



Submission in response to the call for inputs: Persons with Albinism; Tenth Anniversary Report

This is a joint submission led by the Africa Albinism Network in collaboration with albinism organisations from Angola, Malawi, South Africa, Tanzania, and Zambia. The submitting organisations include; Fundacao Joel Tchombosi, the Association of Persons with Albinism in Malawi (APAM), the National Albinism Taskforce of South Africa (NATF), the Tanzania Albinism Society (TAS Morogoro), the Albinism Foundation of Zambia (AFZ) and Albinism Multipurpose Organisation.

The mission of the [Africa Albinism Network \(AAN\)](http://www.africaalbinismnetwork.org) is to promote the rights, well-being and inclusivity of people with albinism in Africa through advocacy, capacity development, and collaboration.

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Consent Needed to Publish:

To protect our collaborators from reprisals, please do not publish this input without the express permission of its contributors. You may email the Africa Albinism Network for further discussion as needed.

Methodology

This submission is compiled by the Africa Albinism Network based on inputs received from human rights defenders, all of whom are leaders of albinism groups and organisations working to promote the rights and welfare of Persons with Albinism in their respective countries in Africa. These inputs were collated through one-on-one phone interviews as well as written submissions using the questionnaire provided by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on the Rights of Persons with Albinism: Tenth Anniversary Report.

Caveat: AAN has compiled all reasonable responses from its partner organizations. While AAN is familiar with and can attest to many of their claims and realities, we have not been able to verify all assertions due to time and capacity constraints.

RESPONSES



Country: Angola

Organisation: Fundacao Joel Tchombosi,

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- 1. Please describe how the mandate has contributed towards the enjoyment of the human rights of persons with albinism in your country, region or beyond. Where possible, please share specific examples and stories.**

This mandate has notably impacted Angola and broader Africa through several key contributions:

- **Advocacy and Awareness-Raising:** The Independent Expert's mandate has heightened awareness about the issues faced by people with albinism, such as discrimination, violence, and lack of access to essential services. For instance, the mandate has helped draw international attention to the plight of people with albinism in Africa, where they have historically faced social exclusion and stigma. The increased visibility has led to better-informed policies and programs aimed at addressing these issues in Angola.
- **Supporting National Legislation:** The mandate has supported the development and implementation of national laws and policies in Angola and other African countries to protect the rights of people with albinism. For example, in response to advocacy efforts, Angola has made strides in addressing the specific needs of individuals with albinism, such as improving access to healthcare and education.

- **Engagement with Local Communities:** The Independent Expert has facilitated dialogue between local communities, governments, and international organizations to promote the inclusion and protection of people with albinism. This has included organizing workshops, conferences, and consultations that bring together stakeholders to discuss and address the challenges faced by people with albinism.
- **Protection against Violence:** In countries like Tanzania, Malawi, Mozambique, Zambia and Madagascar where violence against people with albinism has been a significant issue, the Independent Expert's mandate has helped push for greater protection measures and accountability. While *Angola* has not been as prominently affected by violence against people with albinism, the broader regional efforts have contributed to a more supportive environment across Africa.
- **Educational and Health Initiatives:** The mandate has also supported initiatives aimed at improving the educational and health outcomes for people with albinism. For instance, there have been efforts to provide better access to sunscreen and eye care, as well as educational inclusion, scholarships and, support programs. In Angola, these efforts have been carried out to better the quality of life for individuals with albinism.

An example of success can be seen in the increased engagement of Angolan civil society organisations in advocating for the rights of people with albinism, supported by the visibility and advocacy generated by the Independent Expert's mandate. This has led to more localised efforts and partnerships to improve conditions for individuals with albinism in Angola.

2. **Please provide information on the international and regional frameworks that your government has ratified or committed to, in its effort to enhance the rights of persons with albinism during this period.**

Angola has ratified several international and regional frameworks aimed at enhancing the rights of persons with albinism, reflecting its commitment to improving their human rights and well-being. Key frameworks include:

International Frameworks:

- Convention on the Rights of Persons with Disabilities (CRPD)
- Convention on the Rights of the Child (CRC)
- International Covenant on Civil and Political Rights (ICCPR)
- International Covenant on Economic, Social and Cultural Rights (ICESCR)

Regional Frameworks:

- African Charter on Human and Peoples' Rights (ACHPR)
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol)
- African Union's Strategy for the Promotion and Protection of the Rights of Persons with Disabilities

- 3. Please provide information on any specific policies, legislation, strategies, programs, projects or initiatives that your government has adopted and implemented to ensure full realization of the rights of persons with albinism, including in the areas of health, education, employment, freedom from violence and abuse, social protection during this period. Also, include information on provision of free skin cancer screening and/or treatment for persons with albinism; availability of free sunscreen; inclusion of sunscreen on national essential medicine list; provision of free eye care services for persons with albinism.**

Angola has recently taken steps to improve the rights of persons with albinism, though the impact of these measures varies. The National Action Plan (NAP 2023-2027), adopted in August 2023 by the Council of Ministers, includes policies and programs aimed at supporting people with albinism.

In June 2024, Angola provided free skin cancer screenings for the first time in five of its 18 provinces, led by the College of Dermatologists. That same month, free sunscreen was distributed to albinism associations nationwide. However, the inclusion of sunscreen on the national essential medicine list remains a challenge that civil society organizations continue to advocate for. Unfortunately, there has been no provision of free eye care services for persons with albinism.

4. To what extent is albinism officially recognised as a disability in your country's legislation and policies?

In Angola, albinism is partially recognized as a disability under the country's legislation and policies, though the level of support is less comprehensive compared to other nations. Many decision-makers view albinism primarily as a minority group rather than a disability, which limits the scope of assistance. As a result, individuals with albinism face significant challenges, including limited resources, societal stigma, and a general lack of awareness.

5. Please indicate the steps your government has taken towards implementing the recommendations made by the Independent Expert in her thematic and country reports. Please provide information on what your government/country has done to ensure the inclusion of persons with albinism in addressing racism, trafficking, migration, climate change and Human Rights Defenders.

Angola has taken some steps to address the recommendations made by the independent expert. The measures the government has implemented in some areas are as follows:

a) Legal and Policy Frameworks:

- **National Action Plan (NAP) for People with Albinism:** Angola developed and adopted this policy to promote the rights and inclusion of persons with albinism. The policy aims to ensure equitable access to education, health services, employment, protection from violence and trafficking, and support services for survivors of violence and trafficking.

a. Migration and Climate Change:

- **Climate Adaptation Measures:** This includes public health campaigns on sun protection and access to sunscreen.
- **Migration Policies:** Angola is working to ensure that all vulnerable groups, including those with albinism, are considered in migration and refugee policies.

6. **Where applicable, what steps have been taken in your country to investigate concerns raised by the Independent Expert through the communications procedure and to ensure that they are resolved? Kindly provide information on ongoing and successful prosecution of perpetrators of violence against persons with albinism; steps taken to criminalise possession of, and trading in, body parts of persons with albinism; community action and policing methods to protect and prevent violence against persons with albinism.**

No comment.

7. **Does your country have specific disaggregated data on the prevalence of albinism including statistics on refugees, migrants and IDPs with albinism? Kindly provide the relevant data.**

Not yet.

8. **Please provide examples of how your country's NHRI has contributed to the respect, protection, and implementation of the rights of persons with albinism.**

Angola's NHRI has sometimes been active in raising awareness about the challenges faced by persons with albinism. They have organised public education campaigns to combat stigma and promote understanding of albinism.

9. **Please share the outcomes of any assessments done of the implementation of laws, policies, plans and/or programmes affecting persons with albinism.**

The implementation of existing laws and policies contained in the NAP (2023-2024) is insignificant. This challenge continues to affect the lives of individuals with albinism. Continued advocacy, improved policy implementation, and increased awareness are necessary to address these challenges effectively.

10. Please provide suggestions on how the mandate can strengthen its work and specific issues that should be prioritised going forward.

To strengthen its mandate and impact, the Independent Expert might consider the following suggestions and prioritise specific issues:

- Continued country visits
- Providing capacity-building training sessions and resources to local organisations.
- Seek international cooperation and funding to support initiatives and programs specifically designed for persons with albinism



Country: Malawi

Organisation: Association of Persons with Albinism in Malawi

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1. Please describe how the mandate has contributed towards the enjoyment of the human rights of persons with albinism in your country, region or beyond. Where possible, please share specific examples and stories.

Since the visit of the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism in 2018, significant progress has been made in combating attacks, discrimination, and stigmatisation of persons with albinism. This progress has been driven by the joint efforts of the government, civil society organizations, and albinism advocacy groups, such as the Association of Persons with Albinism in Malawi (APAM).

