Who can change the root cause of the act? What reforms need to be made to tackle root causes? Who can make this happen? (prevention)
- Who can ensure remedial action/ redress when such people/ institutions carry out such actions? How?
- What reforms need to be made to ensure that those responsible for stopping the acts of concern are able to do so efficiently and effectively? Who is able to make these reforms? (protection)
- What reforms need to be made to ensure that those responsible for remedial actions/ redress for the acts of concern are able to do take such actions efficiently and effectively? Who is able to make these reforms? (accountability)

4.2.4 Examining level of compliance with human rights obligations

NHRIs should then carry out an analysis of information collected to determine where the State has met its obligations, how it has done this and any areas where it has failed to do so. This includes the steps taken to ensure appropriate legal and institutional framework for enjoyment of rights, the removal of barriers, and putting in place remedies for violations.

A lack of information is also essential data as States need to understand the situation of persons with albinism in order to develop and implement appropriate measures, including the allocation of budgets to ensure the full enjoyment of their rights. To this end, the Independent Expert on albinism has on a number of occasions called on states to ensure disaggregated data in relation to albinism.⁷¹ The CRPD also calls on States Parties to “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to [the rights contained in the] convention.”⁷²

CASE STUDY 8

Example of a public inquiry which found lack of information - South African Human Rights Commission inquiry into discrimination in the workplace

In 2016, the South African Human Rights Commission carried out a public inquiry into discrimination in the workplace using its powers to carry out research, investigate and report on observance of human rights in the country, and to educate on human rights related matters.⁷³

The public inquiry examined various grounds of unfair discrimination in the workplace. It went further to highlight albinism as a particular form of disability requiring special attention as persons with albinism tend to remain largely invisible when grouped with other forms of disability. It further pointed out the lack of research and data in relation to the challenges and forms of discrimination faced by persons with albinism and called for more to be done in this area.⁷⁴

71 See for example: Report of the Independent Expert on albinism, Albinism worldwide, A/74/190, 18 July 2019, para. 137 (c); Report of the Independent Expert on albinism, Right to access to justice for persons with albinism, A/HRC/40/62, 15 January 2019, para. 110; and Report of the Independent Expert on albinism, Women and children impacted by albinism, A/HRC/43/42, 24 December 2019, para. 109

72 Article 31 of the CRPD

73 Section 13 of the South African Human Rights Commission Act, 40 of 2013

74 South African Human Rights Commission, Report of the South African Human Rights Commission: National Hearing on Unfair Discrimination in the Workplace 8 March 2016; 25 April 2016, page 51, available at: www.sahrc.org.za

TOOL 8: SOURCES OF COUNTRY INFORMATION ON ALBINISM

NATIONAL SOURCES

State/government sources

National census; government budgets; annual report and policies of different ministries particularly those responsible for justice, health, education, welfare, women, children, disability, and finances; government strategic plans; public statements and press releases; and reports to human rights bodies should contain information on government activities, expenditure and budgeting in relation to albinism, as well as identified human rights concerns

Legislative review

The existence and content of laws related to albinism, health, education, employment, gender, children, disability, customary and traditional practices, diversity equality and/or inclusion. Proposed laws and the content of such laws are also vital for indicating direction and political will of the government e.g. does any proposed law related to discrimination or disability include albinism?

CSO sources

National associations of persons with albinism, as well as human rights organisations and charities working on issues related to the criminal justice system, health, education and disability may have information on albinism in their annual and thematic reports, including reports on their activities, public statements, press releases, campaigning material, etc.⁷⁵

Academic institutions

Relevant information may be found from university departments in the field of law, social science, disability, health and education; periodic journal articles; conferences and seminars, as well as documents emanating from conferences such as conference proceedings and conference papers; and published dissertations and thesis. For example, the Centre for Human Rights at the University of Pretoria holds a disability rights conference annually and publishes an African Disability Rights Yearbook.⁷⁶ The University of Pretoria also has a searchable database for dissertations.⁷⁷ Google scholar is a useful search engine for academic papers.⁷⁸

Media

Exposés, reports and articles on albinism;⁷⁹ tv and radio interviews of relevant authorities or organisations on albinism, health, disability, and traditional and customary practices; newspaper reports on statements and reports by the State and NGOs. Information may also be found through a search of social media sites such as Facebook, twitter and LinkedIn

⁷⁵ Information on national organisations or associations dedicated to work on albinism can be found on the action for albinism website at: actiononalbinism.org (accessed 03 August 2020). Other national organisations such as the Centre for Human Rights Education Advice and Assistance (CHREAA) in Malawi have carried out litigation on behalf of persons with albinism.

⁷⁶ www.chr.up.ac.za (accessed 03 August 2020)

⁷⁷ repository.up.ac.za (accessed 03 August 2020)

⁷⁸ scholar.google.co.uk

⁷⁹ See for example, the Mail and Guardian archives on albinism: mg.co.za and results of albinism search on Lusaka Times: www.lusakatimes.com (accessed 03 August 2020)

INTERNATIONAL & REGIONAL SOURCES

Academic institutions based in other countries

Universities often carry out research into countries, other than the ones in which they are based, including on albinism. For example, Coventry University has carried out research into albinism in Southern Africa.

International and regional human rights organisation

Organisations such as Amnesty International and Human Rights Watch have produced reports on the situation of persons with albinism in specific countries.⁸⁰ Statements, annual and thematic reports and campaigning material of such organisations are also invaluable sources of information on the country situation. Other international and regional organisations working on albinism include Beyond Suncare, Standing Voice and Under the Same Sun. Freedom House and The Minority Rights Group have also included information in their annual reports.⁸¹

UN agencies

A number of country offices of UN agencies have taken up work and commissioned research on albinism as part of their mandate. For example, in Mozambique, the International Organisation for Migration (IOM) carried out an analysis specifically in relation to trafficking of persons with albinism.⁸² And in Malawi, the United Nations International Children's Emergency Fund (UNICEF) carried out a study into challenges and best practices in investigations, prosecutions and sentencing in offences against persons with albinism.⁸³ Staff and reports of these UN agencies may be able to provide insight into work on albinism being carried out with the government.

UN treaty bodies

States are required to provide periodic reports to UN treaty bodies. NGOs can also provide parallel reports with their assessment of the State's human rights performance. Following the review, the treaty body produces a document with its assessment of the human rights situation, concerns and recommendations to the State. This document, known as the concluding observations, as well as the State report and NGO parallel reports are important sources of information on human rights concerns in the country and specific State obligations. In relation to albinism, the most relevant documents often come from the Committee on the Rights of Persons with Disabilities, the Committee on the Rights of the Child, Committee on the Elimination of Discrimination against Women, and the Human Rights Committee.⁸⁴

80 See for example: "We are not Animals to be Hunted or Sold" - Violence and Discrimination Against People with Albinism in Malawi, Amnesty International, 7 June 2016, Index number: AFR 36/4126/2016, www.amnesty.org (accessed 03 August 2020); From Cradle to Grave: Discrimination Against Persons with Albinism in Tete Province, Mozambique, Samer Muscati, 13 June 2019, www.hrw.org (accessed 03 August 2020)

81 See for example: Freedom House, Freedom in the World 2018 - Mozambique, 5 October 2018, available at: www.refworld.org [accessed 19 August 2020]; Freedom House, Freedom in the World 2018 - Malawi, 1 August 2018, available at: www.refworld.org [accessed 19 August 2020]; and Minority Rights Group International, Peoples under Threat 2018, 13 June 2018, available at: www.refworld.org [accessed 19 August 2020]

82 Situation Analysis on the Human Rights and Protection of Persons with Albinism in Mozambique with a Special Focus on Human Trafficking, Consultant: Viktoria Perschler, December 2018, available at: unicri.it

83 UNICEF, Study on challenges and best practices in investigations, prosecutions and sentencing in offences against persons with albinism in Malawi Final report, prepared by Redison E. Kapindu, PhD, March 2018. Available at: www.ohchr.org (accessed 27/03/2020)

84 All relevant UN country information documentation can be accessed at: www.ohchr.org. Country specific State reports, parallel reports and concluding observations can be accessed at: tbinternet.ohchr.org (accessed 03 August 2020). And a detailed search for treaty body, UPR and Special Procedures UN documents, including by theme (human rights concern), affected persons (e.g. persons with albinism) and country can be carried out here: uhri.ohchr.org

Example of a treaty body concern and recommendation regarding albinism in Eswatini⁸⁵

CCPR/C/SWZ/CO/1 (CCPR, 2017)

Human Rights Committee

Discrimination against persons with albinism

22. The Committee is concerned at reports of discrimination and violence against persons with albinism. It is also concerned that the State party has yet to adopt effective strategies to ensure that persons with albinism are afforded equal protection in law and in practice (arts. 2, 6 and 26).

CCPR/C/SWZ/CO/1 (CCPR, 2017)

Human Rights Committee

Discrimination against persons with albinism

23. The State party should take steps to ensure that persons with albinism are protected, in law and in practice, against all forms of violence and discrimination.

Universal Periodic Review

As with treaty bodies, States are required to submit their human rights reports to the UPR. However, unlike the treaty body reviews, the UPR involves the review of a State's human rights record (the State under review) by other States (recommending States). Recommending States make recommendations to the State under review for improvement of the human rights situation. The State reports to the UPR, a compilation of UN information, a summary of stakeholder information, and the outcome of the review, which consists of the recommendations made to the State, are useful sources of information.⁸⁶

Example of a UPR recommendation regarding albinism in the Democratic Republic of Congo⁸⁷

A/HRC/42/5 (UPR, 2019)

Universal Periodic Review

119.73 Adopt the necessary measures to prevent and punish all acts of discrimination and violence, in particular against LGBTIQ persons, and persons with albinism, ensuring their protection and due compensation (Argentina);

UN Special Procedures

Reports on country visits of the UN Special Procedures, communications to States on human rights concerns⁸⁸ and country specific press releases. The most relevant are those from the Independent Expert on albinism⁸⁹ and the Special Rapporteur on the rights of persons with disabilities. However, a number of others may also include the situation of persons with albinism in their country reports.⁹⁰ At the time of preparing this manual, the Independent Expert on albinism had visited and produced country reports on Malawi, Mozambique, South Africa and Tanzania in the SADC region.

⁸⁵ Extract from Human Rights Committee. Concluding observations on Swaziland in the absence of a report, CCPR/C/SWZ/CO/1, 23 August 2017, tbinternet.ohchr.org (accessed 19 August 2020)

⁸⁶ In addition to the UN country specific information database, they can be accessed by country here: www.ohchr.org; as well as on www.upr-info.org (accessed 03 August 2020). A detailed search for treaty body, UPR and Special Procedures UN documents, including by theme (human rights concern), affected persons (e.g. persons with albinism) and country can be carried out here: uhri.ohchr.org

⁸⁷ Extract from Report of the Working Group on the Universal Periodic Review, Democratic Republic of the Congo, A/HRC/42/5, 5 July 2019, documents-dds-ny.un.org (accessed 19 August 2020)

⁸⁸ Communications can be found on the Special Procedures communications database by country and by mandate at: spcommreports.ohchr.org (accessed 03 August 2020)

⁸⁹ In addition to the UN country specific information database, reports on country visits of the Independent Expert on albinism are available at: www.ohchr.org (accessed 03 August 2020)

⁹⁰ For example, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Special Rapporteur on the right to education; Special Rapporteur on trafficking in persons, especially women and children; Special Rapporteur on violence against women, its causes and consequences; Working Group on discrimination against women and girls; and the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance

Universal Human Rights Index database

The UN's Universal Human Rights Index database is a tool for finding relevant treaty body, UPR and special procedures' concerns and recommendations. A search can be carried out by, among other things, State, theme (human rights concern), persons affected (e.g. persons with albinism) and relevant body.⁹¹

African Commission

Information can be obtained from State reports to the African Commission, and concluding observations,⁹² as well as mission reports and press releases by special mechanisms of the African Commission.⁹³

ACERWC

As with the African Commission, information can be obtained from State reports to the ACERWC,⁹⁴ concluding observations of the Committee.⁹⁵ The ACERWC also has country and thematic special rapporteurs, the most relevant thematic rapporteurs of which are the Special Rapporteur on Violence against children; Special Rapporteur on Child marriage and Other Harmful Practices; Special Rapporteur on Children in Vulnerable Situations; and Special Rapporteur on Health, Welfare and Development. Their country reports can provide valuable information for NHRIs. For example, the ACERWC has carried out an investigative mission in Tanzania on the situation of children with albinism in the country.⁹⁶

⁹¹ uhri.ohchr.org

⁹² State reports and concluding observations are available by country at: www.achpr.org (accessed 03 August 2020)

⁹³ Available on the pages of the relevant special mechanisms, which can be accessed at: www.achpr.org (accessed 03 August 2020)

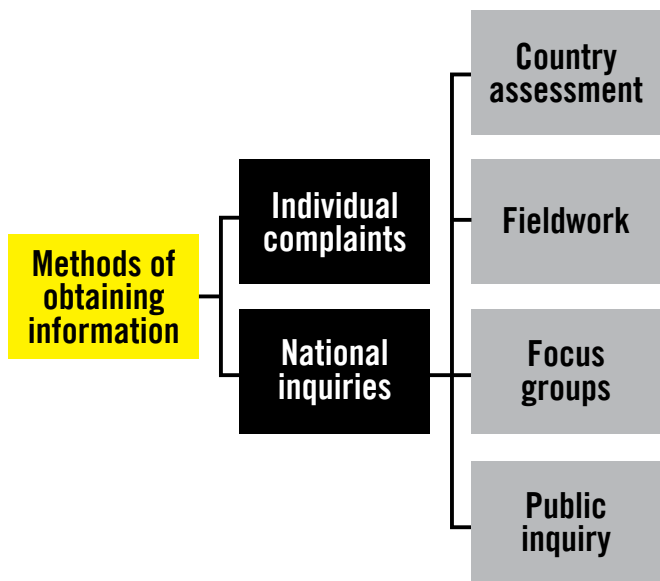
⁹⁴ Available at: www.acerwc.africa

⁹⁵ Available at: www.acerwc.africa

⁹⁶ See Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania, (ACERWC) African Committee of Experts on the Rights and Welfare of the Child, March 2016, www.acerwc.africa (accessed 05 August 2020)

4.3 RESEARCH METHODOLOGIES FOR UNDERSTANDING THE NATIONAL CONTEXT

Broadly speaking NHRIs obtain information on the national context through two processes i.e. individual complaints and national inquiries. For the purposes of this manual, the term national inquiry is used broadly to include further methods such as country assessments, fieldwork, focus groups and public inquiries.



4.3.1 Individual complaints as a method of obtaining information

Some NHRIs are empowered to receive and handle complaints from individuals. The primary purpose of such complaints is to protect the rights of individuals by investigating complaints brought to the NHRI and making recommendations for redress. However, such complaints can also serve as a source of information on issues of concern in a country. They can also point to potential systematic and/or systemic violations requiring further information in the form of a national inquiry. For example, the South African Human Rights Commission used individual complaints it received in relation to employment discrimination as part of its inquiry into workplace discrimination.

TOOL 9: ANALYSING INDIVIDUAL COMPLAINTS FOR INFORMATION ON SYSTEMATIC AND SYSTEMIC VIOLATIONS

In analysing individual complaints for information, particularly on systemic violations on the rights of persons with albinism, NHRIs should consider:

- Who the victim is in the case and whether the victim has albinism (e.g. parents bringing a complaint relating to their child with albinism)
- The characteristics of the person, people or institutions carrying out the act of concern (e.g. private company unfairly dismissing a person with albinism)
- The circumstances of the case and harm caused (e.g. person fired from their job in circumstances that appear to indicate unfair dismissal)
- The apparent cause of the violation (e.g. related to their characteristics and wrong beliefs regarding their characteristics)
- Whether the violation is related to the person's albinism or more than one ground including albinism (e.g. rape of a woman with albinism is predominantly related to her status as a woman and a person with albinism)
- The rights violated in the particular case, how they were violated and by whom
- Where the responsibility for protecting the rights lies
- Available redress
- The number of similar cases involving persons with albinism and violations of a similar nature
- The geographic location of such cases
- The person, people or institutions carrying out the act of concern in such similar cases
- Actions that could have been taken to prevent such violations
- Redress in the similar cases

More information is provided regarding the individual complaints process in the section on protecting rights below.

