

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

**Official visit to Lesotho**

 **10 to 19 April 2024**

**Preliminary findings**

I would like to express my appreciation for the invitation extended to me at the initiative of the Government of Lesotho, to undertake an official visit from 10 to 19 April 2024.

I thank the Ministry of Foreign Affairs and Ministry of Justice, who have been the key focal ministries supporting and facilitating my visit. I also extend my gratitude to the UN Resident Coordinator, the UNCT, particularly OHCHR and UNDP colleagues, for their valuable support, both before and during my visit.

In the course of my visit, I held meetings in Maseru and Thaba-Tseka. I met representatives from the Ministry of Foreign Affairs; Ministry of Law and Justice; Ministry of Health; Ministry of Education; and the College of Education; Ministry of Gender, Youth and Social Development; the President of the Court of Appeal; the Ombudsman; staff and students with albinism at St Catherines School and St Bernadette’s Resource Centre for the Blind. I also met with State medical practitioners, including an ophthalmologist, and oncologist. I met with the UNCT, civil society organizations working on various thematic issues; and those working specifically on albinism. I also met with persons with albinism and their families.

I wish to sincerely thank everyone that took time to meet with me, particularly persons with albinism and their family members, who willingly and openly shared their experiences, including journeys that have been difficult and painful to recount.

**Session of the African Committee of Experts on the Rights and Welfare of the Child (ACERWC)**

During my visit, I also took the opportunity to participate in the 43rd ordinary session of the ACERWC held in Maseru. I met with civil society organizations representing persons with albinism from the Africa region, and along with dozens of persons with albinism, attended the General Day of Discussion on solutions and challenges faced by children with albinism. The General Day of Discussion was a milestone event, and stakeholders including Government representatives, civil society organizations, and persons with albinism from Lesotho were also able to participate.

**Context of the visit**

My visit to Lesotho is unprecedented given that the Government sent me an expedited invitation and support to facilitate my visit. I again commend this as a good practice. While I have received much information on the situation of persons with albinism from various countries in the region, Lesotho is among those countries that I do not often receive information on. It is in this sense, opportune for me to have conducted this visit to better understand the human rights situation of persons with albinism in the country.

**Positive initiatives**

I recognize a series of positive initiatives undertaken by Lesotho which strengthen human rights protection. This includes the ratification of international human rights treaties such as the ICCPR, ICESCR, CRC and CRPD. Lesotho recently signed the African Protocol on the Rights of Persons with Disabilities, in February of this year. Lesotho also adopted the Persons with Disability Equity Act in 2021, which defines disability in line with the CRPD. In terms of policies, Lesotho has a National Strategic Development Plan II extended to 2027/2028 which aims to, inter alia, address poverty, social exclusion, unemployment and health care. The National Social Protection Strategy II (2021-2031) covers various vulnerable groups including persons with disabilities, with reference to a *pro-poor disability grant*.

Lesotho has also taken steps towards establishing a national human rights commission. During the Human Rights 75Initiative last December, Lesotho committed to enhancing its reporting obligations under regional and international human rights law. It also committed to extend standing invitations to Special Procedures, through which I am able to undertake this visit. In commemorating International Human Rights Day last December, the government provided sunscreen to persons with albinism in Thaba-Tseka, providing much needed sun-protection for many who ordinarily would not be able to access this product.

**CHALLENGES**

* **Data and statistics**

There are no existing data on persons with albinism in Lesotho, including from the 2016 census. Though some estimates have referred to around 8,798 persons with albinism in country, with 2,583 in Maseru, this statistic has to be verified. I note the 2026 census will provide an opportunity to include data and statistics on persons with albinism and I have requested that a specific question on albinism be included in this process, as has been done in various other countries in the region. Ensuring that data on persons with albinism are also disaggregated will also help in understanding their human rights situation more accurately. In this regard, I believe it will be beneficial to undertake a situational analysis of persons with albinism in the country as an initial-step to collecting much-needed data and statistics.

* **Stigma and discrimination**

Throughout my visit, I note a prevalent presumption by various stakeholders that persons with albinism are treated “well” and are “just like everyone else” in Lesotho. They often support this by referencing the lack of reported cases of ritual attacks and killings in the country. Although this is indeed a positive marker, the lived reality of persons with albinism in Lesotho is far from “equal.”

The majority of persons with albinism have recounted stories and experiences where they have suffered stigma and discrimination, mostly due to ignorance about albinism or due to false beliefs about the condition. Some myths include persons with albinism not dying, rather they just “disappear”, and some believe they turn into donkeys after death. Others refer to persons with albinism as supernatural beings or their presence as an omen of good luck, as well as bad luck.