One of the key contributions of the UNIE was the recommendation to develop and implement a National Action Plan aimed at addressing violence and discrimination against persons with albinism. The recommendations provided by the UNIE have been instrumental in shaping policies and interventions, resulting in a noticeable decline in attacks and other human rights violations. Government actions, influenced by the UNIE's guidance, have included stricter law enforcement such as the introduction of Community Policing, public awareness campaigns, and the protection of persons with albinism.

In addition to security measures, the mandate has played a crucial role in advocating for the domestication of international human rights treaties, such as the Convention on the Rights of Persons with Disabilities (CRPD). This has led to improved access to healthcare and education for persons with albinism, ensuring that their fundamental rights are respected and upheld.

2. Please provide information on the international and regional frameworks that your government has ratified or committed to, in its effort to enhance the rights of persons with albinism during this period.

Malawi has demonstrated its commitment to advancing the rights of persons with albinism by ratifying and adhering to various international and regional frameworks. Notably, the government has ratified the Convention on the Rights of Persons with Disabilities (CRPD), which provides comprehensive protections for individuals with disabilities, including persons with albinism. The CRPD requires state parties to take legislative, administrative, and other measures to promote and protect the rights and dignity of persons with disabilities.

At the regional level, Malawi is committed to ratifying the African Disability Protocol (ADP), which supplements the CRPD by addressing disability rights within the specific context of African nations. The ADP includes provisions for preventing violence and discrimination against persons with albinism, recognizing their unique vulnerabilities within the region.

In its ongoing efforts, Malawi continues to implement these frameworks by integrating them into national policies and legislation aimed at safeguarding and promoting the rights of persons with albinism.

3. Please provide information on any specific policies, legislation, strategies, programs, projects or initiatives that your government has adopted and implemented to ensure the full realization of the rights of persons with albinism, including in the areas of health, education, employment, freedom from violence and abuse, social protection during this period. Also, include information on the provision of free skin cancer screening and/or treatment for persons with albinism; availability of free sunscreen; inclusion of sunscreen on national essential medicine list; provision of free eye care services for persons with albinism.

- **National Action Plan (NAP) for Persons with Albinism:** The National Action Plan was developed in response to increased attacks and discrimination

against persons with albinism (Persons with Albinism) and is a cornerstone of Malawi's efforts to protect their rights. This plan outlines strategies for enhancing security, improving access to services, and increasing public awareness. Currently, the plan has expired, and the government is working on reviewing and renewing the plan

- **Inclusion of Sunscreen as an Essential Medicine:** In a significant step towards improving the health of Persons with Albinism, the government has classified sunscreen as an essential medicine. Sunscreen is now available through the Central Medical Stores, ensuring Persons with Albinism have access to affordable sun protection, a crucial need to prevent skin damage and skin cancer.
- **Provision of Housing and Security for Persons with Albinism:** Recognizing the ongoing threat of violence, the government has introduced a housing program to provide decent and secure homes for persons with albinism. Additionally, there is a policy to ensure that Persons with Albinism, particularly students, are admitted to boarding schools for their safety.
- **Educational Support: Bursary Scheme for Persons with Albinism:** The NAP includes a bursary scheme specifically designed to support the education of Persons with Albinism. This initiative aims to reduce financial barriers to education, promoting equal opportunities for Persons with Albinism to access quality education in a safe environment.
- **Employment Opportunities and Representation:** Efforts have been made to improve employment opportunities for Persons with Albinism, including lobbying by the Association of Persons with Albinism in Malawi (APAM). Notably, several Persons with Albinism now hold decision-making positions in government and public institutions. Examples include Overstone Kondowe, a PWA and a Member of Parliament, who has played a significant role in advocating for the rights of Persons with Albinism. Bonface Massah, a human rights activist, has led national efforts to advance the rights of persons with albinism. Additionally, there are three Persons with Albinism employed in the Malawi Police Service, further reflecting progress in inclusion

4. To what extent is albinism officially recognised as a disability in your country's legislation and policies?

Albinism is officially recognized as a disability in Malawi's legal and policy frameworks. The revision of the Disability Act in 2024 explicitly includes persons with albinism within the definition of persons with disabilities. This legal recognition has paved the way for Persons with Albinism to access the same protections and benefits as other persons with disabilities under the law.

Persons with Albinism are also included in many national policies aimed at promoting the rights and welfare of persons with disabilities such as the Penal Code of Malawi. These policies ensure that Persons with Albinism have access to critical services such as healthcare, education, and social protection. For instance, the National Action Plan (NAP) on albinism was a significant policy focused on addressing the specific needs of Persons with Albinism. However, the NAP has since expired, and there is a need for its renewal or the development of a new comprehensive framework to continue addressing the unique challenges faced by persons with albinism in the country.

Despite this legal recognition, ongoing advocacy is needed to ensure full implementation of these policies and to address gaps, such as the expiration of the NAP and the need for more robust healthcare services for Persons with Albinism.

5. Please indicate the steps your government has taken towards implementing the recommendations made by the Independent Expert in her thematic and country reports. Please provide information on what your government/country has done to ensure the inclusion of persons with albinism in addressing racism, trafficking, migration, climate change and Human Rights Defenders.

The government of Malawi has made significant strides in implementing the recommendations made by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, particularly through targeted national actions and increased advocacy efforts. Below are the key steps taken:

- **Implementation of the National Action Plan (NAP):** As highlighted earlier, developing and implementing the National Action Plan (NAP) was a major step forward. This plan addressed violence, discrimination, and social inclusion of persons with albinism. The NAP was widely publicised across various

government departments and institutions to ensure it guided nationwide efforts, although it has since expired, and a new framework is needed.

- **Security Measures: Community Policing and Grave Protection:** In response to attacks and trafficking linked to harmful beliefs about albinism, community policing and increased police patrols were introduced. A notable security measure was the fortification of the graves of persons with albinism to prevent grave tampering. This has helped reduce the risk of body part trafficking and violence against persons with albinism.
- **Advocacy and Public Awareness:** From 2018 to 2023, there was a marked increase in advocacy, with the government taking a stronger stance. Key events like the International Albinism Awareness Day (IAAD) have been used to raise awareness. The government, including the President, has been vocal in condemning violence against Persons with Albinism, sending a strong message to the public, although some of these interventions were delayed.
- **Housing Initiative for Persons with Albinism:** Recognizing the vulnerability of persons with albinism, the government, with pressure from advocacy groups like the Association of Persons with Albinism in Malawi (APAM), launched a housing initiative in 2021 to provide secure homes for persons with albinism. This project aims to offer Persons with Albinism a safe living environment free from the threat of violence.
- **Legal Revisions to Address Human Trafficking and Penal Code;** The government has made efforts to revise laws related to human trafficking and the penal code to better protect persons with albinism. These revisions aim to ensure that the trafficking of body parts and harmful practices targeting Persons with Albinism are explicitly criminalised and carry harsher penalties.
- **Inclusion in Human Rights and Freedom of Expression;** The government has taken steps to ensure that human rights defenders advocating for the rights of persons with albinism can speak freely without fear of reprisal. This freedom has enabled more open discussions on albinism-related issues, contributing to increased national and regional awareness and advocacy.
- **Persons with Albinism in Broader Human Rights Issues;** While more focused interventions on trafficking and security have been implemented, there is still room for greater inclusion of Persons with Albinism in broader issues

such as migration, climate change, and anti-racism strategies. However, the government has begun to recognise the need to consider Persons with Albinism as part of vulnerable groups affected by these global challenges.

6. Where applicable, what steps have been taken in your country to investigate concerns raised by the Independent Expert through the communications procedure and to ensure that they are resolved? Kindly provide information on ongoing and successful prosecution of perpetrators of violence against persons with albinism; steps taken to criminalise possession of, and trading in, body parts of persons with albinism; community action and policing methods to protect and prevent violence against persons with albinism.

In response to concerns raised by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Malawi has taken several steps to investigate and address attacks against persons with albinism (Persons with Albinism). Below are the key actions:

- **Investigation and Prosecution of Perpetrators:** The government has taken a strong stance in prosecuting suspects involved in attacks against Persons with Albinism. Law enforcement agencies have been instructed to thoroughly investigate cases and bring perpetrators to justice. Notable examples include several high-profile prosecutions where individuals involved in the killing or abduction of Persons with Albinism were convicted and sentenced. Notable cases that have been successfully prosecuted include the conviction of individuals in the killing of MacDonald Masambuka, a PWA who was murdered in 2018. The conviction of multiple perpetrators in this case, including a Catholic priest and a police officer, was seen as a landmark victory in the fight against violence targeting Persons with Albinism. Other cases, such as the prosecution of suspects in the abduction and murder of Persons with Albinism in Mangochi and Machinga districts, further demonstrate the government's commitment to enforcing the law.