4.3.2 National Inquiries

For the purposes of this manual, a national inquiry is understood as the process of gathering and reviewing information and data to “identify and understand the country’s main human rights problems related to [albinism] and the efforts (or lack thereof) undertaken by the State as the main duty-bearer, and other non-state actors, to address these problems.”⁹⁷

It includes:

- a. Country assessments – desk-based research of available information on albinism in the country;
- b. fieldwork – interviews with key stakeholder, investigations in their communities, and visiting areas of violations or of particular interest to the research;
- c. focus groups – bringing together key stakeholders to discuss the concerns, obtain background information, and provide insight into information that needs to be clarified; and
- d. public inquiry – public investigations of systemic patterns of violations in which the general public and experts are invited to participate.

NHRIs can use all or some of these tools. However, a country assessment (desk research) is always required to supplement information obtained from other tools.

⁹⁷ Definition adapted from UNFPA definition of country assessments in UNFPA, A Guide in Support of National Human Rights Institutions: Country Assessments and National Inquiries on Human Rights in the Context of Sexual and Reproductive Health and Well-being, New York. March 2019, pg. 21

CASE STUDY 9 Example of a public inquiry which included albinism - South African Human Rights Commission inquiry into discrimination in the workplace

In 2016, the South African Human Rights Commission carried out a public inquiry into discrimination in the workplace using its powers to carry out research, investigate and report on observance of human rights in the country, and to educate on human rights related matters.⁹⁸

The public inquiry examined various grounds of unfair discrimination in the workplace. It went further to highlight albinism as a particular form of disability requiring special attention as persons with albinism tend to remain largely invisible when grouped with other forms of disability. It further pointed out the lack of research and data in relation to discrimination against persons with disabilities.⁹⁹

The inquiry consisted of public hearings, the analysis of information received and additional desk research. Stakeholders were invited to make written submissions and appear before the hearing panel. The institution of the public inquiry was motivated by complaints related to workplace discrimination which revealed a systematic pattern of discrimination in the workplace. In planning for the inquiry, the South African Human Rights Commission developed terms of reference, which set out the rationale for the inquiry, scope and objectives, composition of the panel, and in addition identified respondents and stakeholders. The scope of the inquiry was set broadly to allow it to, “fully examine the occurrence of unfair discrimination in the workplace on all grounds, including those which may not receive sufficient attention but may nevertheless occur systemically.”¹⁰⁰ The objectives of the hearing were as follows:

1. Identify different grounds of discrimination in the workplace;
2. Identify and understand the different forms or manifestations of discrimination;
3. Understand the inter-related nature of different grounds of discrimination and the impact of multiple and simultaneous forms of discrimination;
4. Understand the factors contributing to the prevalence of discrimination;
5. Identify existing barriers to substantive equality;
6. To understand the role of numerous stakeholders in relation to the promotion of equality and elimination of unfair discrimination in the workplace;
7. Understand challenges facing stakeholders (including employees, employers, government departments and organisations) with regard to combating discrimination and ensuring equal treatment, access and opportunities;
8. Consider the current regulatory regime in order to gain a better understanding as to why these challenges persist despite a number of laws and policies being in place; and
9. To identify challenges relating to substantive transformation in the workplace, although the intention of the Hearing was not to engage with this issue in detail, noting the role of the Commission for Employment Equity in this regard.

The purpose of such inquiries is to look into incidents or situations to determine whether systemic or other violations have taken place and provide recommendations for redress.

98 Section 13 of the South African Human Rights Commission Act, 40 of 2013

99 South African Human Rights Commission, Report of the South African Human Rights Commission: National Hearing on Unfair Discrimination in the Workplace 8 March 2016; 25 April 2016, page 51, available at: www.sahrc.org.za (accessed 08 August 2020)

100 South African Human Rights Commission, Report of the South African Human Rights Commission: National Hearing on Unfair Discrimination in the Workplace 8 March 2016; 25 April 2016, Annexure A. Available at: www.sahrc.org.za/home (accessed 08 August 2020)

4.3.2.1 Country assessments

A country assessment is desk-based research aimed at gathering information to assist in better understanding a specific issue. It often involves:

- reviewing publicly available information on the issue (albinism in this case) including through an online search;
- obtaining information from key stakeholders through requesting official information that is not easily accessible or written submission from government officials, persons with albinism, academics, NGOs, disability, health, education and other experts; and
- a legislative and policy review process to understand the available laws and policies or lack thereof for the protection of persons with albinism, including enforcing their rights.

4.3.2.2 Fieldwork

Fieldwork involves members of the NHRI visiting communities and other localities to carry out research through interviews and observations. In relation to albinism, NHRIs should consider carrying out such fieldwork in:

- communities with a relatively high population of persons with albinism,
- places where incidents of attacks against persons with albinism are known to have taken place, and
- places providing services such as health and education to persons with albinism

Fieldwork provides the NHRI an opportunity to obtain a clearer picture of the concerns by:

- seeing the environment in which violations occur,
- observing the specific conditions in the area, and
- speaking to those who live and work in the area who might be unable or unwilling to travel to the offices of the NHRI.

Field work also provides an opportunity to use the research process as a means of human rights promotion, particularly as the presence of NHRI staff in the community for the purposes of researching albinism highlights the importance of the concerns in the eyes of the community. For this purpose, NHRIs should ensure their field visit and purpose for it is widely publicised in the community.

TOOL 10: INTERVIEWING MEMBERS OF THE COMMUNITY DURING FIELDWORK

A number of manuals and toolkits provide guidance on interviewing individuals in relation to violations of economic, social and cultural rights, as well as victims of other human rights violations.¹⁰¹ In addition to guidance provided in these sources, NHRIs carrying out research in relation to albinism should take into account the following:

- **Persons with albinism may be victims of physical and/or psychosocial trauma** – they may have been subjected to attacks, or may have had other traumatic experiences such as abandonment. Others may live in fear of attacks due to the prevailing situation of attacks against persons with albinism. Principles relating to interviewing victims of serious human rights violations and vulnerable individuals, including identifying options for referring them for assistance and support, should therefore be taken into account before interviewing persons with albinism.¹⁰²
- **Need for confidentiality and data protection** – in some countries concern has been raised about data enabling criminal gangs to locate persons with albinism for attacks. It is essential that there are systems in place to ensure adequate confidentiality and data protection.
- **Low vision of persons with albinism** - Any documents to be read or signed by persons with albinism on the ground should be in an accessible format. Generally, this should be large print with high contrast (e.g. black text on white background). Avoid pointing things out at a distance and due consideration should be given to the distance between the person with albinism and the person interviewing or addressing them.
- **Nystagmus** – Some researchers believe direct eye contact is essential for determining the credibility of information of person being interviewed. In some cultures, direct eye contact is considered inappropriate. In addition, as persons with albinism often have nystagmus (i.e. repetitive and uncontrolled movements of the eyes), direct eye contact is unlikely.
- **Sensitivity to the sun** – Meetings held with persons with albinism should as far as possible be indoors or under a shade. NHRIs should avoid direct sunlight, including on anything that a person with albinism may be required to look at or read.

101 Handbook on Civil Society Documentation of Serious Human Rights Violations, Public International Law & Policy Group, 2016. Available at: www.vu.nl (accessed 19 August 2020); Haki Zetu: ESC Rights in Practice, Main book, 2010, Amnesty International Netherlands. Available at: www.amnesty.nl (accessed 19 August 2020); OHCHR, Manual on human rights monitoring, Chapter 11 Interviewing, www.ohchr.org (accessed 19 August 2020); Ukweli, Monitoring and Documenting Human Rights Violations in Africa: A Handbook, Amnesty International and Council for the Development of Social Science Research in Africa (CORDESRIA) 2000. Available at: www.amnesty.nl (accessed 19 August 2020); Ukweli, Monitoring and Investigating Sexual Violence, Amnesty International and Council for the Development of Social Science Research in Africa (CORDESRIA) 2000. Available at: www.amnesty.nl (accessed 19 August 2020); Ukweli, Monitoring and Investigating Torture, Cruel, Inhuman or Degrading Treatment, and Prison Conditions Amnesty International and Council for the Development of Social Science Research in Africa (CORDESRIA) 2000. Available at: www.amnesty.nl

102 See for example: Handbook on Civil Society Documentation of Serious Human Rights Violations, Public International Law & Policy Group, 2016. Available at: www.vu.nl. As well as the Draft Murad Code, Institute for International Criminal Investigations, Nadia's Initiative and Foreign and Commonwealth Office, Draft Global Code of Conduct for Investigating and Documenting Conflict-Related Sexual Violence (The Murad Code), available at: www.muradcode.com

- **Language/terminology** – NHRIs should be careful not to use derogatory or offensive terms for persons with albinism. “Albino” is a term which should not be used. Some find “person living with albinism” and the abbreviation PWA offensive as well. Terms in vernacular which describe persons with albinism as money, curse or having supernatural attributes should also be avoided.
- **Observations during fieldwork** – NHRIs should be aware of and observe factors such as the accessibility of printed material providing information to the public in public places, the distance between communities and public services such as police stations and health centres, appropriateness and accessibility of facilities (e.g. are persons required to wait outside in the sun, do lessons take place outside, etc), safety measures in place to prevent attacks, walls, lights, lockable doors, police patrols, etc

4.3.2.3 Focus groups

Bringing together small groups of people to discuss issues related to albinism can help in providing background information and clarifying areas where further details are required. Such focus groups can be of persons with albinism, for example, sharing their experiences and concerns. Interviewing other groups such as police, lawyers, prosecutors, judges, health professionals, educators and business owners can also provide insight into issues such as the perceived barriers to inclusion of persons with albinism in the community, and the presumptions and unconscious bias of such groups in relation to persons with albinism. Bringing individuals such groups together with persons with albinism can further serve as an awareness raising activity and increase understanding of albinism and the experience of persons with albinism.

4.3.2.4 Public inquiry

CASE STUDY 10

The Malawi Human Rights Commission inquiry into the status and protection of human rights of persons with albinism in Malawi.¹⁰³

In 2016, the Malawi Human Rights Commission carried out a public inquiry into the situation of persons with albinism in Malawi. Information was collected from the public through written and oral submissions, including from State officials and public hearings in two districts seen to be representative of the wider national context. In addition, desk research was carried out. The objectives of the inquiry were:

1. To establish root and structural causes of the human rights violations of persons with albinism;
2. To Identify and analyze challenges faced by persons with albinism;
3. To examine the need for change of the laws, policies and practices;
4. To assess effectiveness and appropriateness of existing interventions; and
5. To generate recommendations for appropriate actions.

The report found that attacks against persons with albinism exist, with serious social, economic and human rights challenges for persons with albinism. It uncovered traditional beliefs, myths and the economic incentive of the existence of a market for body parts as root causes of the attacks. The inquiry recommended, among other things, the training of police, prosecutors and magistrates; increased awareness raising campaigns around albinism; the introduction of albinism as a subject into school curriculum; and the establishment of a fund to assist persons with albinism in the construction of houses to improve home security.

The State has taken steps to implement a number of the recommendations since the inquiry. The authorities reportedly provided housing subsidies for persons with albinism,¹⁰⁴ produced a handbook for police, prosecutors and judges working on albinism,¹⁰⁵ and, among other things, increased human rights awareness around albinism, including through the Malawi Human Rights Commission. They have also since appointed a person with albinism to the Commission.

¹⁰³ Report on the Public Inquiry on the Status and Protection of Persons With Albinism in Malawi – 2016. Available at: mhrcmw.org

¹⁰⁴ Nyasa Times, Ministry ready to build 600 houses for persons with albinism, 9 January 2020, www.nyasatimes.com (accessed 01/04/2020)

¹⁰⁵ Handbook for Investigators, Prosecutors and Magistrates on Offences Concerning Persons with Albinism, womenlawyersmalawi.files.wordpress.com (accessed 3 August 2020)

A public inquiry is “a transparent, public investigation into a systemic and systematic human rights problem in which the general public and expert stakeholders (including experts from government, academia, civil society and individuals from affected communities) are invited to participate.”¹⁰⁶

Advantages of public inquiries:

- They are a good way of obtaining more detailed information, as well as clarifying information obtained during a country assessment.
- They provide an opportunity for persons with albinism to share their experiences publicly and have their voices heard.
- They allow for information to be provided publicly by government officials, academics, NGOs and other experts who can be held publicly accountable for the information and opinions they provide.
- They provide NHRIs an opportunity to further examine the information provided during the inquiry by asking follow-up questions for clarification.
- For those NHRIs that have powers to compel witnesses to attend and provide testimony, such powers are strengthened by requiring witnesses to appear publicly.

Prior to commencing the public inquiry, clear terms of reference should be developed in consultation with persons with albinism, or associations representing them. The terms of reference should include the nature and scope of the public inquiry and the role of persons with albinism in the inquiry.

STEPS IN PREPARING FOR A PUBLIC INQUIRY:

The OHCHR recommends the following steps in preparing for a public inquiry:¹⁰⁷



AUTHORITY

The authority of NHRIs to carry out public inquiries emanates from its founding legislation. This should also set out whether the NHRI has powers to compel witnesses, testimony and the provision of official documents, to hold interviews in private if needed,¹⁰⁸ as well as any powers in relation to witness protection. Once an NHRI has established that it is not barred from carrying out a public inquiry and has the requisite associated powers, it should set out clear objectives and expected outcomes of the inquiry. For example, does the inquiry aim to look at all rights of persons with albinism or only certain areas of concern e.g. attacks or education. Does it cover men as well as women with albinism? What is the geographic area of focus? What does the NHRI expect to achieve from the inquiry, in other words, what will it do with the information obtained? How does it see the information contributing to improving the enjoyment of rights of persons with albinism?

¹⁰⁶ UNFPA, A Guide in Support of National Human Rights Institutions: Country Assessments and National Inquiries on Human Rights in the Context of Sexual and Reproductive Health and Well-being, New York. March 2019, pg. 21

¹⁰⁷ Office of the United Nations High Commissioner for Human Rights (OHCHR), Economic, Social and Cultural Rights: Handbook for National Human Rights Institutions, Professional Training Series No. 12, United Nations, New York and Geneva, 2005, pg. 97

¹⁰⁸ Office of the United Nations High Commissioner for Human Rights (OHCHR), National Human Rights Institutions: History, Principles, Roles and Responsibilities, Professional Training Series No. 4 (Rev1), United Nations, New York and Geneva, 2010, page 97

COST ANALYSIS

A cost analysis will then need to be carried out. This should include:

- A consideration of the services which will need to be paid for in the process of the inquiry and how much they will cost.
- How will people be made aware of the inquiry and opportunity to participate? The costs attached to this.
- Whether a venue will need to be hired for the hearings.
- The need for interpreters.
- Whether members of the panel will be paid.
- If transport will be provided.
- Whether there is a need to source a sound system.
- Whether food and refreshments will be provided and to whom.
- Whether there will be media publication of events and if this will need to be paid for.