In schools, children with albinism experience bullying, micro-aggressions and othering, by both teachers and peers. Few receive any form of reasonable accommodation in class. These factors have often contributed to high drop out rates for learners with albinism, particularly in secondary education. False beliefs have also impacted the experiences of mothers with albinism. A number of mothers with albinism experience depression upon discovery that their child has albinism. Several also inform that they were abandoned by their spouse/partner, refusing to accept the child with albinism. I have met a number of single mothers raising children with albinism, often without sufficient financial means.

I note that some children with albinism have been abandoned and left to be cared for by grandparents or community members. In Leribe, a safe house for orphans provides shelter for a number of children with albinism who have been abandoned by their parents and families. When asked about adoption possibilities, I was told that it is harder for children with albinism to find adoptive homes, most likely due to their condition.

I note that persons with albinism, particularly children, are seen as “expensive” to raise and care for. Due to their health needs requiring sunscreen, medical check ups for their visual impairment, parents and family members often highlight the high costs of caring for children with albinism in comparison to those without. In poverty situations, which affects many persons with albinism, this can often result in abandoning a child with albinism or raising a child with albinism without the provision of special requirements to support them.

I am encouraged though, that a number of experiences with maternal care providers or nurses have been positive. I was told by several mothers and grandmothers of persons with albinism that they were often given support by nurses after childbirth delivery which helped them to better accept their infant with albinism.

I note that in some instances, stigma and discrimination are not overt but consist of microaggressions and marginalisation. Persons with albinism also experience “othering”, where they are treated as having lesser value or worth. The name given to a person with albinism – “lesoefe” can also be problematic. While some note that this is merely the word for the condition, others informed me that this term can be derogatory as it objectifies a person with albinism, and focuses on the albinism condition and not the person.

**Health**

The health challenges of persons with albinism were constantly raised as a priority area in need of support and solutions. The risk of skin cancer is extremely high for persons with albinism, and the lack of access to visual aids, including spectacles, can seriously limit their quality of life. Skin cancer is in fact the primary cause of death for persons with albinism in the region, rendering sunscreen an essential medicine – not a cosmetic product. I was informed however that the public health system does not provide sunscreen. Rather, the provision of sunscreen is mainly done via civil society organizations who partner with overseas non-government organizations.

Access to visual aid including spectacles is difficult due to costs and the lack of specialists. A cost of spectacles can range from 3,500 rand to 14,000 rand which is unaffordable for many. Furthermore, there is a severe lack of specialists in the country. I was told that for the whole country, there is one ophthalmologist in the public hospital, one oncologist in Senkatana and one dermatologist in private practice. Often serious medical conditions, including skin cancer, are referred to hospitals in South Africa, though covered by the Lesotho Government. I was saddened to meet one person with albinism who suffers from a deformity on her face due to a reconstruction procedure that went wrong, leaving her in her current painful state. I have noted this case to be serious and can provide further information to assist in obtaining the appropriate treatment for this person, who is also unemployed and widowed.

I have been informed that skin cancer, though treatable, is often detected late and can result in death. I have highlighted that the provision of sunscreen is essential and that it makes more financial sense to invest in sunscreens than to cover the costs of treating skin-cancer.

The impact of stigma and discrimination has led to psycho-social issues for persons with albinism. It is evident that there is a need to provide support for mental health as many experience depression and trauma due to their mistreatment. Some have expressed the need for counseling and have highlighted that persons with albinism, particularly children and youth are often lacking in self-esteem and confidence.

**Education and employment**

Access to education is extremely challenging. There is a great need for reasonable accommodation for learners with albinism. Reasonable accommodation measures in school, including the provision of assistive devices, large print documents, placing of persons with albinism at the front of the class, are fairly easy to implement but are still lacking in many cases, particularly in rural communities where teachers do not have an understanding of albinism. I am also concerned at reports that teachers also discriminate against persons with albinism, along with other students. I met many persons with albinism whose educational prospects were hindered by a lack of financial means or reasonable accommodation.

The inability to finish one’s education also results in difficulty in accessing adequate employment. The majority of persons with albinism I met were either self-employed or unemployed. They were not receiving any government financial assistance and so often relied on relatives and others to support them. As such, poverty is often a reality for many, which in turn impacts the ability to access sunscreen, visual devices and much needed health services.

Social protection benefits are also inaccessible for many persons with albinism. When assessing the various grants that could be provided to them, including due to visual impairment which is also a disability, I found that many are ineligible to receive this support. There is a common misunderstanding by stakeholders that persons with albinism are not persons with disabilities and I have informed them that indeed, visual impairment and extreme susceptibility to skin cancer can render a person as having a disability and therefore eligible to obtain social support. I urge the government to move away from the medical approach to disability that is entrenched in the grant-issuing processes.

I note that lack of access to employment is also due to employers discriminating against persons with albinism. In one case, a qualified person with albinism was asked whether her qualifications were indeed hers, implying that she is not capable of obtaining these credentials.