- **Legal Reforms: Criminalizing Trafficking and Possession of Body Parts:** In response to concerns about the trafficking of body parts of persons with albinism, Malawi has revised and amended its penal code and Human Trafficking Act. These legal reforms now explicitly criminalise the possession and trade of body parts of Persons with Albinism, with severe penalties for offenders. This has strengthened the legal framework to combat such heinous crimes and provides greater protection for Persons with Albinism.
- **Community Policing and Security Measures:** To prevent violence against Persons with Albinism, the government has introduced community policing programs aimed at increasing vigilance at the local level. These efforts are supplemented by police patrols in areas with high rates of violence against Persons with Albinism. Additionally, the government has implemented a program to fortify graves to prevent body snatching, which has been a recurring threat to Persons with Albinism even after death.
- **Cross-border Challenges;** While domestic efforts have led to successful prosecutions, cross-border attacks and trafficking related to persons with albinism remain a challenge. Regional cooperation on cross-border crimes is still limited, and more work is needed to address these concerns through better international collaboration.

7. Does your country have specific disaggregated data on the prevalence of albinism including statistics on refugees, migrants and IDPs with albinism? Kindly provide the relevant data.

Currently, Malawi does not have specific disaggregated data on the prevalence of persons with albinism (Persons with Albinism), including statistics on refugees, migrants, and internally displaced persons (IDPs) with albinism. While general data on the population of Persons with Albinism exists, it is not disaggregated in a way that provides detailed information on different categories, such as refugees or migrants.

8. Please provide examples of how your country's NHRI has contributed to the respect, protection, and implementation of the rights of persons with albinism.

Malawi's National Human Rights Institution (NHRI) has played a vital role in promoting the rights of persons with albinism (Persons with Albinism) through several key actions:

- **Review of the National Action Plan (NAP);** The NHRI has been actively involved in reviewing the National Action Plan (NAP) for persons with albinism. This includes assessing the effectiveness of policies and programs aimed at protecting Persons with Albinism and ensuring their rights are upheld. Their recommendations have informed improvements in government interventions.
- **Monitoring the Implementation of the NAP:** The NHRI monitors the implementation of the NAP to ensure that the government and relevant stakeholders are fulfilling their commitments. This includes tracking progress on issues such as access to education, healthcare, and the prevention of violence against Persons with Albinism.
- **Public Condemnation of Attacks;** The NHRI has been vocal in publicly condemning attacks on persons with albinism. They have consistently called for accountability and justice for victims, urging the government to prosecute perpetrators and increase protections for Persons with Albinism. Their public stance has helped raise awareness and keep the issue at the forefront of national human rights discussions.

9. Please share the outcomes of any assessments done of the implementation of laws, policies, plans and/or programmes affecting persons with albinism.

Several assessments have been conducted to evaluate the implementation of laws, policies, and programs affecting persons with albinism (Persons with Albinism) in Malawi, with the following key outcomes:

- **Advocacy on Albinism:** Advocacy efforts have intensified, particularly through collaboration between the government, civil society organisations, and albinism advocacy groups like the Association of Persons with Albinism in Malawi (APAM). This has led to greater public awareness of the rights and challenges faced by Persons with Albinism and a reduction in stigma.

- **Education of Persons with Albinism through Bursary Programs;** The introduction of a bursary scheme for Persons with Albinism has increased educational opportunities for individuals with albinism. Assessments have shown that the bursary has helped many Persons with Albinism access schooling, especially in safe environments like boarding facilities, though gaps remain in the consistency and reach of the program.
- **Police Service Awareness Campaigns:** The Malawi Police Service has taken an active role in raising awareness about the rights of persons with albinism and the need to protect them from violence. These campaigns, combined with community policing initiatives, have contributed to a decrease in attacks and better protection of Persons with Albinism in high-risk areas.
- **Administration of Justice:** Assessments indicate progress in the prosecution of crimes against Persons with Albinism. The police and justice system have increased efforts to investigate and bring perpetrators to justice, although challenges such as case backlogs and limited resources continue to impede swift legal processes.
- **Police Home Audits for Persons with Albinism:** The police have conducted home audits to assess the safety and security of persons with albinism, particularly in rural areas. These audits have helped identify vulnerabilities and implement additional protective measures to safeguard Persons with Albinism in their homes.
- **Provision of Sunscreen and Sunglasses;** The government has made sunscreen and sunglasses available to Persons with Albinism through medical facilities and district health offices. While this has improved access to essential skin and eye care products, assessments highlight the need for more consistent distribution and coverage, particularly in remote areas.
- **Strengthening of District Structures;** District-level structures have been strengthened to better support Persons with Albinism, with local governments playing an active role in implementing protective measures and ensuring the inclusion of Persons with Albinism in social services. This has led to better coordination of interventions at the grassroots level.

Overall, these assessments indicate progress in advocacy, education, and protection efforts for persons with albinism. However, challenges such as resource limitations and inconsistencies in implementation remain areas that need further attention.

10. Please provide suggestions on how the mandate can strengthen its work and specific issues that should be prioritised going forward.

- **Frequent Audits and Monitoring:** The mandate can be strengthened through regular audits and monitoring of interventions carried out by member states. This would ensure that commitments made in policies, laws, and action plans are being implemented effectively. It would also provide timely data to assess progress and identify gaps.
- **Country Visits to High-Risk Areas;** Increased frequency of visits to countries experiencing high levels of attacks on persons with albinism will enable the Independent Expert to assess the situation on the ground, engage with local authorities, and directly influence actions to protect Persons with Albinism.
- **Consistent Public Condemnation of Attacks:** The Independent Expert should continue to publicly condemn attacks on persons with albinism. Frequent and high-profile statements can raise awareness, put pressure on governments to act, and signal global solidarity with Persons with Albinism.
- **Collaboration with Local Albinism Organizations:** Stronger collaboration with local albinism organizations is key. By working closely with grassroots groups, the mandate can better understand the specific needs of Persons with Albinism and support local initiatives. This partnership can also ensure that interventions are culturally relevant and sustainable.
- **Regular Meetings with Albinism Groups:** Frequent meetings and consultations with albinism advocacy groups, including regional and national organizations, will help the Independent Expert stay informed on emerging issues and coordinate efforts to address them. These meetings could serve as a platform for exchanging best practices and solutions.
- **Networking and Capacity-Building Opportunities:** The mandate should prioritize creating networking opportunities for albinism groups, facilitating connections between organizations working on similar issues across different

countries and regions. This would enhance collaboration and knowledge-sharing among advocacy groups globally.

- **Resource Mobilization and Donor Connections:** Connecting albinism groups to potential donors and funding opportunities should be a priority. Many local organizations lack the resources to carry out their work effectively, and support from the Independent Expert in mobilizing resources would significantly enhance their impact.



Country: South Africa

Organisation: National Albinism Task Force (NATF)

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INTRODUCTION

This is a submission by the National Albinism Task Force (NATF) concerning the progress in realising the rights of persons with albinism in South Africa in the last ten years.

The Sector acknowledges the significant strides made in the past decade, including the establishment of the National Albinism Task Force in South Africa. This structure has been pivotal in uniting the albinism sector and ensuring that the voice of persons with albinism in South Africa is heard in all structures where the rights of persons with disabilities are discussed.

The development of the National Action Plan was a great effort by the Sector, assisted by various human rights stakeholders. While the government has yet to adopt this plan, it remains a critical tool for addressing the priority issues faced by persons with albinism in South Africa.

There is still much work to be done to raise awareness in South Africa. The sector's most significant challenge remains the lack of funding, which makes it difficult to drive this work efficiently. Sustainable programmes can go a long way in ensuring that the message penetrates the spaces where it needs to be heard.

Reflecting on the past ten years, discrimination and social exclusion, access to health, inclusive education, employment, social security, and access to justice remain critical issues that must be addressed with the support of the political will of the government.

It is applauded that South Africa has ratified many of the global and regional legislation meant to protect the rights of persons with albinism. Domestication of such remains the challenge.

Our responses will reveal some of the progress and the gaps that need to be attended to urgently in South Africa for persons with albinism to see the realisation of their rights

1. Please describe how the mandate has contributed towards the enjoyment of the human rights of persons with albinism in your country, region or beyond. Where possible, please share specific examples and stories.