In addition to cost of relevant services and facilities, the emotional and security costs to victims and others, as well as potential impact on the effective administration of justice in relation to specific cases will also have to be counted i.e. could the public inquiry jeopardise any case already or likely to go before a court? Will the inquiry put persons with albinism testifying at risk of attacks? Is there any way of minimising or eliminating such a risk without doing away with the whole public inquiry? The expected outcomes/benefits of carrying out the public inquiry should outweigh the cost.

MEMBERS OF THE PANEL

The UNFPA highlights the importance of ensuring the inquiry panel has the requisite expertise. In relation to albinism, the panel should consist of some expertise on albinism, as well as the thematic focus of the inquiry i.e. administration of justice, traditional and customary practices, health, education, and/or labour. An alternative is to have an advisory group to provide assistance to the panel in preparing the inquiry, interpreting findings and developing appropriate recommendations.¹⁰⁹ Persons with albinism or associations of persons with albinism who understand the concerns should be included in the panel or advisory group.

MEDIA INVOLVEMENT

Public inquiries should also seek to involve the media to ensure work of the NHRI is transparent, that any calls for written submission is widely disseminated and potential witnesses are reached. In addition, media coverage can contribute to raising awareness of the rights of persons with albinism and violations of their rights.

¹⁰⁹ UNFPA, A Guide in Support of National Human Rights Institutions: Country Assessments and National Inquiries on Human Rights in the Context of Sexual and Reproductive Health and Well-being, New York. March 2019, page 23

4.4 FURTHER READING

- UNFPA, A Guide in Support of National Human Rights Institutions: Country Assessments and National Inquiries on Human Rights in the Context of Sexual and Reproductive Health and Well-being, New York. March 2019.
- Asia Pacific Forum of National Human Rights Institutions and the Center for Economic and Social Rights (CESR), January 2015, Defending Dignity: A Manual for National Human Rights Institutions on Monitoring Economic, Social and Cultural Rights, updated August 2018¹¹⁰
- Office of the United Nations High Commissioner for Human Rights (OHCHR), National Human Rights Institutions: History, Principles, Roles and Responsibilities, Professional Training Series No. 4 (Rev1), United Nations, New York and Geneva, 2010.
- Asia Pacific Forum (APF), A Manual on National Human Rights Institutions, May 2015 (updated May 2018).¹¹¹
- Office of the United Nations High Commissioner for Human Rights (OHCHR), Economic, Social and Cultural Rights: Handbook for National Human Rights Institutions, Professional Training Series No. 12, United Nations, New York and Geneva, 2005
- Human Rights Indicators: A Guide to Measurement
- and Implementation, OHCHR, 2012.¹¹²
- EU-OHCHR Bridging the Gap I: Human Rights indicators for the Convention on the Rights of Persons with Disabilities in support of a disability inclusive 2030 Agenda for Sustainable Development.¹¹³

¹¹⁰ www.ohchr.org

¹¹¹ ganhri.org

¹¹² www.ohchr.org

¹¹³ bridgingthegap-project.eu

PROMOTING THE RIGHTS OF PERSONS WITH ALBINISM

OBJECTIVES OF PART 5:

This part looks at promotion of the rights of persons with albinism by NHRIs i.e. ways in which NHRIs can increase the public's knowledge and awareness of such rights, with a view to decreasing their violation and increasing accountability.

By the end of Part 5, NHRIs should:

- have an understanding of how to plan awareness raising
- understand human rights promotion activities that can be carried out in relation to albinism
- have an idea of the targets of the promotion activities and the objectives of such promotion activities in respect of each target

The promotion and protection functions are often referred to jointly giving them equal weight. However, the UN has expressed concern that the promotion role of NHRIs is often overlooked due to the demands of the protection role, which can often absorb the bulk of the resources.¹¹⁴ It is important therefore that NHRIs give due consideration to promoting the rights of persons with albinism. This is in fact a very important part of protecting rights as it helps to tackle root causes of violation of such rights.

In preparing promotion activities it is essential for NHRIs to have a clear understanding of:

- the problem,
- the message to be communicated to various targets to contribute to ending the problem,
- who those targets will be and
- the tools that will be used to promote the rights of persons with albinism within those targets.

Persons with albinism themselves should also be targets of such promotion activities in a way which empowers them to advocate for their own rights.

¹¹⁴ Office of the United Nations High Commissioner for Human Rights (OHCHR), National Human Rights Institutions: History, Principles, Roles and Responsibilities, Professional Training Series No. 4 (Rev1), United Nations, New York and Geneva, 2010, pg. 56

TOOL 11: PLANNING AWARENESS RAISING

- What are the violations that need to end (e.g. attacks and impunity for attacks, inequality in access to health, education or work)?
- What factors fuel such violations or act as a barrier to ending violations? i.e. PESTEL factors?
- Are there political factors that perpetuate violations or act as a barrier to change?
- Are there economic factors that fuel the violations or act as a barrier to full enjoyment of rights by persons with albinism?
- What social factors, including cultural practices, assumptions and wrong beliefs lead to such violations?
- Are there technological factors which fuel violations or hinder enjoyment of rights? Can technological factors help reduce violations?
- Do environmental factors play a role in preventing the full enjoyment of rights on an equal basis with others?
- What are the legal barriers or what legislative reforms need to be put in place to increase the enjoyment of rights?
- What information is likely to change behaviours and increase protection and respect of rights? What needs to be known?
- Who needs to know this and to change their beliefs and behaviours?
- What tools for knowledge dissemination exist?
- What is the best way to reach specific target?
- What level of understanding already exists among the target group?
- What is the best learning method for the target group?
- What are the targets most likely to have access to as a learning tool e.g. TV, radio, social media?
- Who would they listen to?
- What are the available human and financial resources for awareness raising?

The UN manual for NHRIs¹¹⁵ provides detailed information on the types of promotion activities that can be carried out by NHRIs. Broadly speaking these include human rights education and training, public awareness, and policy development.

¹¹⁵ Office of the United Nations High Commissioner for Human Rights (OHCHR), National Human Rights Institutions: History, Principles, Roles and Responsibilities, Professional Training Series No. 4 (Rev1), United Nations, New York and Geneva, 2010

5.1 HUMAN RIGHTS EDUCATION AND TRAINING ON ALBINISM

NHRIs can be involved in the development and implementation of human rights education and training programmes as a method of promoting the human rights of persons with albinism. These include:

5.1.1 Human rights education and training of groups representing persons with albinism

To increase understanding of human rights in general, the prerequisites for the full enjoyment of rights by persons with albinism, and how to enforce such rights.

5.1.2 Human rights education in places of learning

To raise awareness of students of the rights of persons with albinism. This should include increasing understanding of the biological causes of albinism to demystify it. Inclusion of albinism in school and university curriculums, particularly biology, social sciences and law classes can contribute to decreasing the wrong beliefs in the supernatural nature of albinism.

5.1.3 Human rights education and training of professionals

To tackle misconceptions associated with albinism and raise awareness on the role such professionals play in protecting the rights of persons with albinism. Such human rights education and training can be included in required continuing professional development curriculums or be carried out through tailored trainings, seminars, workshops and conferences on, or integrating albinism. Professional targets of such programmes should include:

Agents of the justice sector – police, lawyers, prosecutors and judges, with a view to:

- contributing to changing attitudes and beliefs, thus reducing stigma and intentional or unintentional discriminatory practices;
- increasing understanding of duty of the police to protect the rights of persons with albinism;
- increasing understanding of the duty of police, prosecutors and judges to investigate, prosecute and appropriately sentence cases of attacks against persons with albinism; and
- increasing lawyers' understanding of rights applicable to cases of persons with albinism and their legal assistance needs.

Places of learning in relation to teachers and administration in primary, secondary and tertiary institutions with a view to:

- contributing to changing attitudes and beliefs, thus reducing stigma and intentional or unintentional discriminatory practices; and
- increasing their knowledge regarding inclusive education and reasonable accommodation requirements for persons with albinism.

The health sector including nurses, doctors, midwives, other medical professionals and health administrators, with a view to:

- contributing to changing attitudes and beliefs, thus reducing stigma and intentional or unintentional discriminatory practices;
- increasing their understanding of health needs of persons with albinism in relation to sight and susceptibility to skin cancer; and
- increasing their understanding of the biological causes of albinism, as well as information and services for assistance of parents of children with albinism.

Private and public employees with a view to:

- contributing to changing attitudes and beliefs, thus reducing stigma and intentional or unintentional discriminatory practices; and
- increasing their knowledge regarding non-discrimination laws and policies, as well as reasonable accommodation requirements for persons with albinism.

Other groups - NHRIs will need to identify other groups such as CSOs, religious leaders, architects and town planners, parliamentarians, etc that can also benefit from such human rights education and training.

5.1.4 Publications

Printed information on albinism and the rights of persons with albinism is a good way to reach a large number of literate people. This includes pamphlets, training manuals, handbooks and reports. NHRIs can also include information on albinism in their regular publications such as newsletters and analysis on legislation and policies.

5.2 PUBLIC AWARENESS

While human rights education and training targets specific groups for formalised learning, public awareness aims to ensure information reaches the general public through campaigns and events, including community-based initiatives and media strategies. International Albinism Awareness Day on 13 June provides a good hook for intensifying such activities. In South Africa, the whole month of September is international albinism awareness month.¹¹⁶ It is good practice to have a day or month designated for awareness raising, however such public awareness should be carried out the whole year. In relation to albinism, public awareness campaigns have included events such as Mr. and Ms Albinism, community theatre, competitions, exhibitions, press releases, Op-Eds, blogs, social media campaigns, information on websites, inclusion of albinism as a topic on TV and radio talk shows, tv adverts, public service announcements, public awareness walks, banners, as well as the inclusion of persons with albinism as public figures on TV shows, in government and other public domains.

¹¹⁶ The Independent Expert on albinism, Country Visit Report to the Republic of South Africa A/HRC/43/42/Add.1, para. 27

5.3 POLICY DEVELOPMENT

NHRIs should develop human-rights based albinism policies, ensuring inclusion and active participation of persons with albinism, for their own internal use. In addition, they can contribute to the development of such policies at the local and national level, for example, as part of inclusive education policies, ethical standards and practice guidelines in the health sector, as well as policies on the inclusion of persons with albinism in places of work. NHRIs may seek to initiate such policies with relevant government departments or contribute to the development of policies through their expert knowledge or network of contacts. As with all promotion activities, persons with albinism must be enabled to actively and meaningfully participate in the development of such policies.

5.4 FURTHER READING

- Office of the United Nations High Commissioner for Human Rights (OHCHR), National Human Rights Institutions: History, Principles, Roles and Responsibilities, Professional Training Series No. 4 (Rev1), United Nations, New York and Geneva, 2010.
- Best Practices in the protection of human rights of persons with albinism, Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism.¹¹⁷

¹¹⁷ Best Practices in the protection of human rights of persons with albinism, Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (Presented to the 75th session of the General Assembly, A/75/50343), 17 July 2020, www.ohchr.org

PROTECTING THE RIGHTS OF PERSONS WITH ALBINISM

OBJECTIVES OF PART 6:

This section looks at the ways in which NHRIs can protect rights of persons with albinism. This includes through handling individual cases, preparing amicus briefs, developing or contributing to legislative and policy reform, as well as advocacy to ensure the state puts in place systems and mechanisms to guarantee the full enjoyment of rights by persons with albinism, and redress in cases where violations occur. A lot of NHRIs' work in this regard will involve advocacy for the implementation, by relevant authorities, of specific recommendations developed by the NHRI following its national inquiry.

By the end of Part 6, NHRIs should:

- have an understanding of the tools that can be used by NHRIs for human rights protection
- understand how a human rights investigation differs from a criminal investigation
- be able to identify areas for potential legal reform
- have an idea of how to develop an advocacy strategy
- have knowledge of regional and UN platforms for advocacy and types of advocacy activities that can be carried out at these levels

6.1 INDIVIDUAL COMPLAINTS AS A PROTECTION TOOL

Some NHRIs have quasi-judicial functions and are able to receive and investigate individual complaints, as well as to make recommendations to a relevant State body for remedial action. Some NHRIs are empowered to go further and make orders which may be binding and enforceable.

While the subject matter of such complaints and investigation may be similar to that of a criminal investigation at times, investigations by NHRIs differ from those by police principally as they seek to make determinations related to human rights violations and not a crime.

How do human rights investigations differ from criminal investigations?

	CRIMINAL INVESTIGATION	HUMAN RIGHTS INVESTIGATION
Basis for investigation	National criminal laws e.g. Criminal code and Criminal Procedure Code	National and international human rights laws and guiding principles for human rights investigations
Type of liability	Criminal liability by an individual in relation to intentional or negligent act amounting to a crime	Human rights violation generally by State in relation to action, or failure to prevent, protect or redress violation
Complainant/who can institute complaint	Usually the State in a criminal case with the victim, including dependents in case of death, being interested parties	Victim, family, other interested or concerned groups e.g. CSOs
People heard during investigation/trial	Victim or family, other witnesses, accused, medical and other experts	Victim or family, witnesses, person/institution to which complaint pertains where relevant, State officials, human rights and other experts
Types of evidence	Witness testimonies in court, documentary and physical evidence, including crime scene investigations	Witness testimonies, documentary and physical evidence
Findings	Finding of guilt for contravening section/s of penal code e.g. murder, assault, grievous bodily harm, kidnapping, trafficking, etc	Finding of violation by the State of human rights obligations, either for failure to respect (acts carried out by State officials) or failure to protect rights, such as the right to life, bodily integrity, equality and non-discrimination, access to justice, etc
Sanction	Criminal sentence for perpetrator (e.g. fine or imprisonment) and compensation for victim	Recommendation of required action by the State to address and redress violation

CASE STUDY 11

Fletcher Masina

On 24 May 2016, a 38-year-old man with albinism, Fletcher Masina, was attacked and killed by unknown persons while working in his garden in Zintambira village under Traditional Authority Chakhumbira in Ntcheu district, Central Region, Malawi. Fletcher and his wife went to their vegetable garden in the morning which is some distance from their village. At about lunchtime Fletcher's wife said he told her to go home while he continued working in the garden. At about 7pm his wife said she told her brother that Fletcher had not returned home. A search party was sent to the garden to look for him but all they saw was blood all over the garden and signs of a struggle. They tried to follow the blood trail but it was too dark to see anything. The next day, police and relatives continued the search and found Fletcher's body a few hundred meters from the garden with both hands and legs cut off.¹¹⁸

In the case above the focus of the NHRI investigation would be to ascertain any violation of rights by the State and specifically which rights. Focus should be on understanding the circumstances of the killing and how that relates to the obligations of the State and what the State did or did not do in respect of that obligation.

Examples of questions include:

- Who is the victim(s)?
- What is the main act(s) of concern?
- Who is carrying/carried out the act of concern (the perpetrator)?
- Was it carried out because of the persons albinism? Is it likely that the victim would have been treated in the same way or that the perpetrator would have carried out the act if the victim did not have albinism?
- What rights does this act(s) potentially violate?
- What steps should be taken by the State to ensure respect, protection and fulfilment of the rights?
- Was the State or a State agent the perpetrator or involved in the crime (i.e. did the State respect the right by not violating it)?
- Which State institution(s) has the responsibility of making sure such acts do not happen (duty to protect)? How?
- Did the State institution take all appropriate measures to prevent the act from taking place and protect the victim in this case?
- Which State institution(s) has the responsibility of making sure individuals are fully able to enjoy this right (duty to fulfil)? How?
- Did the State institution(s) take all appropriate measures to ensure the victim was able to fully enjoy the right in this case?
- Which State institution(s) has the responsibility of ensuring accountability for such acts?