**Remote rural areas**

I had the privilege of visiting one of the most remote villages in Thaba-Tseka. I had to walk on foot for almost an hour to access a family with albinism as it was not possible to access this village by vehicle. What I witnessed confirms that persons with albinism are among the furthest left behind, particularly when living in the most remote areas of the country. I learned that none of the persons with albinism I met in this remote village knew what sunscreen was and due to lack of financial means, they dropped out of school and were unemployed. One young lady with albinism was pregnant and would need to walk two hours over the mountainous terrain to access the nearest health-care facility.

Children living in these areas also had to walk one hour to and one hour from school in order to access an education. Some of these children were as young as 6 years old and had to get to school by foot every day.

Poverty seemed to affect many persons with albinism in Maseru due to unemployment, but even more so in rural communities who are at grave risk of being forgotten. I urge the government to ensure that persons with albinism in the most remote and rural areas are included in obtaining the support they need to live a more meaningful life.

**Raising awareness and representation**

It is clear to me that albinism is still profoundly misunderstood, and the lack of knowledge about the condition has contributed to the myriad of challenges and struggles that many persons with albinism experience. I underscore the importance of establishing a robust nation-wide program to debunk myths, educate and raise awareness about persons with albinism in order to effectively combat stigma, prejudice and discrimination. This program needs to be ongoing until albinism is well-understood and the marginalization and exclusion of persons with albinism are effectively addressed.

Commemoration of International Albinism Awareness Day (13 June) at the national, provincial and community level – and not just among albinism communities will also help in eliminating misbeliefs and ignorance about albinism.

I am pleased to note that there are a number of high-profile and influential persons with albinism in Lesotho who have overcome extraordinary hurdles to succeed in their various areas of influence. Among these are State representatives, members of the judiciary, academics and civil society organization leaders. I highlight the need to increase greater representation of persons with albinism in all spheres of society to also eliminate stigma and discrimination and showcase the amazing skills and abilities they have. Many persons with albinism are extremely gifted and with great potential to excel in life, but their aspirations are cut short by discrimination and a lack of resources and support.

**Empowerment and capacity building**

I note that there are only about two main civil society organizations working on albinism in Lesotho, although with memberships around the country. I stress the importance of empowering, equipping and building the capacity of these organizations as they provide key services to persons with albinism. I welcome efforts by the Government, UN, development partners and the private sector to provide support, both in capacity-building and in resources, to these organizations as they are essential links to persons with albinism in the country. Although the two CSOs were established to be support groups for persons with albinism, empowering them to advocate for their rights is essential.

Finally, a multisectoral approach, which includes government, CSOs, persons with albinism and other key stakeholders must be established to address the multi-faceted challenges experienced by persons with albinism. I encourage the Government to refer to national action plans on albinism adopted by various countries in the region as a basis to address the needs of persons with albinism in a holistic manner. Using the human rights-based approach to provide solutions for persons with albinism can also be aided through reference to the AU Plan of Action to end attacks and other human rights violations targeting persons with albinism.

I stand ready to provide support, including technical assistance, to address the various human rights challenges of persons with albinism in Lesotho.

**Preliminary recommendations**

A comprehensive list of recommendations will be provided in the official report of my visit to Lesotho, which will be presented at the UN human rights council in March 2025.

The following are preliminary recommendations:

* Undertake a situational survey on the human rights challenges experienced by persons with albinism
* Include a question on albinism in the forthcoming census in 2026
* Establish a multisectoral approach to dealing with persons with albinism as vulnerable groups
* Include persons with albinism as part of the key vulnerable groups under social development assessments for social protection benefits
* Consider a quota for persons with disabilities to also include persons with albinism in employment recruitment
* Include sunscreen in the national essential medicines list
* Provide sunscreen through the public health system to ensure nation-wide distribution, including to remote rural areas
* Provide subsidy for visual devices for persons with albinism
* Train and provide more dermatologists, oncologists, and ophthalmologists in the public sector
* Train teachers, health care workers, and key public services providers on albinism
* Provide support including psychosocial and socio-economic support to persons with albinism and their family members
* Include albinism in education curricula including in subjects such as *Life Skills* which could assist in raising awareness and enhancing understanding of albinism
* Commemorate International Albinism Awareness Day (13 June) annually
* Undertake targeted campaigns engaging local community leaders particularly in rural areas to raise awareness and debunk myths and false beliefs about persons with albinism
* Support and build capacity of civil society organizations working on persons with albinism
* Review and amend the Disability Act to align it fully with the CRPD
* Mainstream albinism into relevant national policies, in line with the efforts to achieve the 2030 Agenda for Sustainable Development Goals
* Adopt and fund a national action plan on albinism, with reference to the AU Plan of Action as guidance on key areas of focus
* Ensure albinism is covered in stakeholder reports to the international and regional human rights mechanisms, including treaty bodies and the Universal Periodic Review
* Pass the law establishing the National Human Rights commission as a lasting and affordable means for enforcement and meaningful enjoyment of human rights for all including persons with albinism in Lesotho.

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