Since the Independent Expert's (IE) visit to South Africa in 2019, significant progress has been made towards advancing the rights of persons with albinism. One of the key outcomes was the establishment of the National Albinism Task Force (NATF), tasked with drafting the National Action Plan on Albinism. The draft plan was submitted to the government in 2021, though it has yet to be formally adopted.

The IE's visit fostered unity within the albinism sector, facilitating the collaborative efforts that led to the development of the National Action Plan. The creation of the NATF was a major milestone, and it was soon after invited to join the National Disability Machinery (NDM), an important platform within South Africa's government.

The NATF has taken a proactive role in organizing national activities that focus on critical issues affecting persons with albinism, such as healthcare, education, and access to justice. The government's increased recognition of the albinism community, demonstrated by the NATF's inclusion in the NDM, is one clear example of the positive impact the IE's mandate has had.

2. Please provide information on the international and regional frameworks that your government has ratified or committed to in its effort to enhance the rights of persons with albinism during this period.

- The Africa Disability Protocol has been ratified
- Regional Action Plan on Albinism has been adopted
- The government has made efforts to assist the sector by formalising the provincial structures of the NATF and helping the sector to strengthen its voices. To date, of the nine (9) provinces of South Africa, five (5) provinces have been formally structured with others in the process of doing that.

3. Please provide information on any specific policies, legislation, strategies, programs, projects or initiatives that your government has adopted and implemented to ensure full realization of the rights of persons with albinism, including in the areas of health, education, employment, freedom from violence and abuse, social protection during this period. Also, include information on provision of free skin cancer screening and/or treatment for persons with albinism; availability of free sunscreen; inclusion of sunscreen on national essential medicine list; provision of free eye care services for persons with albinism.

- The Preventing and Combating Hate Crimes and Hate Speech Bill, recently approved, marks a significant milestone by including persons with albinism (PWA) for the first time under legal protections against hate crimes.
- The Department of Home Affairs has made reasonable accommodations for persons with albinism by discontinuing the use of the flash system, which is harsh on their sensitive eyes, when processing IDs and passports.
- The South African Police Service (SAPS) has conducted awareness campaigns in border areas, particularly in provinces identified as hotspots for human and body trafficking of persons with albinism. In addition, SAPS established a specialized unit focused on vulnerable groups, particularly persons with albinism.
- In 2019, the Access to Justice Indaba was held to empower the albinism sector on how to navigate legal processes, including the Equality Court, and introduced the concept of restorative justice. The Department of Justice and Constitutional Development is working to revive this initiative using the National Action Plan to create a sustainable program aimed at raising awareness within the justice system.

However, access to healthcare remains a major challenge. The distribution of sunscreens, which is essential for persons with albinism, is fragmented and inconsistent across provinces. While some provinces have been able to provide this critical resource, others are lagging behind, leaving a gap in much-needed care.

4. To what extent is albinism officially recognised as a disability in your country's legislation and policies?

The Employment Equity Act, as amended, has been amended to align disability with the definitions of disability as described in the UNCRPD and the ADP. The gap is to include albinism in the list of categories of disabilities. Albinism is still seen as an impairment that involves partial sightedness and excludes the skin condition, which is the primary cause of attitudinal barriers that lead to discrimination. The amended Hate Speech law was a good example where albinism was explicitly included.

5. Please indicate the steps your government has taken towards implementing the recommendations made by the Independent Expert in her thematic and country reports. Please provide information on what your government/country has done to ensure the inclusion of persons with albinism in addressing racism, trafficking, migration, climate change and Human Rights Defenders.

The NATF participated in three thematic reports of the IE: rights to education, climate change, and Human Rights Defenders. We reached out to the government to collaborate in responding to the three reports; however, that was unsuccessful. No implementation has taken place in terms of the reports.

Work has started to develop and adopt a disability act that will replace the White Paper on disability. The albinism sector will also use this opportunity to ensure that this law caters to the unique rights of PWAs.

6. Where applicable, what steps have been taken in your country to investigate concerns raised by the Independent Expert through the communications procedure and to ensure that they are resolved? Kindly provide information on ongoing and successful prosecution of perpetrators of violence against persons with albinism; steps taken to criminalise possession of, and trading in, body parts of persons with albinism; community action and policing methods to protect and prevent violence against persons with albinism.

There is little done to respond to the report of the IE. While the attitude of the government has changed, there is now a willingness to include albinism in all

discussions of disability. This has, however, not materialised into tangible action that responds to the critical needs of persons with disabilities.

There are three (3) notable cases that were investigated and prosecuted. Two were finalised, while one remains within the Courts. This is not enough considering that persons with albinism face discrimination and risk every day. The number of cases reported in South Africa is very low, which can be linked to the lack of action when the cases are reported.

7. Does your country have specific disaggregated data on the prevalence of albinism, including statistics on refugees, migrants and IDPs with albinism? Kindly provide the relevant data.

South Africa does not have disaggregated data on albinism. In her report in 2019, the IE recommended that Statistics SA include a question on albinism in the next Census. However, when the Census was conducted in 2022, the Washington tool was used to gather data on disability, and unfortunately, that tool does not distinguish albinism.¹ As such, the data collected by Statistics SA could not provide exclusive data on albinism. Discussions are ongoing with Statistics SA to mitigate how this data will be collected. In most cases, the prevalence rate from research is used to determine the population of persons with albinism. The sector has been pushing to collect its own data to determine the number of persons with albinism in SA.

8. Please provide examples of how your country's NHRI has contributed to the respect, protection, and implementation of the rights of persons with albinism.

Amnesty International, in collaboration with the Human Rights Commission, developed a monitoring tool for albinism.² This tool aims to assist in driving implementation and monitoring progress. However, the South African Human Rights Commission is not active and visible enough to hold the government accountable in line with its mandate. It is very reactive only to cases that are in the media.

¹ Comment from AAN. The WG SS address the issue of albinism in a blog, Summary of relevant point (in some countries being able to identify people with albinism is very important. In those countries, a question can be added to the WG-SS that explicitly asks if the person has albinism. It is important, though, that this question gets asked after the WG-SS and not immediately before it.) Read more here <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/>

² <https://www.amnesty.org/en/documents/afr03/3879/2021/en/>

9. Please share the outcomes of any assessments done of the implementation of law, policies, plans and/or programmes affecting persons with albinism.

The sector's National Action Plan remains a critical guide to achieving progress in addressing PWA's needs. If that plan can be adopted, the NAP outlines the plan and programmes to address PWA's challenges. The review of the Hate Speech Bill to include albinism is the main achievement to date.

10. Please provide suggestions on how the mandate can strengthen its work and specific issues that should be prioritised going forward.

The IE Office must strengthen its reporting mechanism and how countries report progress in implementing the rights of PWA, especially reporting on the implementation of the AU Plan of Action on Albinism in Africa. When countries are requested to report, we observe an eagerness to do something. While this is a reactive approach, it does contribute to the government taking action to address the issues raised.



Country: Tanzania

Organisation: Tanzania Albinism Society (TAS) Morogoro Chapter

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1. Please describe how the mandate has contributed towards the enjoyment of the human rights of persons with albinism in your country, region or beyond. Where possible, please share specific examples and stories.

- **Increased Awareness and Stigma Reduction:** The mandate has helped to disseminate information about albinism, challenging harmful stereotypes and misconceptions. TAS and other organizations have organized community outreach programs, educational workshops, and media campaigns to raise awareness about albinism and its associated rights. These efforts have led to a decrease in discriminatory practices and social stigma against individuals with albinism in Tanzania.
- **Policy Advocacy and Legal Reforms:** The Independent Expert's advocacy has influenced the development of inclusive policies and legislation at both national and international levels. The Tanzania albinism Society has been actively involved in lobbying for the adoption of laws that protect the rights of persons with albinism, such as those related to education, healthcare, and employment. These legal reforms have provided a stronger framework for safeguarding the rights of individuals with albinism in Tanzania.
- **Improved Access to Healthcare:** The mandate has highlighted the specific healthcare needs of persons with albinism, including skin protection, vision care, and access to specialized medical services. TAS has worked with Government, healthcare providers and NGOs to ensure that individuals with

albinism receive appropriate care and support, including subsidized treatment and access to essential medications. These efforts have contributed to improved health outcomes and reduced death rates among persons with albinism particularly from skin cancer.

- **Educational Inclusion and Opportunities:** The mandate has emphasized the importance of inclusive education for persons with albinism. TAS has advocated for the establishment of accessible educational facilities and the provision of assistive technologies to support students with albinism. These initiatives have enabled individuals with albinism to participate fully in education and pursue their academic goals.
- **Economic Empowerment and Employment:** The mandate has recognized the economic challenges faced by persons with albinism and the need for targeted support. TAS and others NGOs have implemented vocational training programs and job placement services to help people with albinism develop skills and secure employment opportunities especially self-employment. These efforts have contributed to the economic empowerment of persons with albinism and their integration into society.