118 "We Are Not Animals to Be Hunted or Sold": Violence And Discrimination Against People With Albinism in Malawi, AFR 36/4126/2016, Amnesty International 2016

- Did the State institution(s) take appropriate steps to ensure accountability and redress for the act which violated the victims' rights e.g. crime scene and forensic investigations, ensuring cross-border cooperation, availability of police, prosecutors and judges with adequate capacity?
- Have there been similar cases?
- How prevalent are such cases?
- How has the State responded to such cases?
- Has the State taken adequate measures to prevent such attacks from happening and to protect persons with albinism?
- What steps should be taken by the authorities to respect, protect and fulfil the rights? Which authorities/institutions specifically?

6.2 AMICUS BRIEFS

In their capacity as experts on human rights in a particular country, NHRIs can serve as an *amicus curiae* (“friend of the court”) and submit amicus briefs to courts, as a way of contributing to change in practice and in law in relation to the treatment of persons with albinism. Amicus briefs are submissions to a court in respect of a particular case, by a person or entity that is not party to the court case. They seek to provide information, expertise, or insight on an issue in the case. The OHCHR has encouraged NHRIs to use relevant concluding observations in their amicus briefs to promote the enactment of jurisprudence by the courts, in accordance with international standards.¹¹⁹

CASE STUDY 12

Maldives: 15-year-old girl sentenced to be flogged

The Human Rights Commission of the Maldives (HRCM) used an amicus brief to protect the rights of a 15-year-old girl sentenced to flogging. The girl had been sexually abused by her stepfather since the age of nine. She had become pregnant and had given birth to the stepfather's child, whom the stepfather had killed. The girl was charged and convicted by the Juvenile Court of having sexual relations outside marriage and sentenced to be flogged.

The HRCM commenced an investigation when the girl's situation came to its attention. When the case was appealed to the High Court, the HRCM sought leave to appear as a “friend of the court” (*amicus curiae*) and to submit its investigation report highlighting the many State violations. The Court granted the HRCM leave to appear and the HRCM was able to present human rights arguments. After hearing from the State, the HRCM and the girl's defence lawyer, the High Court overturned the decision of the Juvenile Court.¹²⁰

¹¹⁹ Common approach to engagement with national human rights institutions, Note by the Secretariat, HRI/MC/2017/3, 9 June 2017. Available at: www.ohchr.org (accessed 13 August 2020)

¹²⁰ Excerpt and adaptation from Asia Pacific Forum (APF), *A Manual on National Human Rights Institutions*, May 2015 (updated May 2018), page 221 ganhri.org (accessed 30 July 2020)

6.3 LEGISLATIVE REFORM

In most cases legal reform will need to be carried out to ensure equal access and enjoyment of all rights by persons with albinism. Such legal reform often requires introduction of new laws, or repeal of laws which violate rights, or both. Most persons with albinism have low vision and as a result, often benefit from legislation to protect persons with disabilities. However, not all countries have such legislation. In addition, their vulnerability to the sun and susceptibility to skin cancer is not recognised as an impairment in many countries. Laws may therefore need to be introduced to ensure access to social protection measures, appropriate and adequate healthcare and health services, inclusive education, and reasonable accommodation in schools and in the workplace for persons with albinism, as well as to prohibit unfair discrimination on the basis of albinism.

In relation to attacks, laws may need to be introduced to appropriately criminalise attacks and all acts associated with the attacks. This includes ensuring anti-trafficking laws cover the trafficking of persons with albinism for the purposes of the removal of any part of their body; the criminalisation of the possession of body parts; and the criminalisation of harmful practices related to the accusation of witchcraft and ritual attacks. In addition, such laws will need to ensure penalties are commensurate with offences. For example, following advocacy from organisations working on albinism, Malawi reformed its Anatomy Act to ensure criminalisation of possession of body parts.

NHRIs can play a role in advocating for legal reform, commenting on relevant draft laws, working with legislators in drafting bills and ensuring the active and meaningful participation of persons with albinism in the development of laws.

TOOL 12: AREAS FOR LEGAL REFORMS IN RELATION TO ALBINISM

In relation to attacks	<ul style="list-style-type: none">■ Ensuring prohibition of hate crimes applies to advocacy of violence against persons with albinism■ Ensuring trafficking and all acts associated with it are penalised and extend to the trafficking of persons with albinism for the purposes of removing body parts, including hair and nails■ Ensuring the criminalisation of the possession of body parts■ Ensuring all acts of assault or killings resulting from accusations of witchcraft or ritual attacks are penalised and serve as an aggravating factor in sentencing■ Ensuring that sentences for attacks against persons with albinism are commensurate to the crime
In relation to health	<ul style="list-style-type: none">■ Legal recognition that persons with albinism are entitled to benefits for persons with disabilities by virtue of their low vision and susceptibility to the sun■ Provision of social protection measures for persons with albinism, including free sun care products, skin cancer screening and treatment, as well as appropriate eye testing and provision of assistive devices
In relation to education	<ul style="list-style-type: none">■ Legal framework for inclusive education and reasonable accommodation in schools, including tertiary institutions
In relation to work	<ul style="list-style-type: none">■ Legal framework for positive discrimination and reasonable accommodation in employment
Other	<ul style="list-style-type: none">■ Legal recognition of international albinism awareness day

6.4 NATIONAL AND INTERNATIONAL ADVOCACY

In addition to advocating for legal reform, NHRIs can contribute to the protection of the rights of persons with albinism through carrying out national and international advocacy for policy and practice reform. Information obtained from national inquiries and individual cases can be used for the development of recommendations to government authorities and advocacy strategies for the implementation of such recommendations. This section sets out how advocacy is developed as well as the various national and international forums where advocacy can be carried out and the opportunities for advocacy in these forums.

6.4.1 Developing an advocacy strategy

In developing an advocacy strategy, NHRIs should set clear advocacy goal and objectives. The goal should set out the change hoped for in the long term and the objectives i.e. the short-term action they wish others to take to achieve the goal. NHRIs will also need to carry out a stakeholder analysis to determine:

- those who could potentially affect or be affected by the advocacy,
- those who will support or oppose the advocacy,
- the relative powers of the stakeholders in contributing to or opposing the advocacy,
- those who have powers to make relevant changes and
- those who can influence those with powers.

The stakeholder analysis should seek to identify the targets of the advocacy. Advocacy messaging and activities should then be developed taking into account the appropriate language and messaging

which is likely to convince the target to implement the desired objectives. While flexibility may be required, advocacy activities should have a timeline and include key dates for certain activities to ensure opportunities are not missed. For example, certain activities may need to be carried out before or on a specific date, such as the opening of parliament or a commemorative date.

6.4.2 National

National advocacy strategies in relation to albinism are aimed at legislative, policy and practice reform. In relation to attacks, NHRIs will have to identify specific targets in the criminal justice system for the purposes of ensuring appropriate systems and mechanisms for increased protection and investigation of attacks by the police, successful prosecutions and appropriate sentencing. In relation to this, the Independent Expert has called for capacity building of police, prosecutors and judges, as well as provision of social protection to strengthen the capacity of persons with albinism to mitigate risk of attacks.¹²¹ Human rights promotion activities such as human rights education and training, awareness raising and policy development can contribute to this. An example of such capacity-building initiative is Malawi's Handbook for Investigators, Prosecutors and Magistrates on Offences Concerning Persons with Albinism.¹²² In addition, NHRIs can advocate for relevant legal reform.

Similarly, in relation to health, education and employment, advocacy for adoption of laws, policies, and capacity building of relevant targets to change attitudes and practices can be carried out. Advocacy activities may include writing to relevant targets, meetings to discuss concerns and recommendations, press releases, public statements, op-eds, blogs, petitions, social media

¹²¹ Right to access to justice for persons with albinism - Report of the Independent Expert on the enjoyment of human rights by persons with albinism, A/HRC/40/62, ap.ohchr.org

¹²² Handbook for Investigators, Prosecutors and Magistrates on Offences Concerning Persons with Albinism, womenlawyersmalawi.files.wordpress.com

and writing campaigns aimed at getting the general public to raise the concerns and recommendations with their MPs and relevant targets.

6.4.3 Sub-Regional level¹²³

Engagement with SADC is a little opaque compared with other institutions. The heads of state and government meet annually during the SADC Summit. However, there is currently no room for civil society direct engagement during the SADC Summit. Platforms for advocacy at SADC level include:

- SADC National Committees (SNC) or SADC contact points – these are contacts at national level through which, theoretically, input can be made on formulation of regional policies and strategies.¹²⁴ However, it is often difficult to make contact with these contact persons and they do not always have capacity as individuals often carry out other functions in their government, as well as being part of the SNC. NHRIs can seek to engage with the SNC, where possible to raise awareness of concerns related to albinism and the need for regional policies, particularly in relation to investigation of attacks against persons with albinism of a transnational character, such as trafficking, and creation of regional policies to ensure full enjoyment of rights by persons with albinism.
- Establishing a memorandum of understanding (MoU) with SADC secretariat – SADC secretariat has signed MoUs for cooperation with the civil society groups. Such MoUs in theory should enable greater cooperation and collaboration between the SADC secretariat and these bodies, which in turn should increase opportunity for input into regional policies and strategies. The MoUs also grant

greater access to the meetings of the SADC summit, however this is often only to the opening and closing ceremonies. While few CSOs have managed to obtain such MoUs, it may be worth NHRIs in SADC seeking such an MoU to facilitate closer engagement.

- SADC CSO forum – the forum is held in the run up to the SADC summit and organised by SADCNGO, SATUCC and FOCCISA. It provides an opportunity for CSOs engagement on concerns relevant to the region. CSOs can propose topics for the agenda, organise panels and advocate for the adoption of CSO resolutions on issues of concerns. These resolutions are then fed back to the SADC secretariat through the SADCCNGO, which has an MoU with the secretariat. NHRIs can participate in the forum. While the forum provides an opportunity for awareness raising and potentially feeding issues related to albinism into the advocacy work of other CSOs, it is not clear how much impact it has on the policies of SADC.
- The SADC Parliamentary Forum (SADC-PF) - is a regional inter-parliamentary body composed of Members of Parliament from SADC Member State national parliaments, representing over 3,500 parliamentarians in the SADC Region. However, unlike other regional parliamentary forums, the SADC-PF has no legislative or oversight function. Despite this, it is a good forum for advocacy for coordinated legislation in relation to albinism. The SADC PF can also adopt motions on various issues signalling the importance of these to the people of SADC. In 2019, it adopted a motion on attacks against persons with albinism.¹²⁵

¹²³ For further information on engaging with SADC see: Lisa Gürth, Merran Hulse, Helena Kavsek, Verena Stauber, Daniel Wegner and Jan Weinreich, *Civil Society Engagement in Regional Governance: A Network Analysis in Southern Africa*, German Development Institute, Discussion Paper, 30/2018. And Theresa Reinold, *Civil society participation in regional integration in Africa: A comparative analysis of ECOWAS, SADC, and the EAC*, April 2019 *South African Journal of International Affairs*

¹²⁴ See www.sadc.int

¹²⁵ See Seychelles condemned the attacks, abductions, killings and discrimination against people with albinism at the 45th Plenary assembly of SADC Parliamentary Forum, the National Assembly of Seychelles, 30 July 2019, nationalassembly.sc (accessed 24 August 2020)

- The Southern African Regional Police Chiefs Co-operation Organisation (SARPCCO) – is the regional body for police cooperation in Southern Africa. It focuses on combatting crimes of a transnational character, including trafficking in persons and crimes against women and children. It has adopted multilateral agreements on combatting crime and mutual assistance.¹²⁶ However, it does not appear to have given specific attention to the transnational character of attacks against persons with albinism at present and there is scope for advocacy for it to work more in this area.
- The Chairs of the Ministerial Committees of SADC – Sectoral and cluster ministerial committees of SADC consists of ministers from each SADC member State. These committees are responsible for overseeing integration activities related to their thematic areas. Relevant committees include Ministers responsible for Social and Human Development and Special Programmes (HIV and AIDS; education, labour; employment and gender); Ministers responsible for Politics, Defence and Security; and Ministers responsible for Legal Affairs and Judicial matters. NHRIs can seek to engage with the Chairs of these committees for the purposes of advocating for integrated response to concerns related to work, health, attacks and legal reform. Engagement at this level enables NHRIs to engage simultaneously with relevant officials from the member States. For example, all Attorney-Generals are part of Committee of the Ministers responsible for Legal Affairs and Judicial matters. They can therefore all be engaged through this committee.

Advocacy activities at SADC level often include:

- Meetings and side events on the margins of the SADC summit
- Press releases, campaigns and other forms of media engagement directed at the SADC summit, particularly around the time of the SADC summit
- Participation in the SADC CSO forum
- Engagement with the SNC and technical bodies of the SADC secretariat
- Lobbying of other SADC bodies such as the SADC PF and SARPCCO for motions and agreements Working with regional networks of CSOs, including those which do not have MoUs with the SADC secretariat. Of particular interest in relation to albinism is the Gender Protocol Alliance which works on issues related to the empowerment of women and the implementation of the SADC Gender Protocol. It has managed to successfully advocate for adoption of the revised protocol following the end of the 2015 target included in the original SADC Gender Protocol. NHRIs can collaborate with the alliance to ensure application of the Protocol to women with albinism. SATUCC is also of particular interest as it has been working on the ratification of the SADC Protocol on Employment and Labour.¹²⁷ Recently it was announced that this Protocol was to be reviewed. The protocol contains an article on the right to work for persons with disabilities. The announcement of the review provides an opportunity for NHRIs to input into the new protocol issues related to enjoyment of rights by persons with albinism.

¹²⁶ SARPCCO Multilateral Cooperation Agreement on Combating Crime within the Region and SARPCCO Agreement in Respect of Cooperation and Mutual Assistance in the Field of Crime Combating

¹²⁷ SADC Protocol on Employment and Labour. Adopted in 2014, but awaiting ratification from two-thirds of States. Available at: www.sadc.int (accessed 28 August 2020)

6.4.4 African Regional level

African political and human rights bodies can play an important role in influencing national institutions to make reforms necessary for the full enjoyment of human rights by persons with albinism. Opportunities available to NHRIs include through the African Commission and the African Committee of Experts on the Rights of the Child.

6.4.4.1 African Commission

In 1989, the African Commission introduced the process of granting affiliate status to NHRIs to formalise the relationship between itself and NHRIs.¹²⁸

Criteria for granting of affiliate status

To be granted affiliate status, the prospect NHRIs must fulfil the following requirements:

- It must be duly established by law;
- It must be a national human rights institution or other specialized human rights institution of a State Party to the African Charter;
- Its independence must be guaranteed by law;
- It must have as broad a mandate as possible, capable of promoting, protecting and monitoring human rights through various means;
- It must be characterized by effective functioning;
- It must be adequately funded and not subject to financial control;
- It must be accessible to the general public; and
- It must be composed of diverse membership representative of the society.¹²⁹

The affiliate status is similar to the observer status enjoyed by NGOs. It grants NHRI's the right to be invited to sessions of the Commission, and to participate in deliberations on issues that are important to them, although they do not have voting rights during such deliberations. In addition, NHRIs have the right to submit proposals which may be put to a vote.

¹²⁸ The 1998 resolution has since been superseded by the Resolution on the Granting of Affiliate Status to National Human Rights Institutions and specialized human rights institutions in Africa - ACHPR/Res.370(LX)2017

¹²⁹ ACHPR/Res.370(LX)2017, *Ibid*

NHRIs in SADC with affiliate status at the African Commission¹³⁰

NHRI	STATE	SESSION
Zimbabwe Human Rights Commission	Zimbabwe	60th Ordinary Session 8 May to 22 May, 2017
Commission for Gender Equality of the Republic of South Africa	South Africa	62nd Ordinary Session 25 April to 9 May, 2018
L'Observatoire National Des Droits De L'Homme De La République Démocratique Du Congo	Democratic Republic of Congo	36th Ordinary Session 23 November to 7 December, 2004
Commission for Human Rights and Good Governance of Tanzania	Tanzania	35th Ordinary Session 21 May to 4 June, 2004
Permanent Human Rights Commission of Zambia	Zambia	35th Ordinary Session 21 May to 4 June, 2004

Advocacy opportunities available at the African Commission for NHRIs include:

- Submitting a parallel report to the African Commission which includes information on violation of rights of persons with albinism – States Parties to the African Charter on Human and Peoples' Rights are required to submit a report to the African Commission every two years on legislative or other measures taken to give effect to the rights and freedoms contained in the African Charter and the Maputo Protocol. While there is no explicit requirement for States to ensure contribution from NGOs and NHRIs to the State report, NHRIs are not barred from seeking to make a contribution and including information on albinism. In addition, the State report is published on the African Commission website once received and the African Commission may invite institutions to submit information relating to the report.
- This provides an opportunity for NHRIs to raise concerns regarding albinism, particularly if such information is absent or insufficient in the State report. Furthermore, even without an invitation, NHRIs can submit a parallel report in which they document concerns related to albinism, and how they relate to State obligations under the African Charter and Maputo Protocol, as well as provide recommendations for State action. Such recommendations can echo the content of recommendations already made by the NHRI to the State, but not yet adopted by the State. The parallel report should be sent to the African Commission at least 60 days before the examination of the report.¹³¹

Recently Malawi submitted its report to the African Commission and included concerns related to albinism in the report.¹³² The Malawi Human Rights Commission also submitted a shadow report and included albinism in it.

¹³⁰ See www.achpr.org

¹³¹ Rules 73 and 74 of the Rules of Procedure of the African Commission on Human and Peoples' Rights

¹³² Available at: www.achpr.org (accessed 20 August 2020)

TOOL 13: EXAMPLES OF ISSUES TO RAISE PER ARTICLE OF THE AFRICAN CHARTER AND MAPUTO PROTOCOL

ARTICLE	ALBINISM RELATED CONCERN
AFRICAN CHARTER	
Article 1: Adoption of legislative and other measures to give effect to rights	Failure to recognise albinism/vulnerability to the sun & susceptibility to skin cancer as an impairment/disability in law and thus to provide legal basis for special measures for persons with albinism
Article 2: Non-discrimination	Stigma & discrimination against persons with albinism in society, access to health, education, work, housing, other relevant areas of life
Article 3: Equal protection of the law	Failure to adequately criminalise, investigate and prosecute offences against persons with albinism in a timely manner
Article 4: Right to life	Killings of persons with albinism & failure to take adequate measures to prevent deaths from skin cancer of persons with albinism
Article 5: Dignity and prohibition of torture	Failure to protect from and prosecute cases of persons forcibly cutting off body parts of persons with albinism, State complicity in killings and severing of limbs of persons with albinism, and State inability or unwillingness to prevent, investigate, prosecute or adequately sentence cases of attacks against persons with albinism
Article 6: Liberty and security of persons	Failure to take measures to protect from and prosecute cases of abduction, trafficking and severing of limbs and rape of persons with albinism
Article 9: Access to information	Failure to take measures to ensure information is in an accessible format for persons with albinism e.g. large text for educational pamphlets
Article 15: Work	Failure to put in place measures to ensure equal opportunity of work for persons with albinism, including reasonable accommodation requirements and affirmative action
International Convention for the Protection of All Persons from Enforced Disappearance of 2006 (ICPPED)	Abductions of persons with albinism involving State agents may amount to enforced disappearances. States Parties have a duty to investigate all disappearances, including those not carried out by State agents. Inability or unwillingness of State to investigate disappearances of persons with albinism may amount to acquiescence by the State, therefore rendering such disappearance an enforced disappearance

ARTICLE	ALBINISM RELATED CONCERN
AFRICAN CHARTER	
Article 16: Health	Failure to put in place measures to ensure equality and non-discrimination in access to healthcare, and ensure the highest attainable standard of health, including measures to minimise visual impairments and mitigate risk of cancer, as well as treatment for skin cancer for persons with albinism
Article 17: Education	Failure to put in place measures to ensure equal access to education for persons with albinism, including inclusive education and reasonable accommodation requirements
Article 18: Protection of the family and protection of women, children and those with disability	<p>Failure to take adequate measures to prevent separation of family due to albinism e.g. mothers and children with albinism being banished from home or abandoned, students being forced to live in boarding schools to minimise risks of attacks</p> <p>Failure to take adequate measures to prevent HP-AWRA, such as abandonment of children with albinism and/or their mothers, accusation of children with albinism and/or their mothers of witchcraft, rape of children with albinism and/or their mothers</p> <p>Failure to recognise persons with albinism as persons with disability deserving of special measures</p>
ARTICLE	ALBINISM RELATED CONCERN
MAPUTO PROTOCOL	
Article 2: Non-discrimination	Stigma & discrimination against women and girls with albinism in society, including HP-AWRA such as rape, abandonment and accusation of witchcraft
Article 3: Dignity	Rape, accusations of witchcraft, stigma, abandonment, exclusion from society of women and girls with albinism
Article 4: Life, integrity and security of person	Superstitions and beliefs, killings, abductions, trafficking, rape, severing of limbs of women and girls with albinism; as well as failure to put in place measures for rehabilitation of women and girls with albinism victim of trafficking and other forms of violence, to prevent unnecessary and foreseeable death from skin cancer of women and girls with albinism
Article 5: Harmful practices	HP-AWRA as a result of superstitions and beliefs related to women and girls with albinism and their mothers

ARTICLE	ALBINISM RELATED CONCERN
MAPUTO PROTOCOL	
Article 8: Access to justice	Ensuring appropriate access to justice and legal support to women and girls who are victim of HP-AWRA due to albinism
Article 12: Education	Equal access to education and training opportunities for women and girls with albinism and their mothers, stereotypes and discrimination in media and books against women and girls with albinism and/or their mothers, abuse in educational facilities including boarding schools for children with albinism
Article 13: Economic and Social Welfare	Special measures for women and girls with albinism and their mothers, particularly those who are victim of HP-AWRA and to prevent such harmful practices
Article 14: Health	Equality and non-discrimination in access to healthcare, and ensure the highest attainable standard of health, including measures to minimise visual impairments and mitigate risk of cancer, as well as treatment for skin cancer for persons with albinism, as well as access to information regarding genetics of albinism
Article 16: Housing	Appropriate housing with adequate facilities (e.g. walls and locked doors) to mitigate vulnerability to attack. Discrimination in renting
Article 16: Health	Failure to put in place measures to ensure equality and non-discrimination in access to healthcare, and ensure the highest attainable standard of health, including measures to minimise visual impairments and mitigate risk of cancer, as well as treatment for skin cancer for persons with albinism
Article 18: Positive cultural context	Superstition, beliefs and myths which perpetuate attacks
Article 23: Women with disability	Recognition of women with albinism as deserving of these rights
Article 24: Women in distress	Recognition of women with albinism as deserving of these rights
Article 25: Remedies	Ensuring appropriate remedies to women and girls with albinism and their mothers whose rights have been violated

*The Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa contains a number of articles which can also be used, as indicated in part 3 of this manual. However, it had not come into effect at the time of writing.

- **Carrying out advocacy activities during and on the margins of public sessions of the African Commission** – The African Commission generally holds two ordinary sessions every year, usually in April/May and October/November. It may also hold extraordinary sessions. The agenda includes deliberations, reports on activities of the African Commission, consideration of complaints and periodic reports. The consideration of reports, reports on the activities of the African Commission and some of the deliberations are held during the public sessions, as opposed to the consideration of complaints and other deliberations which are held in private. NHRIs can propose topics for inclusion in the agenda and attend the public sessions to listen to the deliberations, reports on activities of the Commission and the State reporting. This provides an opportunity for the NHRIs to obtain further information on the perspective of the situation of persons with albinism in their country and any undertaking by the State in this regard. Silence on the issue may be an indication of the need to increase awareness and advocacy with the State.

In addition to attending the public sessions, NHRIs with affiliate status can present written and oral statements during the discussion of the general situation of human rights. The oral statements tend to be 3 – 5 minutes long and can relate to any human rights situation. NHRIs can present statements on the situation of persons with albinism in their country or ensure that albinism is included in statements about the general human rights situation. Alternatively, NHRIs may elect to make a statement during the presentation of the reports by commissioners. It is important to note that

commissioners tend to have a thematic, as well as a country focus.¹³³ The oral statement in this regard can therefore either relate to the thematic or country focus. For example, if the Special Rapporteur on Rights of Women is also the country rapporteur for Mozambique, an oral statement made following her/his report can relate to an issue on Mozambique even if not specifically about women (e.g. raising concerns about education of persons with albinism in Mozambique) or to the thematic focus (e.g. concerns about women with albinism in one or more member States).

In addition, NHRIs can use the opportunity of the African Commission session to raise awareness of the rights of persons with albinism with NGOs, government officials and members of the African Commission through organising relevant formal and informal meetings, discussions, panels and other activities.

- **Advocating for the adoption of soft law relevant to albinism** – The African Commission has adopted general comments, guidelines, principles and declarations to elaborate on rights contained in the African Charter and its protocols. These documents help to provide a clearer picture of State responsibilities in relation to specific articles e.g. General Comment No. 3 which relates to Article 4 of the African Charter.¹³⁴ They can also provide clarity in respect of a specific issue, rather than an article. For example, the Guidelines on Combating Sexual Violence and Its Consequences in Africa provide clarity on the obligations of the State and specific measures that should be taken by them to combat such violence.¹³⁵

133 The list of Commissioners and their thematic, as well as country focus can be found at: www.achpr.org (accessed 06 August 2020)

134 General Comment No. 3 on the African Charter on Human and Peoples' Rights: The Right to Life (Article 4)

135 African Commission on Human and Peoples' Rights, Guidelines on Combating Sexual Violence and Its Consequences In Africa. Available at: www.achpr.org (accessed 06 August 2020)

- The African Commission has adopted the RAP¹³⁶ and a number of resolutions on albinism.¹³⁷ It has further developed the Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa, which specifically recognises albinism as being covered by it. However, this protocol has not yet come into effect. In addition, the African Commission has not yet developed its jurisprudence around albinism. NHRIs can work with persons with albinism, NGOs and others to advocate for adoption of the Protocol on the Rights of Persons with Disabilities in Africa, as well as advocate for and contribute to the drafting and adoption of guidelines in relation to albinism. These can then be used in enforcing the rights of persons with albinism at the national level. Advocacy for such documents should be carried out in-between and during the sessions of the African Commission.
- **Bringing a communication before the African Commission** – These are quasi-judicial decisions of the African Commission on violations of rights at the national level and calling on the particular State to carry out corrective measures. They are also sometimes referred to as complaints. NHRIs can work with associations of persons with albinism to bring a communication on the violations of rights of persons with albinism before the African Commission.¹³⁸ The process for submitting a communication and the communication procedure is explained in the African Commission's Rules of Procedure¹³⁹ and various manuals and documents developed

by NGOs.¹⁴⁰ Alternatively, NHRIs can submit amicus briefs or expert legal opinions in relation to specific Communications before the court relating to the rights of persons with albinism. Decisions of the African Commission can be used as source of law in national courts, as well as to advocate for relevant change with the authorities.

- **Submitting information to Commissioners for follow-up** – The African Commission does not have a special mechanism dedicated to albinism like the UN. However, there are other special mechanisms with relevant mandates that can receive cases related to the violation of the rights of persons with albinism. Depending on the particular violation, these include the Working Group on rights of older persons and people with disabilities; Special Rapporteur on Rights of Women; and the Working Group on Economic, Social and Cultural Rights. Country commissioners can also receive information on any human rights concerns in the country which they cover. The special mechanisms are mandated to publicly intervene where violations of rights are brought to their attention. They can also analyse national legislation, policies and practice within States to ensure compliance with human rights. They can do this through raising concern with the government in writing, in person or through public statements. They may also work with the Commission in passing a country resolution raising concern on the specific issue.

136 See 373 Resolution on the Regional Action Plan on Albinism in Africa (2017-2021) - ACHPR/Res.373(LX)2017;

137 See for example, 349 Resolution on the Attacks on Persons with Albinism in Malawi - ACHPR/Res.349(EXT.OS/XX)2016; and 263 Resolution on the prevention of attacks and discrimination against persons with albinism - ACHPR/Res.263(LIV)2013

138 Filing a Communication Before the African Commission on Human and Peoples' Rights: A Complainant's Manual, [redress.org](https://www.redress.org); Litigating Before the African Commission on Human and Peoples' Rights: A Practice Manual, www.equalitynow.org

139 Rules of Procedure of the African Commission on Human and Peoples' Rights. Approved by the African Commission on Human and Peoples' Rights during its 47th ordinary session held in Banjul (The Gambia) from May 12 to 26, 2010

140 See for example: Filing a Communication Before the African Commission on Human and Peoples' Rights: A Complainant's Manual, [redress.org](https://www.redress.org); Litigating Before the African Commission on Human and Peoples' Rights: A Practice Manual, www.equalitynow.org (accessed 05 August 2020)

Examples of responses by the African Commission on albinism concerns in a country setting

In May 2014, the chairperson of the Working Group on the Rights of Older Persons and People with Disabilities in Africa put out a public statement condemning the murder of Munghu Lugata, a 40-year-old woman with albinism in north-western Tanzania. The chairperson further recognised the efforts of the government of Tanzania to fight such violations, but called on the “authorities to assume full responsibility, and to duly investigate and bring perpetrators of these gross human rights violations to justice; in accordance with its regional and international human rights obligations.”¹⁴¹

In 2016, the African Commission also passed a resolution in relation to attacks against persons with albinism in Malawi condemning the systematic attacks and calling on Malawi to “urgently take all necessary measures to ensure the effective protection of persons with albinism and members of their families;... ensure accountability by duly investigating and bringing perpetrators ... to justice, and by ensuring that victims and members of their families have access to appropriate remedies”; as well as “take effective measures to eliminate all forms of violence and discrimination against persons with albinism, and to increase education and public awareness-raising activities.”¹⁴²

6.4.4.2 African Committee of Experts on the Rights of the Child

The ACERWC is an important advocacy target for the protection of the rights of children with albinism. There are a number of toolkits available for better understanding of working with this body.¹⁴³ Specifically in relation to protection of children with albinism, NHRIs can carry out the following advocacy activities:

- **Contributing to State reports** – The ACERWC receives and examines reports from States Parties regarding measures taken, and progress made towards implementing the provisions of the African Charter on the Rights of the Child. This includes in respect of ensuring the right of children to equality and non-discrimination,¹⁴⁴ to have their best interest as the primary consideration in all actions concerning them,¹⁴⁵ survival and development,¹⁴⁶ education,¹⁴⁷

141 Statement by the Chairperson of the Working Group on the Rights of Older Persons and People with Disabilities in Africa on the murder of Munghu Lugata, a 40-year-old woman with albinism in north-western Tanzania on 12 May 2014. Done in Banjul, 26 May 2014. Available at: www.achpr.org (Accessed 13 August 2020)

142 349 Resolution on the Attacks on Persons with Albinism in Malawi – ACHPR/Res.349(EXT.OS/XX)2016. Available at: www.achpr.org (accessed 13 August 2020)

143 See for example, ACPF & ACERWC (2015). Training Toolkit on the African Charter on the Rights and Welfare of the Child. Addis Ababa. The African Child Policy Forum (ACPF) & The African Committee of Experts on the Rights and Welfare of the Child (ACERWC), 2015, available at: www.socialserviceworkforce.org (accessed 05 August 2020)

144 Article 3 of the African Charter on the Rights of the Child

145 Article 4 Ibid

146 Article 5 Ibid

147 Article 11 Ibid

special measures of protection for children with disabilities,¹⁴⁸ health,¹⁴⁹ protection against child abuse and torture,¹⁵⁰ parental care and protection,¹⁵¹ protection against harmful social and cultural practices,¹⁵² and not to be sold, trafficked or abducted.¹⁵³ States are required to submit their reports every three years following the submission of their initial report. Unlike with the African Commission, the ACERWC specifically requires States to ensure the process of drafting the State report is consultative and inclusive of children, NGOs and other relevant stakeholders. NHRIs should therefore seek to contribute to State reports.