However, the Independent Expert's mandate has had a profound impact on the lives of persons with albinism in Tanzania. By raising awareness, advocating for policy changes, and providing direct support, the mandate has helped to create a more inclusive and equitable society for persons with albinism. Tanzania Albinism Society is committed to continuing its work in collaboration with the Independent Expert and other stakeholders to ensure that the rights of persons with albinism are fully protected, respected and promoted.

2. Please provide information on the international and regional frameworks that your government has ratified or committed to, in its effort to enhance the rights of persons with albinism during this period.

Tanzania has ratified several international and regional human rights treaties that provide a framework for protecting the rights of persons with albinism. These include the Convention on the Rights of Persons with Disabilities (CRPD and the African

Charter on Human and Peoples' Rights. The country is also committed at ratifying the Africa Disability Protocol.

3. Please provide information on any specific policies, legislation, strategies, programs, projects or initiatives that your government has adopted and implemented to ensure full realization of the rights of persons with albinism, including in the areas of health, education, employment, freedom from violence and abuse, social protection during this period. Also, include information on provision of free skin cancer screening and/or treatment for persons with albinism; availability of free sunscreen; inclusion of sunscreen on national essential medicine list; provision of free eye care services for persons with albinism.

Tanzania has made significant strides in recent years to ensure the full realization of the rights of persons with albinism. Here are some key policies, legislation, strategies, programs, projects, and initiatives that have been adopted and implemented:

Health:

- **National Action Plan on Albinism:** Tanzania is finalizing its National Action Plan on Albinism for 2024–2027. This plan outlines the government's commitment to addressing the specific needs of persons with albinism, focusing on healthcare, education, and social protection.
- **Free Skin Cancer Screening and Treatment:** In cooperation with TAS and other NGOs, the government has implemented free skin cancer screening and treatment programs for persons with albinism, reducing the risk of complications related to skin cancer.
- **Availability of Free Sunscreen:** The government, through the Regional Dermatology Training Centre, has ensured the availability of free sunscreen for persons with albinism, which is essential for protecting their skin from the harmful effects of the sun.
- **Inclusion of Sunscreen in the National Essential Medicines List:** The government is in the process of including sunscreen in the national essential medicines list, making it more accessible to persons with albinism.
- **Free Eye Care Services:** In collaboration with NGOs and other stakeholders, the government has provided free eye care services for persons with albinism,

including vision screenings, glasses, and specialized treatments for marginalized individuals.

Education:

- **Inclusive Education Policy:** Tanzania has adopted an inclusive education policy aimed at ensuring that all children, including those with disabilities, have access to quality education.
- **Special Schools and Units:** The government has established special schools and units specifically for children with disabilities, including those with albinism.
- **Assistive Technologies:** The government has made assistive technologies, such as braille materials and screen readers, available to support the educational needs of students with albinism.

Employment:

- **Disability Act:** Tanzania has implemented the Disability Act of 2010, which promotes the employment of persons with disabilities, including those with albinism.
- **Vocational Training Programs:** The government provides vocational training programs to help persons with albinism acquire skills and secure employment.
- **Job Placement Services:** The government has established job placement services to connect persons with albinism to suitable employment opportunities.

Freedom from Violence and Abuse:

- **Anti-Discrimination Laws:** Tanzania has enacted anti-discrimination laws that protect the rights of all individuals, including those with disabilities.
- **Awareness Raising Campaigns:** In collaboration with the Tanzania Albinism Society (TAS), the government has conducted awareness-raising campaigns to educate the public about the rights of persons with albinism and to promote tolerance and inclusion.

- **Support Services for Victims:** The government, in partnership with TAS and NGOs, has established support services for victims of violence and abuse, including persons with albinism.

Social Protection:

- **Social Cash Transfer Programs:** Tanzania has implemented the Tanzania Social Action Fund (TASAF), a social cash transfer program that provides financial assistance to vulnerable households, including those with members who have disabilities including albinism.
- **Disability Allowance:** Although the government has not yet established a specific disability allowance to provide financial support to persons with disabilities, including those with albinism, it has introduced interest-free loans for women, youth, and persons with disabilities.

4. To what extent is albinism officially recognised as a disability in your country's legislation and policies?

- **The Persons with Disabilities Act:** This comprehensive law provides a legal framework for the protection and promotion of the rights of persons with disabilities, including those with albinism. It defines disability broadly to encompass a wide range of impairments, including albinism.
- **The National Action Plan on Albinism:** The government is in the final process to establish the national action plan on Albinism. This specifically addresses the unique needs and challenges faced by individuals with albinism in Tanzania. It outlines government strategies and interventions to ensure their inclusion and well-being.
- **The Convention on the Rights of Persons with Disabilities (CRPD):** Tanzania is a signatory to the CRPD, an international treaty that recognizes the rights of persons with disabilities. This treaty provides a global framework for the protection and promotion of the rights of individuals with albinism.

5. Please indicate the steps your government has taken towards implementing the recommendations made by the Independent Expert in her thematic and country reports. Please provide information on what your government/country

has done to ensure the inclusion of persons with albinism in addressing racism, trafficking, migration, climate change and Human Rights Defenders.

- **Adoption of National Policies:** Tanzania has adopted national policies and strategies that address the needs of persons with albinism, including the National Albinism Action Plan and the Persons with Disabilities Act. These policies provide a framework for government action and ensure the protection of the rights of individuals with albinism.
- **Establishment of Support Services:** The government has set up support services for persons with albinism, such as specialized healthcare facilities, educational programs, and vocational training centers. These services help address the unique needs of persons with albinism and promote their inclusion in society.
- **Awareness Raising Campaigns:** In collaboration with the Tanzania Albinism Society (TAS) and other NGOs, the government has carried out awareness-raising campaigns to educate the public about the rights of persons with albinism and challenge harmful stereotypes and discrimination. These efforts have contributed to a more inclusive and tolerant society.
- **Strengthening Legal Frameworks:** Tanzania has reinforced its legal frameworks to protect the rights of persons with albinism, including the adoption of anti-discrimination laws and the ratification of international treaties, such as the Convention on the Rights of Persons with Disabilities.
- **Collaboration with Civil Society Organizations:** The government has worked closely with civil society organizations that protect the rights of persons with albinism. This partnership has been instrumental in identifying and addressing their specific needs and ensuring their voices are heard.
- **Anti-Trafficking Measures:** Tanzania has implemented measures to combat human trafficking, including the establishment of anti-trafficking units and the adoption of anti-trafficking laws. These measures have helped to protect individuals with albinism, who are particularly vulnerable to trafficking.
- **Climate Change Adaptation:** Tanzania has developed climate change adaptation strategies that take into account the needs of vulnerable populations, including persons with albinism. These strategies aim to reduce

the impact of climate change on individuals with albinism and to ensure their resilience.

- **Protection of Human Rights Defenders:** Tanzania has taken steps to protect human rights defenders, including those working on the rights of persons with albinism. This includes the adoption of laws that protect human rights defenders and the establishment of mechanisms for their support.

6. Where applicable, what steps have been taken in your country to investigate concerns raised by the Independent Expert through the communications procedure and to ensure that they are resolved? Kindly provide information on ongoing and successful prosecution of perpetrators of violence against persons with albinism; steps taken to criminalise possession of, and trading in, body parts of persons with albinism; community action and policing methods to protect and prevent violence against persons with albinism.

- **Establishment of Investigation Units:** The government has created specialized units within law enforcement agencies to investigate cases of violence and discrimination against persons with albinism. These units focus on identifying perpetrators, gathering evidence, and ensuring justice is served.
- **Collaboration with Civil Society Organizations:** The government collaborates with civil society organizations that work to protect the rights of persons with albinism. This partnership is crucial in addressing concerns raised by the Independent Expert and ensuring that victims of violence and discrimination receive the necessary support.
- **Strengthening Legal Frameworks:** Tanzania has reinforced its legal frameworks to protect persons with albinism, including adopting anti-discrimination laws and ratifying international treaties such as the Convention on the Rights of Persons with Disabilities. These frameworks support the investigation and prosecution of violence and discrimination cases.
- **Ongoing and Successful Prosecution of Perpetrators:** Tanzania has made progress in prosecuting those responsible for violence against persons with albinism. Despite ongoing challenges, there have been successful prosecutions, and the government continues working to ensure accountability and justice for victims.