- **Submitting parallel reports** - In addition to contributing to the State report, NHRIs can submit parallel reports.¹⁵⁴ The ACERWC has produced guidelines on parallel reports and participation in pre-sessions of the report review to assist those engaging with the process such as NHRIs.¹⁵⁵ The ACERWC can share the State report with NHRIs and if this is not done, NHRIs should consider requesting State reports from the ACERWC for reference when developing their parallel reports. The ACERWC also informs entities that state reports will be considered, enabling them to engage with the process. In the parallel report, NHRIs can provide additional information not included in the State report, as well as include country-specific recommendations for the protection of the rights of children with albinism. As with the State report, such parallel reports should involve the meaningful participation of children, particularly children with albinism.

- **Requesting a private meeting with the ACERWC during the pre-session of the State report** - Prior to the review of the State report, the ACERWC holds a pre-session to enable it to conduct a preliminary review of the report, examine complimentary information, identify areas of concern and develop questions for the State party. Even though NHRIs are not included in the guidelines as entities which can participate in pre-sessions, they can also request private meetings with the ACERWC during the pre-sessions. Such requests need to be made three months before the pre-session.¹⁵⁶ This provides an opportunity for the NHRIs to raise specific concerns, including apparent mistakes or omissions in the State report, as well as advocate for the inclusion of certain recommendations in the concluding observations of the ACERWC.

- **Bringing a communication before the ACERWC regarding the violation of the rights of children with albinism** – As with the African Commission, the ACERWC is empowered to receive complaints against States Parties to the African Charter on the Rights and Welfare of the Child and make quasi-judicial decisions regarding violations of the rights contained in the African Charter on the Rights of the Child. While not specifically mentioned as entities that can bring such complaints, NHRIs should be able to submit complaints to the ACERWC in respect of the violations of the rights of children with albinism. A case of a child or a number of children which is emblematic of a systemic violation of rights can be brought before the ACERWC with the view of ensuring the State takes measures to protect that right. Alternatively, NHRIs can submit legal opinions or amicus briefs in relevant complaints related to the rights of children with albinism.

148 Article 13 Ibid

149 Article 14 Ibid

150 Article 16 Ibid

151 Article 19 Ibid

152 Article 21 Ibid

153 Article 29 Ibid

154 In General Comment 5 on “State Party Obligations Under the African Charter on the Rights and Welfare of the Child (Article 1) and Systems Strengthening for Child Protection” (ACERWC GC 5), the ACERWC recognised the role of NHRIs in contributing to such reports and submitting complimentary reports.

155 See ACERWC Guidelines on the Complementary Report, the Conduct of and Participation in Pre-sessions. (2015) available at www.acerwc.org

156 ACERWC GC 5, 6.9 Independent monitoring, pg. 51, see footnote 32

- **Carrying out advocacy activities during and on the margins of the public session of the ACERWC** – Like the African Commission, the ACERWC holds regular meetings to discuss issues related to its mandate and carry out activities such as review of reports and deliberation on communications. The ordinary sessions take place in March or April, and October or November every year. It can also hold extraordinary sessions. Public sessions of the ordinary sessions are open to the general public. The ACERWC has included engagement with NHRIs in its agenda in the past, e.g. during its 35th Session the ACERWC held a discussion on sexual exploitation of children and an engagement with NHRIs from Burkina Faso, DRC, Mali, Niger, Nigeria, Sudan, and South Sudan. NHRIs from SADC can request similar engagement meetings focusing on children with albinism.

- **Letters to the ACERWC in respect of a specific situation of violation of the rights of children with albinism and request for action** – NHRIs can write to the ACERWC to bring to its attention situation of concern regarding the rights of children with albinism and request them to take action. For example, in 2014, at the request of the NGO, Under the Same Sun, the ACERWC undertook an investigative mission on the situation of children with albinism in Tanzania.¹⁵⁷ NHRIs can advocate for such investigations requesting the ACERWC to request a mission from the State and the State to accept such a mission. The ACERWC will also seek to meet with the NHRI during such investigation providing the NHRI an opportunity to provide relevant information.

- **Advocating for and participating in the development of principles and guidelines by the ACERWC in relation to the rights of children with albinism** – The ACERWC has the power to develop soft law through the interpretation of the provisions of the African Charter on the Rights of the Child, as well as adoption of general comments which provide further clarity on the provisions of the charter or application of the charter to specific themes. To date, the ACERWC has developed general comments on ending child marriage, the responsibilities of the child, children of imprisoned parents, birth registration, name and nationality, and prevention of statelessness.¹⁵⁸ Together with persons with albinism and NGOs, NHRIs can advocate for and contribute to development of similar jurisprudence on the duties of States, including measures to be taken by them to protect the rights of children with albinism.

¹⁵⁷ Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania, (ACERWC) African Committee of Experts on the Rights and Welfare of the Child, March 2016, www.acerwc.africa (accessed 05 August 2020)

¹⁵⁸ www.acerwc.africa (accessed 05 August 2020)

6.4.4.3 Pan African Parliament

The Pan African Parliament (PAP) was set up by the African Union (AU) as a “platform for people from all African states to be involved in discussions and decision-making on the problems and challenges facing the continent.”¹⁵⁹ It currently does not have law-making functions, but can issue resolutions and recommendations on important development and social issues in Africa. These resolutions and guidelines, although non-binding on member States, have an impact on AU policy due to the advisory role of the PAP.

In 2018, the PAP adopted a resolution on persons with albinism in Africa,¹⁶⁰ acknowledging the importance of this issue and indicating its willingness to engage on concerns related to the rights of persons with albinism. Broadly speaking, advocacy opportunities for NHRIs with PAP include:

- Advocacy around the PAP proceedings and public hearings – The proceedings of the PAP are supposed to be open to the public.¹⁶¹ NHRIs can therefore attend. PAP also holds public hearings/ public participation forums on issues of importance. NHRIs can participate in both. While they may not be able to contribute during the PAP proceedings, they can also use such forums, when they occur, to carry out advocacy around the margins of the meeting. They can also use the opportunity to meet formally or informally with members of the PAP to raise relevant concerns. In addition, they can raise issues relevant to albinism during the public hearings/public participation forums. This includes inputting into relevant model laws
- Petition PAP – individuals or groups of individuals can petition the PAP on issues relevant to the activities of PAP which impact on them directly. NHRIs can work with persons with albinism to bring a petition before PAP.¹⁶²
- Lobbying for a motions or model laws – NHRIs can carry out advocacy for the adoption of relevant motions, guidelines or model laws. For example, the UN Independent Expert on albinism is currently working with the PAP to develop guidelines on harmful practices related to accusation of witchcraft and ritual attacks.

Relevant advocacy targets for the PAP include the women’s, Southern Africa and East Africa caucuses, as well as the Committee on Justice and Human Rights, Committee on Health, Labour and Social Affairs, Committee on Education, Culture, Tourism and Human Resources, and the Committee on Gender, Family, Youth and People with Disabilities.

The Centre for Human Rights at the University of Pretoria, has developed a toolkit to assist CSOs seeking to engage with the PAP. It is also relevant for NHRIs.¹⁶³

159 Information from the parliament’s website: www.panafricanparliament.org

160 Pan African Parliament adopts a Resolution on Persons with Albinism in Africa (PAP.4/PLN/RES/05/MAY.18), www.chr.up.ac.za

161 Rule 35 of the PAP Rules of Procedure

162 Rule 72 of the PAP rules of procedure

163 Toolkit for Civil Society Advocacy In The Pan-African Parliament, Centre for Human Rights, University of Pretoria, 2020, www.chr.up.ac.za

6.4.5 UN Level

The OHCHR encourages the participation of NHRI in the promotion and protection of human rights at the UN level. There are a number of opportunities available for NHRIs to raise national concerns related to albinism at the UN. These include through the treaty bodies, the UPR, Human Rights Council and special procedures.

6.4.5.1 UN Treaty bodies

Just like with the African Commission and ACERWC, NHRIs can contribute to the review of State reports to UN treaty bodies. This includes:

- contributing to the State report;
- providing written submissions to the list of issues;¹⁶⁴
- submitting alternative reports prior to the examination of State party reports;
- meeting with Committee members to discuss concerns related to albinism and suggest recommendations for the concluding observations;
- attending the interactive dialogues between the Committees and States Parties examined;
- delivering oral statements during the interactive dialogues in relation to the CRPD and CERD; and
- submitting written contributions to the follow-up to the concluding observations issued by the Committees.

In relation to albinism, the most relevant treaty bodies are the Committee on the Rights of Persons with Disabilities, Committee of Economic, Social and Cultural Rights (CESCR), Committee on the Elimination of Discrimination against Women, the Committee on the Rights of the Child, Committee on Elimination of Racial Discrimination (CERD), the Human Rights Committee, and Committee against Torture in cases where attacks meet the criteria for torture. A number of documents to assist stakeholders, including the NHRIs, in engaging with reporting to the treaty bodies have been produced by the OHCHR,¹⁶⁵ and there is also other available material for those seeking to better understand the process.¹⁶⁶

¹⁶⁴ The list of issues is a list of issues and questions which is sent to the State party in advance of the session where their report will be reviewed through a constructive dialogue

¹⁶⁵ See www.ohchr.org (accessed 07 August 2020)

¹⁶⁶ Information Note: National Human Rights Institutions (NHRIs) interaction with the UN Treaty Body System, OHCHR National Institutions and Regional Mechanisms Section, 5 April 2011; GANHRI background paper - NHRIs and the UN treaty bodies - May 2016; and Amrei Müller and Frauke Seidensticker, Handbook: The Role of National Human Rights Institutions in the United Nations Treaty Body Process, German Institute for Human Rights, December 2007. All available at: nhri.ohchr.org (accessed 07 August 2020)

TOOL 14: ISSUES ON ALBINISM TO BE RAISED BEFORE DIFFERENT UN TREATY BODIES

TREATY BODY	ALBINISM CONCERNS TO BE RAISED
CERD	<ul style="list-style-type: none"> ■ Recognition of discrimination against persons with albinism as discrimination on the basis of colour and therefore falling within the framework of ICERD. ■ Lack of adequate investigations, prosecutions and appropriate sentencing in respect of attacks against persons with albinism (Article 2, 5(a) and (b)) ■ Failure to take measures to combat superstitions and other wrong beliefs which lead to attacks (Article 2, 4(a)) ■ Inadequate measures to prevent discrimination on the basis of colour in relation to work, housing health, education, participation in cultural activities, access to public areas manifested through stigma and HP-AWRA (Article 2, 5(e))
Human Rights Committee	<ul style="list-style-type: none"> ■ Stigma and discrimination against persons with albinism in society, access to health, education, work, housing, other relevant areas of life (Article 2, 3) ■ HP-AWRA against women with albinism or mothers of children with albinism (Article 3) ■ Killings, cutting off body parts, rape, abductions, trafficking of persons with albinism and failure to take adequate measures to prevent such deaths, protect persons with albinism and ensure adequate remedies (Article 6, 9, 16, 23, 24, 26) ■ Failure to take adequate measures to prevent deaths from skin cancer of persons with albinism (Article 6) ■ State complicity in killings and cutting of limbs of persons with albinism, unwillingness or inability to adequately prevent and respond to such acts. (Article 7)
CESCR	<ul style="list-style-type: none"> ■ Resource mobilisation for measures for persons with albinism, including social protection measures (Article 2, 9, 10) ■ Failure to put in place measures to ensure equal opportunity of work for persons with albinism, including reasonable accommodation requirements and affirmative action (Article 2, 3, 6, 7, 11) ■ Failure to put in place measures to ensure equality and non-discrimination in access to healthcare, and ensure the highest attainable standard of health, including measures to minimise visual impairments and mitigate risk of cancer, as well as treatment for skin cancer for persons with albinism. (Article 2, 3, 12) ■ Failure to put in place measures to ensure equal access to education for persons with albinism, including inclusive education and reasonable accommodation requirements (Article 2, 3, 13, 14) ■ Stigma and discrimination in respect of housing, particularly rentals (Article 2, 3, 11)

TREATY BODY**ALBINISM CONCERNS TO BE RAISED****Committee on the Elimination of Discrimination against Women**

- Stigma & discrimination against women and girls with albinism in society, including HP-AWRA such as rape, abandonment and accusation of witchcraft (Article 2, 3, 5)
- Trafficking of women with albinism (Article 6)
- Lack of appropriate measures to equal access to education and eliminate intersectional discrimination in education against women and girls with albinism, as well as training for mothers of children with albinism (Article 2, 3, 5, 10, 14(d), 16(e))
- Lack of appropriate measures to ensure equal opportunities of employment and eliminate intersectional discrimination against women with albinism and mothers of children with albinism in employment (Article 2, 3, 5, 11, 13)
- Intersectional discrimination and stigma in health services and failure to put in place measures to ensure access to health on an equal footing with others for women and girls with albinism and mothers of children with albinism, including information to help ensure health and well-being of family such as prevention of skin cancer (Article 2, 3, 5, 10(h), 12, 14(b))
- Lack of adequate measures, such as awareness raising to prevent and redress exclusion from society of women and girls with albinism, and mothers of children with albinism due to superstition and wrong belief (Article 2, 3, 5, 13(d))
- Ensuring appropriate access to justice and legal support to women and girls who are victim of HP-AWRA due to albinism and taking measures to prevent intersectional discrimination in this regard (Article 2, 3, 5, 15(1))

Committee against Torture

- Recognition of complicity of State agents in attacks against persons with albinism may amount to cruel, inhuman, or degrading treatment, or torture
- Recognition that inability or unwillingness of State to adequately investigate attacks against persons with albinism may constitute acquiescence by the State rendering the attacks torture within the definition of the Convention
- Failure of State to take steps to prevent, investigate, prosecute and ensure adequate redress for such attacks (Articles 2, 4, 12, 13, 14, 16)
- Duty of State to cooperate in criminal proceedings related to attacks against persons with albinism (Article 9)
- Duty not to expel, return or extradite a person with albinism back to a country where there are substantial grounds for believing they would be in danger of being killed or having their limb cut off (Article 3)

TREATY BODY

ALBINISM CONCERNS TO BE RAISED

Committee on the Rights of the Child

- Stigma and discrimination against children with albinism resulting in HP-AWRA and violations of their rights (Article 2, 3, 6, 9, 16, 19, 20, 32, 34, 35, 36, 37, 39)
- Lack of measures to ensure access to education and health on equal footing with others (Article 2, 3, 4, 6, 17, 24, 27, 28, 29)
- Failure to put in place special measures for the protection of children with albinism (Article 2, 3, 19, 23, 26, 39)

Committee on the Rights of Persons with Disabilities

- Recognition of persons with albinism as groups with an impairment that requires the removal of barriers to the full enjoyment of their rights, in line with the CRPD (Article 2)
- Failure to take adequate measures to protect the right to life, liberty, security, freedom from torture, integrity, education, health, work, adequate standard of living of persons with albinism and ensure enjoyment of all these rights on an equal footing with others (Article 4, 10, 14, 15, 17, 24, 25, 27, 28, 29)
- Failure to ensure adequate statistics and data in relation to persons with albinism to ensure protection of their rights (Article 31)

Example of CESCR recommendations to South Africa¹⁶⁷

Persons with albinism

23. The Committee is concerned that persons with albinism continue to be subjected to attacks and face discrimination in enjoying their rights under the Covenant, including the right to work and the right to education. It is also concerned about the lack of a comprehensive legal and policy approach to the situation of persons with albinism (art. 2 (2)).