- **Criminalization of Possession and Trading in Body Parts:** Tanzania has enacted laws that criminalize the possession and trading of body parts of persons with albinism. These laws impose severe penalties on offenders and have helped deter trafficking while protecting individuals with albinism from harm.
- **Community Policing:** The government has promoted community policing initiatives, fostering cooperation between law enforcement agencies and local communities. These programs help build trust and identify potential threats to the safety of persons with albinism.
- **Awareness Raising Campaigns:** The government has conducted campaigns to raise public awareness about the rights of persons with albinism, promoting tolerance and inclusion. These efforts have helped reduce stigma and create a more supportive environment for individuals with albinism.
- **Victim Support Programs:** The government has established victim support programs that provide assistance to individuals affected by violence or discrimination. These programs offer counselling, legal aid, and various forms of support to help victims recover and seek justice.

7. Does your country have specific disaggregated data on the prevalence of albinism including statistics on refugees, migrants and IDPs with albinism? Kindly provide the relevant data.

Unfortunately, specific disaggregated data on the prevalence of albinism in Tanzania, particularly statistics on refugees, migrants, and internally displaced persons (IDPs) with albinism, is unavailable. However, according to the 2022 National Census and Housing Report, Tanzania has 74,273 persons with albinism, of which 42,686 are male and 31,587 are female.

8. Please provide examples of how your country's NHRI has contributed to the respect, protection, and implementation of the rights of persons with albinism?

Advocacy and Awareness Raising:

- **Investigating Human Rights Violations:** The Commission for Human Rights and Good Governance (CHRAGG) has investigated numerous cases of human

rights violations against persons with albinism, including discrimination, violence, and trafficking. These investigations have helped to raise awareness of the challenges faced by individuals with albinism and to hold perpetrators accountable.

- **Issuing Recommendations:** The CHRAGG has issued recommendations to the government and other stakeholders to address the root causes of human rights violations against persons with albinism. These recommendations have helped to shape government policies and practices.
- **Organizing Awareness Campaigns:** The CHRAGG has organized awareness campaigns to promote the rights of persons with albinism and to challenge harmful stereotypes and discrimination. These campaigns have helped to create a more inclusive and tolerant society.

Monitoring and Reporting:

- **Monitoring Government Compliance:** The CHRAGG has monitored the government's compliance with international human rights standards and national laws that protect the rights of persons with albinism. This monitoring has helped to ensure that the government is fulfilling its obligations.
- **Issuing Reports:** The CHRAGG has issued reports on the human rights situation in Tanzania, including reports on the rights of persons with albinism. These reports have documented the challenges faced by individuals with albinism and have made recommendations for improvement.

Collaboration with Civil Society Organizations:

- **Partnerships:** The CHRAGG has partnered with civil society organizations that work to protect the rights of persons with albinism. These partnerships have helped to strengthen the CHRAGG's capacity to address the needs of individuals with albinism and to ensure that their voices are heard.

9. Please share the outcomes of any assessments done of the implementation of law, policies, plans and/or programmes affecting persons with albinism.

Assessing the Implementation of Laws, Policies, and Programs Affecting Persons with Albinism in Tanzania

Unfortunately, there is no specific, publicly available assessments of the implementation of laws, policies, plans, and programs affecting persons with albinism in Tanzania. This lack of data could be due to several reasons, including lack of data on the implementation of laws, policies, and programs affecting persons with albinism in Tanzania.

10. Please provide suggestions on how the mandate can strengthen its work and specific issues that should be prioritised going forward.

Focus Areas

- **Intersectionality:** Explore how albinism intersects with other marginalized identities, such as gender, sexual orientation, and socio-economic status, to identify unique vulnerabilities and develop targeted interventions.
- **Climate Change and Albinism:** Investigate the specific impacts of climate change on persons with albinism, including increased risk of skin cancer due to rising temperatures and changes in weather patterns particularly in Africa. Advocate for climate-resilient policies and programs that address the unique needs of individuals with albinism.
- **Mental Health:** Address the mental health challenges faced by persons with albinism, including anxiety, depression, and trauma. Promote access to mental health services and support programs.
- **Technology and Albinism:** Explore the potential of technology to improve the lives of persons with albinism, such as assistive devices, telemedicine, and online education. Advocate for policies that promote digital inclusion and accessibility for individuals with albinism.
- **Data Collection and Analysis:** Support the collection and analysis of disaggregated data on albinism, including prevalence rates, access to services, and experiences of discrimination. This data can inform evidence-based policies and interventions.

Strategies

- **Collaboration with Regional and International Organizations:** Strengthen partnerships with regional and international organizations, such as the African Union, the United Nations, and relevant NGOs like Tanzania Albinism Society(TAS) and Africa Albinism Network (AAN), to enhance advocacy and support for persons with albinism.
- **Capacity Building:** Provide training and capacity building programs for governments, civil society organizations, and individuals working on albinism rights to strengthen their knowledge and skills.
- **Visibility and Awareness Raising:** Continue to raise awareness of the rights of persons with albinism through public campaigns, media outreach, and social media engagement.
- **Advocacy and Policy Development:** Advocate for the adoption of inclusive laws and policies that protect and promote the rights of persons with albinism at national, regional, and international levels.
- **Monitoring Evaluation and Learning:** Regularly monitor the implementation of laws, policies, and programs affecting persons with albinism and evaluate their effectiveness. Use this information to inform future recommendations, interventions and learning.



Country: Zambia

Organisation: Albinism Foundation of Zambia and Albinism Multipurpose Organisation

Contact Person: Baidon Chandipo, Executive Director / Gift Sakala

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1. Please describe how the mandate has contributed towards the enjoyment of the human rights of persons with albinism in your country, region or beyond. Where possible, please share specific examples and stories.

The mandate of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism has had a profound impact in Zambia and across the region. By working closely with governments, civil society organizations, and local communities, the mandate has addressed critical issues such as discrimination, violence, and access to essential services for individuals with albinism. Below are key contributions of this mandate to the human rights of persons with albinism in Zambia and beyond:

Raising Awareness and Combating Stigma

- **Public Education Campaigns:** In Zambia, the mandate has been instrumental in launching public awareness campaigns aimed at dispelling myths and harmful beliefs surrounding albinism. These campaigns educate the public, emphasizing that albinism is a genetic condition, and challenge the false notion that persons with albinism possess magical powers. These efforts have significantly reduced stigma and social exclusion. The mandate also provided financial and moral support for International Albinism Day in 2022.

Addressing Attacks and Violence

- **Combatting Ritual Killings:** In Zambia, persons with albinism have faced violent attacks, including ritual killings driven by superstitions that their body parts bring wealth and fortune. The mandate has collaborated closely with the Zambian government, traditional leaders, and law enforcement agencies to address these atrocities. Through regional partnerships, the mandate has advocated for stronger legislation, thorough investigations, and enhanced protection mechanisms for persons with albinism.
- **Regional Cooperation:** The mandate has also encouraged Zambia to work with neighbouring countries, such as Malawi, Tanzania, and Mozambique, where similar attacks have been reported. This cross-border cooperation has improved intelligence-sharing, leading to the arrest and prosecution of traffickers involved in ritual killings. For instance, after the attack on Miriam Kumwenda, suspects who fled to Malawi were apprehended and sentenced.

Strengthening Legal Protections

- **Improved Legal Frameworks:** The mandate has supported efforts to strengthen Zambia's legal framework to better protect persons with albinism. Provisions have been incorporated into the national human rights framework that recognize the unique challenges faced by persons with albinism. These include stricter penalties for those involved in ritual killings and violence, alongside policies ensuring better access to healthcare, education, and social protection. The mandate has also organized a lawyers' caucus workshop, facilitated strategic litigation clinics, and held a colloquium workshop to support these legal reforms.
- **Zambia's Commitment to Protection:** In 2018, President Edgar Lungu declared his commitment to protecting persons with albinism, endorsing policies that safeguard their rights. This commitment was the result of advocacy efforts by the mandate and other human rights groups.

Access to Healthcare

- **Skin Cancer Prevention:** Due to their lack of melanin, persons with albinism are particularly vulnerable to skin cancer. In Zambia, the mandate has worked with health authorities and international organizations to improve access to sunscreen and healthcare services. In 2018, sunscreen was included on Zambia's national essential medicines list, recognizing it as a critical health need and ensuring its availability through public health facilities. This policy shift has made sunscreen more accessible and affordable, which is crucial for skin cancer prevention.

Promoting Inclusive Education

- **Support for Children with Albinism:** A significant achievement of the mandate in Zambia has been its advocacy for inclusive education. Schools are now encouraged to provide targeted support for children with albinism, ensuring they are not bullied or discriminated against. Additionally, educational materials have been adapted for children with visual impairments to ensure their full participation in the classroom.
- **Teacher Training:** Teachers in Zambia have been trained to understand the needs of children with albinism, particularly in accommodating their visual impairments and fostering an inclusive learning environment.

Empowerment and Advocacy

- **Support for Albinism Organizations:** The mandate has collaborated with local and regional organizations representing persons with albinism, helping amplify their voices in policy-making and human rights discussions. In Zambia, organizations like the Albinism Foundation of Zambia (AFZ) have been empowered to advocate for better protection and services for persons with albinism.
- **Regional Advocacy:** Zambia has participated in regional advocacy efforts led by the mandate, which promote coordinated responses to the challenges faced by persons with albinism. These efforts involve sharing best practices and strategies to combat discrimination and violence at a regional level.

2. Please provide information on the international and regional frameworks that your government has ratified or committed to, in its effort to enhance the rights of persons with albinism during this period.

The Zambian government has not yet ratified international frameworks such as the African Disability Protocol (ADP) or adopted the African Union Plan of Action (2021-2031) on attacks against persons with albinism, which aim to enhance the rights of persons with albinism. However, in the draft amendment bill of the Persons with Disabilities Act of 2012, the government has recognized and directly included issues affecting persons with albinism, reflecting its commitment to addressing their specific needs at the national level.

3. Please provide information on any specific policies, legislation, strategies, programs, projects or initiatives that your government has adopted and implemented to ensure full realization of the rights of persons with albinism, including in the areas of health, education, employment, freedom from violence and abuse, social protection during this period. Also, include information on provision of free skin cancer screening and/or treatment for persons with albinism; availability of free sunscreen; inclusion of sunscreen on national essential medicine list; provision of free eye care services for persons with albinism.

The Government of Zambia has made limited progress in addressing the specific needs of persons with albinism. However, it has taken steps to protect the rights of persons with disabilities more broadly. Notably, the draft amendment of the Persons with Disabilities Act of 2012 directly includes provisions affecting persons with albinism, such as the guarantee of free sunscreen.

At the national level, the Ministry of General Education has declared that persons with albinism should be integrated into mainstream schools, recognizing their ability to be included alongside their peers. To fully realize this, it is essential to raise awareness within communities, among other learners, and teachers. Strong strategic advocacy from the albinism community is crucial to making this vision a reality.

Additionally, the government has allocated funding through the Yellow Book to support the International Albinism Awareness Day, celebrated on June 13 each year. This day is a vital opportunity for raising awareness of the issues facing persons with albinism. However, without effective advocacy skills, the albinism community may not be able to fully utilize this platform. Therefore, while there are policy openings within the Zambian government, strong and strategic advocacy is needed to actualize these opportunities.

4. To what extent is albinism officially recognised as a disability in your country's legislation and policies?

In Zambia, albinism is not explicitly recognized as a standalone disability in most legislation and policy. However, an analysis of how albinism is recognized as a disability reveals several important insights.

The Government of the Republic of Zambia (GRZ) acknowledges persons with albinism as persons with disabilities. This is reflected in the draft amendment of the Persons with Disabilities Act of 2012, which directly addresses issues affecting individuals with albinism. However, albinism has not been adequately recognized within the disability movement in Zambia, leading to a lack of participation and benefits for persons with albinism in disability programs. Several factors contribute to this gap between albinism and disability:

- **Lack of Recognition:** Albinism is not explicitly mentioned in the definition or description of disability in legislation, nor is it listed among the different types of disabilities. This lack of reference contributes to the marginalization of issues related to albinism.
- **Loss of Confidence:** Many persons with albinism have lost confidence in the disability movement due to their exclusion. Consequently, they may feel disillusioned and see little benefit in participating in disability programs.
- **Inequitable Opportunities:** The Zambia Agency for Persons with Disabilities (ZAPD) has struggled to balance and provide equal opportunities for its affiliate organizations that address various types of disabilities. As a result, the albinism community feels overlooked and unsupported by this umbrella organization.

- **Independence from the Disability Sector:** Some African countries have begun to address albinism independently, enacting policies specific to albinism and separating it from broader disability discussions. This trend has influenced some persons with albinism in Zambia, who now consider distancing themselves from the disability sector, believing they can advocate for their rights independently.
- **Internal Division:** There is a division within the albinism community itself. Some individuals advocate that albinism is not a disability and refuse to engage with the disability movement, while others assert that it is indeed a disability and actively participate in disability programs.

Overall, while the GRZ recognizes persons with albinism as individuals with disabilities, significant challenges remain in ensuring their inclusion and participation in the broader disability movement in Zambia. Addressing these challenges is crucial for fostering a more inclusive society for all individuals, regardless of their condition.

5. Please indicate the steps your government has taken towards implementing the recommendations made by the Independent Expert in her thematic and country reports. Please provide information on what your government/country has done to ensure the inclusion of persons with albinism in addressing racism, trafficking, migration, climate change and Human Rights Defenders.

The Zambian Government has made limited progress in safeguarding the lives and well-being of persons with albinism, particularly in addressing issues such as racism, trafficking, migration, climate change, and the protection of human rights defenders. However, there have been some notable steps taken to consider the needs of persons with albinism:

- **Inclusive Employment Opportunities:** The government has demonstrated its commitment to inclusivity by ensuring that no citizen is left behind in employment opportunities. There is observable evidence of increasing employment among persons with albinism within government positions, which signifies a positive shift toward greater representation.
- **Willingness to Collaborate:** The government has begun to show signs of willingness to engage with the albinism community. There are instances where

government officials consult albinism organizations to gather essential information and insights, indicating a more collaborative approach.

- **Provision of Sunscreen Lotion:** The government has continued to purchase sunscreen lotion for persons with albinism over the past few years. While this initiative is currently implemented without a formal policy framework, and the provision is not consistently guaranteed, it is a step in the right direction. Sunscreen is often available at various health centers, demonstrating a recognition of the health needs of persons with albinism.

However, there remains a pressing need for the government to establish a comprehensive policy that ensures the consistent availability of sunscreen as an essential medicine for all Zambians with albinism. Engaging with the government through relevant mandates could help solidify this initiative and enhance the protection and support for persons with albinism across the country.

6. Where applicable, what steps have been taken in your country to investigate concerns raised by the Independent Expert through the communications procedure and to ensure that they are resolved? Kindly provide information on ongoing and successful prosecution of perpetrators of violence against persons with albinism; steps taken to criminalise possession of, and trading in, body parts of persons with albinism; community action and policing methods to protect and prevent violence against persons with albinism.

Despite the arrest of some perpetrators, the Zambian Government has not demonstrated a serious commitment to addressing cases involving attacks against persons with albinism. Many reported incidents often fade without appropriate action or resolution. There is a pressing need for more robust measures to protect persons with albinism in Zambia.

The mandate should assist the albinism community in Zambia in engaging with the government to develop effective policing strategies aimed at preventing violence against persons with albinism. It is essential that these strategies are formulated and implemented at a regional level to ensure the safety and well-being of individuals with albinism throughout the country.

More proactive and sustained efforts are necessary to ensure that cases are taken seriously and that victims receive justice and protection from further harm.

7. Does your country have specific disaggregated data on the prevalence of albinism including statistics on refugees, migrants and IDPs with albinism? Kindly provide the relevant data.

Zambia lacks specific and comprehensive disaggregated data on the prevalence of albinism, including statistics on refugees, migrants, and internally displaced persons. While the government and civil society organizations have made efforts to document cases of albinism, reliable and disaggregated data remains limited.

According to the 2010 Census on Population and Housing, the national population of individuals with albinism was recorded at 25,324. The number of persons with albinism in rural areas was notably higher than in urban areas, with 16,937 individuals in rural regions compared to 8,387 in urban areas. Lusaka Province had the highest population of individuals with albinism, totalling 3,495, while North-Western Province reported the lowest at 1,387. Furthermore, the literacy rate among the albino population stood at 66.1 percent.

Overall, these figures highlight the need for more detailed data collection and analysis to better understand the circumstances of persons with albinism in Zambia and to inform policies and interventions that address their unique challenges.

8. Please provide examples of how your country's NHRI has contributed to the respect, protection, and implementation of the rights of persons with albinism?

The National Human Rights Institution (NHRI) in Zambia is mandated to protect and promote human rights across the country, including the rights of vulnerable groups such as persons with albinism. The NHRI has played a significant role in advocating for legal reforms aimed at safeguarding individuals with albinism from violence and discrimination. However, this advocacy often addresses albinism as a component of broader disability issues rather than recognizing it as a distinct category of disability.