24. The Committee recommends that the State party intensify its efforts to eliminate discrimination and violence against persons with albinism, including by strengthening the legal framework, raising public awareness and engaging with traditional leaders and healers in a coordinated and coherent manner, as well as by facilitating the access of persons with albinism to work and education by providing them with the necessary support and assistance.

¹⁶⁷ Committee on Economic, Social and Cultural Rights, Concluding observations on the initial report of South Africa, E/C.12/ZAF/CO/1, 29 November 2018, available at: tbinternet.ohchr.org (accessed 20 August 2020)

6.4.5.2 UPR

The UPR is similar to the State reporting under the treaty bodies, but consists of the review of State reports by other States. As with the treaty bodies, NHRIs can seek to contribute to the State report and may also submit a parallel report to the UPR outlining concerns related to persons with albinism in the country. The UPR relates to all treaties ratified by the State and parallel reports do not have to follow the articles of any particular treaty, but must specify the human rights concerns. NHRIs can suggest recommendations in relation to albinism for recommending States. Such recommendations can echo those in the NHRI national report to the State. They can also carry out in-country lobbying of embassies within their countries to raise awareness of the concerns and advocate for the inclusion of questions and recommendations related to albinism by these embassies during the review of the State report.

As embassies (or permanent missions) in Geneva are usually the ones carrying out the reviews, some organisations prefer to carry out advocacy in Geneva. The organisation UPR-Info¹⁶⁸ carries out a pre-session prior to the review of a country report to enable organisations and NHRIs to address representatives of diplomatic entities in Geneva regarding their concerns and lobby for the inclusion of recommendations during the review. Attendance of the UPR pre-session also provides an opportunity for NHRIs to organise meetings with diplomatic entities outside of the formal UPR pre-sessions.

While NHRIs and NGOs cannot make any statements during the actual review, accredited¹⁶⁹ NHRIs can attend and observe the dialogue. A report is then written within 48 hours summarizing the list of questions and recommendations, as well as those accepted and noted by the State. This report, known as the outcome of the State's review, is publicly adopted at the following Human Rights Council session, usually about four months following the review. Accredited NHRIs can submit a written statement regarding the UPR review and attend the session of the Human Rights Council when the outcome of the State's reviews is considered, as well as make an oral statement.¹⁷⁰ Following the adoption of the outcome, NHRIs play an important role in following-up the UPR review by publishing and disseminating the outcomes, carrying out national advocacy for the implementation of the recommendations, and monitoring and reporting on the implementation of the recommendations.¹⁷¹

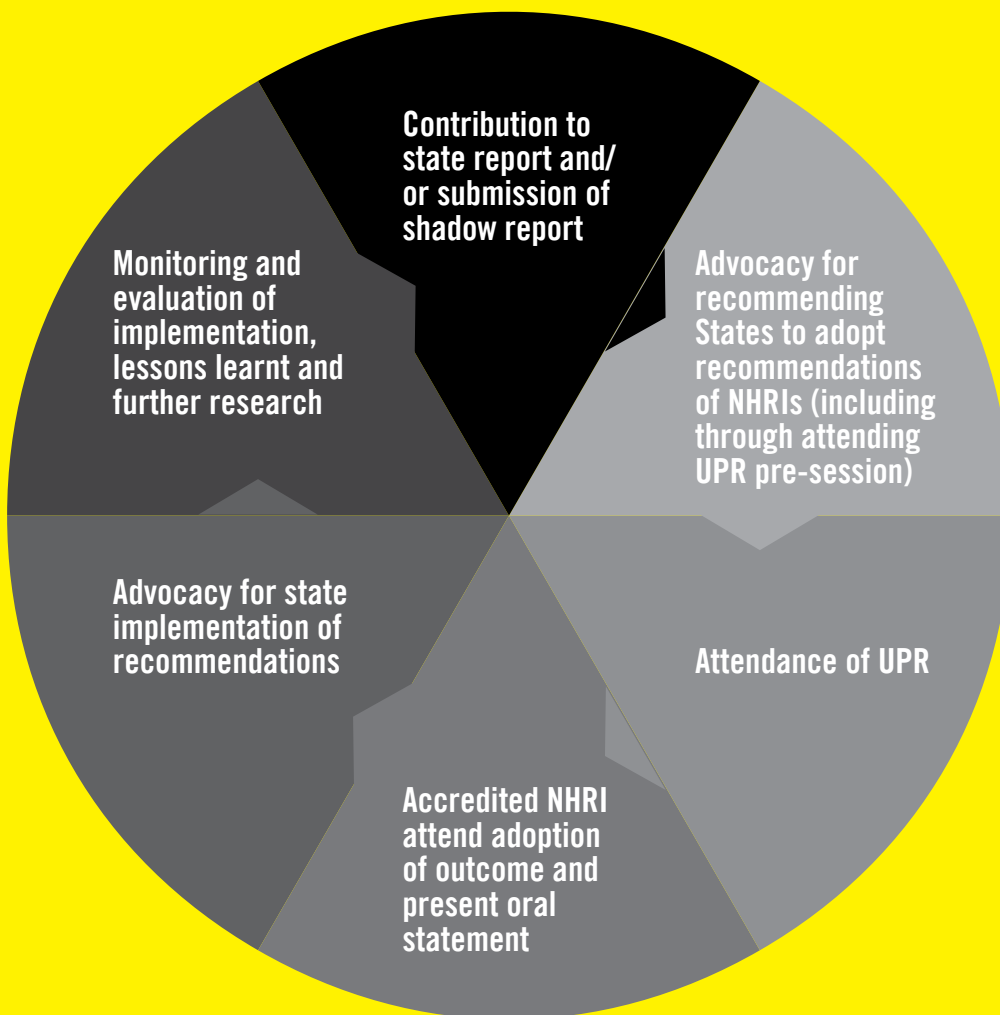
168 www.upr-info.org

169 For information on accreditation for the UPR session see: www.ohchr.org (accessed 07 August 2020)

170 For guidance on submitting UPR parallel reports see: www.ohchr.org (Accessed 07 August 2020)

171 For further information on engaging with the UPR process see: The Universal Periodic Reporting Process: A Guide for National Human Rights Institutions, Northern Ireland Human Rights Commission and Commonwealth Forum of National Human Rights Institutions, September 2016, www.upr-info.org, as well as www.ohchr.org, National Human Rights Institutions and the Universal Periodic Review: nhri.ohchr.org

CYCLE OF NHRI ACTIVITIES IN RELATION TO UPR



6.4.5.3 Advocacy during the Human Rights Council sessions

In addition to submitting written and oral statements during the review of the outcome of UPR reports, accredited NHRIs can deliver statements during the presentation of reports of the various special procedures. The most relevant reports in relation to albinism are those of the Independent Expert on albinism, as well as the Special Rapporteur on disability. The report of both usually takes place during the March session and tend to follow each other. Statements on albinism therefore are mainly made under the report of the Independent Expert on albinism. NHRIs can further raise various issues under the reports of other special procedures, such as the special rapporteur on health in relation to health of persons with albinism, or the special rapporteur on trafficking in relation to trafficking of persons with albinism.

Example of country specific oral statement made following the report of the Independent Expert on albinism¹⁷²

Oral statement to the UN Human Rights Council, 34th Session

Agenda Item 3: General Debate on the Report of the UN Independent Expert on the enjoyment of Human rights by persons with albinism

03 March 2017

Mr. President,

The International Bar Association's Human Rights Institute (IBAHRI), the Southern Africa Litigation Centre (SALC) and the Malawi Centre for Human Rights Education, Advice and Assistance (CHREAA) welcome the reports of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. We oppose discrimination of any kind and support this mandate.

The organisations welcome steps taken by countries to increase the protection for persons with albinism as highlighted in the reports. However, we agree with the Independent Expert that more has to be done to increase such protection, including addressing legal gaps which allow perpetrators of attacks against persons with albinism to go unpunished.

We further caution states to ensure, that in seeking to protect the rights of persons with albinism, policies and practices are not implemented which inadvertently further violate their rights. A case in point is the judgement by a court in Malawi which sentenced a man with albinism to a penalty ten times higher than usual for being drunk. The justification for this increased penalty was that given the risks persons with albinism face, the court expected him to be more cautious. The review court reduced the sentence, but reinforced the discriminatory position. Such judgements further victimises persons with albinism and violate their right to dignity, fair trial and equality. We remind the authorities that it is primarily the responsibility of the state to protect, promote and fulfil the rights of all persons without discrimination.

The organisations offer our technical support to the mandate of the Independent Expert and to States in ensuring increased protection of the rights of persons with albinism. To this end, the International Bar Association has set up a taskforce on albinism to carry out relevant legal research into albinism.

Lastly the organisations would like to highlight the recent killing of a woman with albinism, Mercy Banda, in Malawi. We urge all states to assist countries like Malawi in their initiatives to protect persons with albinism.

We thank you for your consideration.

172 Available at www.ibanet.org (accessed 8 August 2020)

Example of oral statement on albinism during the presentation of the report of another mandate¹⁷³

United Nations Human Rights Council
35th Regular Session 06 June to 23 June 2017
Agenda Item 9

INTERACTIVE DIALOGUE WITH THE SPECIAL RAPPORTEUR ON CONTEMPORARY FORMS OF RACISM, RACIAL DISCRIMINATION, XENOPHOBIA AND RELATED INTOLERANCE

Oral statement of the International Bar Association's Human Rights Institute
19 June 2017

The International Bar Association's Human Rights Institute (IBAHRI) welcomes the reports of the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance.

...

As an organisation, we believe that all forms of discrimination and intolerance are unacceptable. In a recent report entitled, "Waiting to Disappear", the IBAHRI highlights the multiple and intersecting forms of discrimination experienced by persons with albinism, including based on their race, colour and gender.

In this regard, we note the related report of the High Commissioner for Human Rights on the impact of multiple and intersecting forms of discrimination and violence in the context of racism, racial discrimination, xenophobia and related intolerance on the rights of women and girls. Women with albinism and mothers of children with albinism in particular are victims of discrimination, stigmatisation and ostracism, which deepen their poverty and expose them to sexual violence.

The IBAHRI calls on all states to ensure that due regard is given to persons with albinism when developing policies and programmes to combat racism, xenophobia and related intolerances.

Thank you, Mr President.

173 Available at: www.ibanet.org (accessed 08 August 2020)

NHRIs can also take the opportunity of the Human Rights Council session to organise, support and participate in side events on albinism. For example, in 2017, Amnesty International organised a side event on the situation of persons with albinism in Malawi on the margins of the 34th session of the Human Rights Council. Among the panellist was the Malawi permanent mission to Geneva. Human Rights Council sessions also provide an opportunity for meetings with procedures to raise issues of concern and advocate for appropriate intervention by them.

6.4.5.4 Engagement with special procedures

In addition to making oral statements during the Human Rights Council session, NHRIs can advocate their States to extend an invitation to the Independent Expert on albinism to carry out a country visit. They can further provide information to the Independent Expert prior to the visit and meet with the Independent Expert during the official visits. In the SADC region, the Independent Expert has visited Malawi, Mozambique, South Africa and Tanzania.¹⁷⁴ All NHRIs from these countries engaged with the Independent Expert during the official visit. NHRIs play an important role in following up implementation of recommendations made by the Independent Expert in the country reports with the authorities.

Outside of official visits, NHRIs can bring cases of concern to the attention of the Independent Expert on albinism in writing throughout the year. These can include information on a case of attack against a person with albinism as soon as possible after it occurs, or issues of systemic violations of the rights of persons with albinism. The Independent Expert may choose to respond with a press release or public statement, or by writing to the authorities expressing concern and asking for remedial action to be taken. Such letters by special procedures to governments are later published¹⁷⁵ and can be used for national advocacy. NHRIs should include all special procedures with overlapping mandates on such letters.

¹⁷⁴ All the reports are available at: www.ohchr.org (accessed 20 August 2020)

¹⁷⁵ They can be found in the Communications database at: spcommreports.ohchr.org (accessed 07 August 2020)

CASE STUDY 13

Rape of a girl with albinism

Maria, a 17-year-old girl with albinism disappears from her home. A friend informs the family that she had seen Maria with a strange woman and that Maria had said she was going with the woman for work. Maria is found two days later in the home of a business man 30Km away. Maria reports that she was being held against her will and that the man had forced himself upon her. Maria's parents reach an agreement with the business man to pay damages for their daughter and he agrees to marry her as his second wife.

A communication to special procedures in relation to the above case can be addressed to:

- the Independent Expert on albinism - due to her albinism,
- Special Rapporteur on disability - albinism falls under disability,
- Special Rapporteur on health - rape relates to sexual health,
- Special Rapporteur on racism – she was more likely targeted on the basis of her colour,
- Special Rapporteur on torture – if this is part of a wider pattern of rape against women with albinism which is not addressed,
- Special Rapporteur on trafficking – she was taken from her home to another place through deception for the purposes of exploitation,
- Special Rapporteur on violence against women – rape is violence against women,
- and potentially, the Working Group on women and girls – where local laws permit marriage in case of rape and thereby absolve perpetrator from prosecution.

Some special procedures also produce open letters or comments on country specific legislation and policy, which are published on their webpage.¹⁷⁶ To date the Independent Expert on albinism has not done this, but it is conceivable where legislative or policy concerns are brought to her attention. NHRIs can also submit such concerns to other special procedures where issues overlap e.g. concern about a proposed bill impacting on health of persons with albinism to the Special Rapporteur on health, Special Rapporteur on disability, as well as the Independent Expert on albinism.

During the run-up to elections in Malawi, the Independent Expert on the enjoyment of human rights by persons with albinism; the Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression; the Special Rapporteur on the rights to freedom of peaceful assembly and of association; and the Special Rapporteur on the situation of human rights defenders sent a joint communication to Malawi raising concerns about attacks against human rights defenders. In the communication they took the opportunity to raise concerns regarding attacks of persons with albinism during election time and request information on measures taken to protect them.¹⁷⁷ The government of Malawi responded setting out the measures taken.¹⁷⁸

176 See for example comments on legislation and policy by the Special Rapporteur on independence of judges and lawyers: <https://www.ohchr.org/EN/Issues/Judiciary/Pages/Legislation.aspx> and Statements and open letters by the Special Rapporteur on health, www.ohchr.org (accessed 07 August 2020)

177 Mandates of the Independent Expert on the enjoyment of human rights by persons with albinism; the Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression; the Special Rapporteur on the rights to freedom of peaceful assembly and of association and the Special Rapporteur on the situation of human rights defenders, 17 July 2019, REFERENCE: UA MWI 3/2019. Available at: spcommreports.ohchr.org (accessed 13 August 2020)

178 The government's response is available at: spcommreports.ohchr.org (accessed 13 August 2020)

Example of communication sent to Zambia by various special procedures in relation to an attack of a person with albinism¹⁷⁹

PALAIS DES NATIONS • 1211 GENEVA 10, SWITZERLAND

Mandates of the Independent Expert on the enjoyment of human rights by persons with albinism; the Special Rapporteur on the rights of persons with disabilities; the Special Rapporteur on extrajudicial, summary or arbitrary executions; and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment

REFERENCE:
AL ZMB 2/2020

21 May 2020

Excellency,

We have the honour to address you in our capacities as Independent Expert on the enjoyment of human rights by persons with albinism; Special Rapporteur on the rights of persons with disabilities; Special Rapporteur on extrajudicial, summary or arbitrary executions; and Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, pursuant to Human Rights Council resolutions 37/5, 35/6, 35/15 and 34/19.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received **concerning the killing and dismemberment of Mr. Emmanuel Phiri, a person with albinism in the Chipata district, and the desecration of a grave to steal the body parts of a deceased person with albinism in the Kaoma district.**

According to the information received:

On 24 March 2020, the dismembered body of Mr. Emmanuel Phiri, 43 years old, was found near Yamene Farms in a field near Lundazi Road in Chipata district, in eastern Zambia, close to the border with Malawi. The body was missing the eyes, tongue and both hands. The body was found by a local person in the area and could not be immediately identified. Efforts were made through announcements in

¹⁷⁹ Full communication available at: spcommreports.ohchr.org

Excerpt of response from government of Malawi to joint special mechanisms regarding measures to protect persons with albinism during elections¹⁸⁰

2.5 Please provide information about measures taken-specifically in the lead-up to elections-to ensure the security and safety of all persons living in Malawi, including persons with albinism?