To enhance the effectiveness of its efforts, the NHRI should initiate programs specifically focused on albinism. This targeted approach would allow for a more comprehensive understanding of the unique challenges faced by persons with albinism and would better address their specific rights and needs.

9. Please share the outcomes of any assessments done of the implementation of law, policies, plans and/or programmes affecting persons with albinism.

The Albinism Foundation of Zambia, as part of the PAIRS-IV project, conducted a comprehensive disability assessment study to evaluate how the National Health Insurance Scheme (NHIS) addresses the needs of persons with albinism and other forms of disabilities. The study aimed to assess the level of access and utilization of the NHIS among persons with disabilities (PWDs) and to identify gaps in the scheme's implementation from a disability perspective. The findings from this research will inform advocacy interventions focused on the priorities of persons with albinism (PWAs) and the broader PWD community, as well as raise awareness about the NHIS and its relevance to their health needs.

The study revealed that the NHIS was developed without adequately considering disability-related needs, resulting in a "disability-blind" planning and implementation process. This oversight has created systematic barriers that contribute to low awareness and utilization of the scheme among PWDs. Key barriers identified include insufficient consultation and engagement with persons with disabilities and organizations representing them; cumbersome and lengthy registration processes; the use of non-accessible communication formats; and restrictive policy benefits that fail to cover essential albinism-related health needs, as well as necessary assistive devices. Consequently, individuals bear the financial burden of procuring critical assistive devices and products themselves.

To address these challenges, the study recommended several key actions:

- **Inclusion of Albinism-Related Health Needs:** Incorporate albinism-related health needs into the benefits package, ensuring the consistent provision of sunscreen as an essential health need, along with comprehensive coverage for skin cancer prevention, detection, and treatment services.

- **Awareness-Raising Initiatives:** Promote awareness of the NHIS and its benefits through an inclusive lens, and provide disability awareness training for policymakers and healthcare workers.
- **Expanded Research:** Conduct further research into the health needs and service utilization among PWDs to better understand their specific requirements.
- **Administrative Simplification:** Streamline administrative processes and exceptions, and decentralize the registration process to include rural health posts.
- **Stakeholder Engagement:** Enhance stakeholder engagement by actively consulting persons with disabilities and disability advocates as key stakeholders in the planning and implementation of the NHIS.
- **Disaggregated Data Collection:** Collect disaggregated disability data based on specific types of disabilities to improve planning, budgeting, and tracking of service usage, ultimately enhancing the overall effectiveness and accessibility of services for PWDs.

10. Please provide suggestions on how the mandate can strengthen its work and specific issues that should be prioritised going forward.

The mandate can be significantly strengthened by continuing to engage with albinism organizations and Human Rights Defenders on issues that affect their communities. Additionally, the mandate should establish strong collaborations with the Africa Albinism Network (AAN), the Zambia Agency for Persons with Disabilities (ZAPD), the Zambia Federation for Disability Organisations (ZAFOD), and other disability organizations globally. Key priorities for this collaborative effort include:

- **Strengthening Legal Protections:** Work closely with the government to advocate for the classification of attacks against persons with albinism as non-bailable offenses, ensuring that perpetrators face appropriate consequences.
- **Addressing Hate Speech:** Assist the government and Zambia Police in prosecuting not only hate speech directed at persons with albinism but also any life-threatening comments that may incite violence against them.
- **Improving Data Collection:** Collaborate with the government to ensure that disaggregated data on the number of persons with albinism is comprehensively

captured during census collections, facilitating better policy formulation and resource allocation.

- **Promoting Albinism Awareness:** Work in tandem with the government to treat issues related to albinism with the urgency and seriousness they warrant, raising awareness at all levels of society.
- **Capacity Building:** Provide capacity-building initiatives for Zambian albinism organizations to enhance their advocacy for human rights and improve their organizational development.
- **Drafting National Action Plans:** Partner with the Africa Albinism Network (AAN) to ensure that all African countries develop and adopt National Action Plans on albinism, which should be formally signed by their respective governments.
- **Ratifying the African Disability Protocol:** Support efforts in all African states that have not yet ratified the African Disability Protocol (ADP) to do so, ensuring a more comprehensive framework for the rights of persons with disabilities.



Additional questions for UN and Regional bodies

1. Please highlight measures your institution has taken to integrate an albinism perspective into your work.

At the Africa Albinism Network (AAN), we have taken several targeted measures to integrate an albinism perspective into our work as this forms the core of what we do:

- **Advocacy and Awareness Campaigns:** We actively engage in national and international advocacy to raise awareness about the challenges faced by persons with albinism, such as discrimination, violence, and exclusion. Our campaigns are tailored to amplify the voices of persons with albinism and promote their rights at national and international levels such as engaging with the African Union and the United Nations human rights mechanisms.
- **Capacity development and Empowerment:** We provide training and capacity-development programs for persons with albinism to enhance their skills in advocacy and leadership. This helps to ensure they can participate meaningfully in decision-making processes at various levels. For instance, since our establishment in 2021, we have organised two regional learning forums bringing together over 150 albinism group leaders from over 30 countries across Africa. We have also organised several other national level Learning forums focused on developing the capacities of albinism group leaders as well as human rights defenders with albinism in countries such as Kenya, South Africa, Namibia, Mozambique, Angola, Zambia, Togo, Madagascar etc.
- **Human Rights Monitoring and Reporting:** AAN works closely with human rights bodies, such as the UN Human Rights Council and the African Commission on Human and Peoples' Rights, as well as the African Committee of Experts on the Rights and Welfare of the Child to document and report on human rights violations against persons with albinism. Our reports focus on the

specific challenges persons with albinism face and advocate for policy changes that reflect their needs.

- **Collaboration with Stakeholders:** We partner with governments, civil society organizations, and international bodies to ensure that the rights of persons with albinism are mainstreamed into broader human rights and social development frameworks. Our goal is to ensure that persons with albinism are not only included in policy discussions but that their specific needs are addressed.

2. Please indicate what steps you have taken to implement the specific recommendations made by the Independent Expert to your institution, including in thematic reports.

Our work's thematic approach reflects three major areas we contribute to the UNIE reports. Refer to our thematic page for more information on steps taken to implement specific recommendations by the UNIE.

- Human Rights Defender: <https://africaalbinismnetwork.org/thematic-areas/human-rights-defenders/>
- Women Impacted by Albinism: <https://africaalbinismnetwork.org/thematic-areas/women-impacted-by-albinism/>
- Climate Change and Albinism: <https://africaalbinismnetwork.org/thematic-areas/climate-change-albinism/>

3. Please show how you have collaborated with the mandate in your work.

Since its establishment in 2021, the Africa Albinism Network (AAN) has actively collaborated with the UN Independent Expert on the enjoyment of human rights by persons with albinism (UNIE) to contribute to thematic reports. These contributions were based on inputs gathered from albinism groups across Africa. Key reports include:

- Harmful Practices and Hate Crimes Targeted at Persons with Albinism (January 2022)
- Persons with Albinism on the Move (July 2022)
- Human Rights Defenders Working on Albinism (December 2022)

- Climate Change and Persons with Albinism (July 2023)
- Access to Education (January 2024), to be presented to the Human Rights Council in March 2024.
- Persons with albinism and the Rights to family life in October 2024

In addition, AAN supports countries in developing or implementing National Action Plans (NAPs) in line with the African Union’s Plan of Action 2021–2031. For instance, in Tanzania, where the NAP on albinism is still pending adoption, AAN collaborated with the UNIE to organize a stakeholder engagement in February 2024. This engagement aimed to highlight the importance of adopting the NAP and furthering discussions on the situation of persons with albinism in the country.

In September 2024, AAN partnered with the UNIE during a public hearing for the case Centre for Human Rights and Others vs. the United Republic of Tanzania at the African Court on Human and Peoples’ Rights. This collaboration helped bring albinism issues to the forefront of legal discussions.

In October 2023, AAN and UNIE co-organized a training for human rights defenders with albinism from five Lusophone countries, in partnership with UNESCO Mozambique. The event gathered 30 participants from civil society, government, and international organizations, and addressed key human rights, health, and discrimination issues. Recommendations emphasized the need for inclusive program design to overcome linguistic and financial barriers, while also promoting greater understanding of albinism.

Children with Albinism:

Following her effective advocacy at the 42nd Ordinary Session of the African Committee of Experts on the Rights and Welfare of the Child (ACERWC) in November 2023, the UNIE secured a “Day of General Discussion on Children with Albinism” at the 43rd Ordinary Session in April 2024. AAN ensured youth participation during the general discussion. Currently, guidelines for African States on the rights of children with albinism are under development and a team including AAN Advocacy Manager made a presentation of the Guiding Note to the Working Group on Children with Disabilities.