2.5.1 A number of measures were put in place by the Government of Malawi to deal with attacks against persons with albinism prior to May, 21 general elections. The following are some of the initiatives that were undertaken to ensure the safety of persons with albinism:

- (a) In order to improve prosecution competence, the Director of Public Prosecutions (DPP) directed that all case dockets from Police Prosecutors be submitted to her office for purposes of perusal, directions and prosecutions by her officers; which has significantly improved the quality of prosecutions in these cases;
- (b) In order to clear a backlog of these cases, especially those relating to more serious criminal charges like murder, the Government through Ministries of Justice, and Gender as well as the Judiciary have made a commitment to prioritize prosecution of all serious

¹⁸⁰ Full text available at: spcommreports.ohchr.org

6.5 FURTHER READING

- Office of the United Nations High Commissioner for Human Rights (OHCHR), National Human Rights Institutions: History, Principles, Roles and Responsibilities, Professional Training Series No. 4 (Rev1), United Nations, New York and Geneva, 2010.
- Asia Pacific Forum (APF), A Manual on National Human Rights Institutions, May 2015 (updated May 2018).¹⁸¹
- Office of the United Nations High Commissioner for Human Rights (OHCHR), Economic, Social and Cultural Rights: Handbook for National Human Rights Institutions, Professional Training Series No. 12, United Nations, New York and Geneva, 2005

For information specifically on SADC:

- Lisa Gürth, Merran Hulse, Helena Kavsek, Verena Stauber, Daniel Wegner and Jan Weinreich, Civil Society Engagement in Regional Governance: A Network Analysis in Southern Africa, German Development Institute, Discussion Paper, 30/2018.¹⁸²
- Theresa Reinold, Civil society participation in regional integration in Africa: A comparative analysis of ECOWAS, SADC, and the EAC, April 2019, South African Journal of International Affairs.¹⁸³

For information on working with the African Commission:

- Filing a Communication Before the African Commission on Human and Peoples' Rights: A Complainant's Manual, 2013.¹⁸⁴
- Litigating Before the African Commission on Human and Peoples' Rights: A Practice Manual, Equality Now, September 17, 2018¹⁸⁵
- A Guide to the African human rights system: Celebrating 30 years since the entry into force of the African Charter on Human and Peoples' Rights 1986 – 2017, Edited by Centre for Human Rights, Faculty of Law, University of Pretoria, Pretoria University Law Press (PULP), 2017.¹⁸⁶

For information on engaging with the African Committee of Experts:

- Training Toolkit on the African Charter on the Rights and Welfare of the Child, the African Child Policy Forum (ACPF) & The African Committee of Experts on the Rights and Welfare of the Child (ACERWC), 2015.¹⁸⁷

181 ganhri.org

182 www.die-gdi.de

183 www.tandfonline.com

184 redress.org

185 www.equalitynow.org

186 Available at: www.pulp.up.ac.za

187 www.socialserviceworkforce.org

For information on engaging with the PAP:

- Toolkit for Civil Society Advocacy in The Pan-African Parliament, Centre for Human Rights, University of Pretoria, 2020¹⁸⁸
- Website of the Pan-African Parliament, au.int

For information on engaging with the UN:

- Information Note: National Human Rights Institutions (NHRIs) interaction with the UN Treaty Body System, OHCHR National Institutions and Regional Mechanisms Section, 5 April 2011.¹⁸⁹
- GANHRI background paper - NHRIs and the UN treaty bodies - May 2016.¹⁹⁰
- Amrei Müller and Frauke Seidensticker, Handbook: The Role of National Human Rights Institutions in the United Nations Treaty Body Process, German Institute for Human Rights, December 2007.¹⁹¹
- The Universal Periodic Reporting Process: A Guide for National Human Rights Institutions, Northern Ireland Human Rights Commission and Commonwealth Forum of National Human Rights Institutions, September 2016.¹⁹²

188 www.chr.up.ac.za

189 Available at: nhri.ohchr.org

190 Ibid

191 Ibid

192 www.upr-info.org

MONITORING, EVALUATION AND LEARNING

OBJECTIVES OF PART 7

This section briefly examines monitoring, evaluation, learning and research in relation to the work of NHRIs. It also highlights the importance of continuous monitoring and evaluation of government policies, programmes and practice in relation to the fulfilment of the rights of persons with albinism.

By the end of Part 7, NHRIs should:

- know the difference between monitoring and evaluating
- have an idea of how to monitor and evaluate outputs and outcomes of their activities
- have an idea of how to monitor and evaluate the impact of their work
- understand the importance of monitoring and evaluating implementation of recommendations by the State
- know what sources to refer to for further information on monitoring and evaluation

The ultimate purpose of promotion and protection work is to contribute to ensuring full enjoyment of rights by persons with albinism. It is therefore essential that NHRIs take time to continually monitor and evaluate the work done to assess the impact it has had on the enjoyment of rights by persons with albinism.

Monitoring of performance requires an ongoing process of gathering information to check the progress against stated objectives, budget and timelines. It seeks to determine whether a project or programme is meeting its stated objectives within the given time and resources. Information gathered during the monitoring phase can be used for evaluation of the work done.

Evaluation, on the other hand, is carried out at a set period in the project, for example midway or at the end. It aims to determine whether the project or programme has had, or is having, the desired impact. The evaluation process includes judgements on the efficiency, impact and sustainability of the work.

As with all processes impacting on the rights of persons with albinism, NHRIs should ensure their genuine participation and inclusion in the monitoring and evaluation process, including the development of monitoring and evaluation plans. Persons with albinism, and their representative organisations, for example, can assist in developing tools and indicators for monitoring and evaluation, as well as provide information regarding their own experiences.

In addition, NHRIs need to monitor and evaluate the work of the State in this regard to ensure it is having tangible, positive impact on the rights of persons with albinism.

7.1 MONITORING, EVALUATION AND LEARNING IN RESPECT OF NHRIS' OWN WORK

In monitoring and evaluating projects or programmes on albinism, NHRIs should seek to learn lessons on the implementation of outputs, the results or outcomes of such outputs, how they have contributed (or not) to the overall objectives, as well as the overall impact of the project or programme implemented.

7.1.1 Monitoring and evaluation of outputs

Outputs relates to what is created at the end of a process, for example trainings offered or manuals published. NHRIs should ensure they carry out monitoring (and evaluation) of all outputs, including if they were delivered on time, according to budget, effectively, lessons learnt and any changes that may need to be made for follow-up. In evaluating whether the outputs were successfully delivered, NHRIs should:

- compare planned dates, times and resources to the actual delivery date, times and use of resources.
- obtain feedback on the output from target groups through feedback questionnaires, surveys, observations, or interviews.
- make an assessment of what went right, what didn't work and the level at which the output was successful.
- make a determination on whether any changes will need to be made to similar trainings in future or in relation to any follow-up trainings.

7.1.2 Monitoring and evaluation of outcomes

Outcomes relate to the results of the activity or output, primarily on the target group. The evaluation will relate to whether the desired outcomes of that output were achieved. This often requires an assessment immediately following the specific activity, as well as continued monitoring of the outcomes long term, for example, whether participants of a training apply lessons learnt in their work on the ground, or make any changes to their working methods as a result of the training.

7.1.3 Monitoring and evaluation of impact

This relates to monitoring, and eventual evaluation, of the overall impact of all outputs and outcomes of the project on the lives of persons with albinism. It includes both positive and negative changes.

To help in measuring impact of their work, NHRIs will need to develop indicators for their own work. Such indicators will differ from those developed in relation to State compliance of human rights as they seek to monitor and evaluate different areas. As with indicators for human rights, there are no set indicators for monitoring and evaluating internal work. However, a group of organisations have developed an impact tool with illustrative indicators for measuring impact of NGO work in various areas such as advocacy, capacity building and health.¹⁹³ In relation to impact, indicators will need to relate to the actual changes in the lives of persons with albinism.

NHRIs should seek to draw lessons from the evaluation and feed such lessons into further development of its promotion and protection work in relation to albinism, including any required further research or changes.

¹⁹³ The tool is known as Impact builder and is available at: www.bond.org.uk (accessed 25 August 2020)

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Monitoring and evaluation

After carrying out a public inquiry into albinism, an NHRI initiates a project on enhancing human rights protections for persons with albinism. As part of this project, it implements the following activities:

- i) 3 trainings of organisations of persons with albinism to increase their capacity to advocate for their rights using the human rights framework
- ii) a production of a publication to assist organisations of persons with albinism in their work
- iii) advocacy at the regional and international level for adoption of relevant laws at the national level

In relation to the training, the desired outcome is that staff of organisations of persons with albinism have improved knowledge and skills in relation to human rights, as well as change their practices to include human rights advocacy in relation to their work on albinism. The trainings are set for specific dates and have an allocated budget.

Output monitoring and evaluation – The NHRI implements the first training and carries out an evaluation of its success. The evaluation is carried out by comparing planned dates and expenditure to actual implementation dates and expenditure. It also provides feedback questionnaires to participants seeking their views on whether the teaching methods were effective (e.g. pitched at the right level), if the moderator communicated well, whether the resources were appropriate, whether the setting was appropriate and any other comments they have. The NHRI also has staff observing the interactions during the training to assess the appropriateness of methods used. Based on the first evaluation the NHRI realises the visual presentations were not accessible to persons with albinism in the group, and some of the participants had very little human rights knowledge compared to others. The NHRI uses this information to make alterations to the following training, including ensuring accessibility for persons with albinism, and carrying out pre-evaluation assessments to ensure participants have more or less the same level of understanding. It carries out the same assessment in relation to the other trainings, which run according to plan without any changes needed.

Outcome monitoring and evaluation – The NHRI also carries out an assessment of the outcomes of the trainings. It uses pre- and post-training tests to gauge the level of the participants' understanding of human rights before and after the training. The NHRI uses the following indicators for assessment:

- the number and description of cases where staff have applied learning back in the workplace as a result of the support they received from the NRHI, and
- the number of representatives of organisations of persons with albinism that can describe specific changes they have made to their practice as a result of the support they received from the NHRI.¹⁹⁴

¹⁹⁴ Example from the Impact builder

It uses questionnaires sent to participants after the training to ascertain whether the outcomes have been achieved. As the increased knowledge and skills manifests over time, they send the questionnaires 6 months and a year after the training. In addition, the NHRI includes trainees in their promotion activities and is able to observe implementation of learnt knowledge and skills through their joint work and discussions.

Impact evaluation – throughout the cycle of the project, the NHRI carries out similar assessments in relation to its other activities and continually gathers information in relation to its work from media monitoring, surveys of communities, legal and policy analysis, review of recommendations of international bodies in relation to albinism to see if any have adopted recommendations suggested by the NHRI, and for information on positive or negative changes to the lives of persons with albinism which could be related to their work. They use indicators such as:

- number and description of policies/laws/budgets/practices that are developed/changed/adopted in relation to albinism with a verifiable contribution from the NHRI
- number and description of policies/laws/budgets/practices that are implemented
- Prosecutions and appropriate penalties are enforced for attacks against persons with albinism
- Proportion of public health clinics and hospitals and other facilities offering healthcare provision for persons with albinism, particularly skin cancer screening and testing

7.2 MONITORING, EVALUATION AND LEARNING IN RESPECT OF STATE DELIVERY OF RIGHTS

The initial research into the situation of persons with albinism will provide information on State compliance with its international obligation, including areas where the State is meeting its obligations, and areas where a lot more needs to be done. The initial report can provide recommendations to the State for improvement in these areas. However, NHRIs also need to carry out continuous monitoring and evaluation of the States work in relation to albinism with a view to:

- a. ensuring full implementation of recommendations from international bodies – NHRIs are required to monitor compliance of State with concluding observations and other recommendations of international bodies, such as the UPR and those from the special procedures. This includes ensuring any laws and policies adopted as a result of such recommendations are being implemented and having the desired effect on the rights of persons with albinism.
- b. ensuring the State is progressively realising rights and not taking any retrogressive steps - International treaties recognise that States may not be able to implement all rights straight away, but they require them to, at the very least, use the maximum of its available resources to realise rights and to ensure the protection and fulfilment of the rights is continually being improved (i.e. ensure progressive realisation of rights).
- c. carrying out benchmarking of the State's compliance with its obligations – ensuring States are taking sufficient steps towards meeting relevant targets, either set by the State in its national plans or other personal commitments, or global goals accepted by the State such as the SDGs,¹⁹⁵ and the revised SADC Protocol on Gender and Development.¹⁹⁶

¹⁹⁵ www.un.org

¹⁹⁶ The revised SADC Protocol on Gender and Development, available at: www.tralac.org

Indicators should once again be used to monitor progress of States in implementing its obligations. The indicators can also provide a measure of progress overtime when compared to information gathered through the same indicators during the initial research. Outcome indicators can help in monitoring the actual impact on the lives of persons with albinism of actions taken.

Research will need to be carried out to ascertain the actual impact of steps taken as they may have inadvertent negative impacts. Lessons need to be drawn from the monitoring and evaluation of work and then fed back into the development of further work in this area to ensure progressive realisation of rights. Recommendations can include the need for further research to ensure better understanding and development of appropriate recommendations.

Malawi unintended consequences of positive implementation

In 2016, the Chief Justice of Malawi passed a directive that only senior members of the judiciary should take on cases of attacks against persons with albinism. The directive was passed to ensure speedy disposal of the cases and consistency in the way they were handled. However, this led to a delay in the handling of such cases, apparently due to a lack of sufficiently qualified magistrates to take on such cases and the need for such magistrates to travel.

7.3 FURTHER READING

- Human Rights Indicators: A Guide to Measurement and Implementation, OHCHR, 2012.¹⁹⁷
- Learning from our experience: human rights education monitoring and evaluation toolkit, Amnesty International, 2010
- Haki Zetu: ESC rights in practice: Main book, Amnesty International, 2010
- Impact Builder, Online monitoring and evaluation tools, Bond, www.bond.org.uk

¹⁹⁷ www.ohchr.org

FURTHER RESOURCES

- Compendium of documents on National Human Rights Institutions in eastern and Southern Africa, Edited by Charles M Fombad, Pretoria University Law Press (PULP), 2019. Available at: www.pulp.up.ac.za
- Human Rights indicators for the Convention on the Rights of Persons with Disabilities: bridgingthegap-project.eu
- Impact Builder: www.bond.org.uk
- OHCHR Charter Body Database: ap.ohchr.org
- OHCHR Country information Database – Africa Region: www.ohchr.org
- OHCHR Special Procedures Database: spinternet.ohchr.org
- OHCHR Human Rights Indicators Tables: www.ohchr.org
- UNDP-OHCHR Toolkit for Collaboration with National Human Rights Institutions, December 2010, ganhri.org
- Dissemination platform of the Global SDG Indicators Database, unstats.un.org
- Universal Human Rights Index Database: uhri.ohchr.org
- UN Treaty Body Database – Country specific: tbinternet.ohchr.org



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