

Submission to the 96 Pre-Sessional Working Group of the Committee on the Rights of the Child on the situation of children with albinism in Namibia

Submitted on 1st August 2023

Submitting organizations:

Africa Albinism Network welcomes the opportunity to submit this report for consideration during the 96th Pre-sessional Working Group of the Committee on the Rights of the Child (CRC Committee) state review of Namibia. The [Africa Albinism Network \(AAN\)](#) works to protect the rights of people with albinism in Africa from targeted violence, ritual attacks, and discrimination through the promotion of the [AU Plan of Action on albinism \(2021-2031\)](#) and the capacity development of albinism groups.

Contact:

- Africa Albinism Network: info@africaalbinismnetwork.org.
Website: www.africaalbinismnetwork.org

Introduction

Albinism is a relatively rare, non-contagious, genetically inherited condition in which a person produces little to no melanin, resulting in little to no pigmentation, in the skin, hair, and eyes. This lack of melanin often results in a pale or “white” appearance compared to other members of their family, community, or ethnic group causing hypervisibility. In addition, the lack of melanin results in two congenital and permanent health conditions: visual impairment of varying degrees as well as high vulnerability to skin damage from ultraviolet rays, including skin cancer. Albinism affects people worldwide regardless of race, ethnicity, or gender.¹

In Africa, estimates of the occurrence of albinism range from 1 in every 5,000 people to 1 in every 15,000. In some populations in the region, including in Southern Africa,

¹ Report of the Independent Expert on the enjoyment of human rights by persons with albinism Worldwide A/74/190.

it may be as high as 1 in 1,000.² Up-to-date reliable statistics on the number of persons with albinism remain a challenge on the continent.

Methodology

This report is based on first-hand knowledge and experience of the Africa Albinism Network, report on the public hearings on discrimination and other challenges faced by persons with albinism in Namibia by the Office of the Ombudsman of Namibia as well as reliable research, credible media reports, and insights from the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism.

The human rights situation of children with albinism in Namibia

Children with albinism in Namibia belong to a less visible group of individuals with disabilities who face multiple and intersecting barriers to accessing their human rights. Based on the 2011 population census of Namibia, it was reported that there were 1,153 individuals with albinism, constituting approximately 1.2 percent of the total population. However, the census data did not provide any specific information regarding the number of children with albinism residing within Namibia's jurisdiction, which is a notable limitation. This lack of detailed information concerning the population of children with albinism is regrettable as it hinders a comprehensive understanding of the needs and challenges faced by this specific demographic group.

This submission specifically highlights the government of Namibia's failure to ensure that children with albinism in the country are able to enjoy their rights to inclusive education, proper healthcare, personal safety, social security benefits, and, most importantly, the right to life.

Compliance with the provisions of the UN Convention on the Rights of the Child

Articles 6 & 37: Right to life and freedom from torture or cruel, inhuman, or degrading treatment or punishment of children

² Preliminary Report of the United Nations High Commissioner for Human Rights, "Persons with Albinism," September 12, 2013 at para 14, http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_EN_G.doc, and Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", BMC Public Health, vol. 6, No. 212 (August 2006). www.biomedcentral.com/1471-2458/6/212

Since 2010, Namibia has recorded five cases of attacks against individuals with albinism, with two of them resulting in fatalities and three survivors.³ While none of these reported attacks targeted children with albinism directly, there have been instances where children were concealed from the public for prolonged periods. A striking example is a 34-year-old woman with albinism, who had to remain hidden from society for 22 years – therefore, since childhood – due to the community's hostility towards her family because of her genetic condition. She recounted how people avoided visiting her family's home and maintained distance, all because of the presence of an albino child in the household.⁴

The full extent of violent crimes targeting children with albinism in Namibia is unknown, as most attacks against persons with albinism are believed to go unreported for various reasons, including the involvement of family members, a culture of silence around such crimes as well as a lack of formal monitoring mechanisms to accurately track and report cases. These attacks are often driven by erroneous beliefs that the body parts of persons with albinism when used in witchcraft rituals can bring riches, success, power, or sexual conquest. The body parts of children are considered even more potent because of their innocence. These myths and the resulting attacks are often perpetuated and fuelled by unscrupulous traditional healers. Children with albinism are at a heightened risk of being attacked, their safety and security is thus an issue of grave concern that needs to be addressed.

Article 2: Prohibition against discrimination on the basis of color

Stigma towards persons with albinism due to their coloring and appearance is widespread due to ignorance and myths associated with the condition. Some communities in Namibia believe that persons with albinism are “ghosts” or have magical powers; that they are the result of incest or a curse. Others also hold the belief that the hair and blood of a child with albinism are sources of power and wealth. It is common to see people spitting on themselves upon encountering a person with albinism because of the belief that they are a source of misfortune.

³ <https://www.underthesamesun.com/wp-content/uploads/2023/07/Attacks-of-PWA-1-page-07.05.23.pdf>

⁴ <https://www.nbcnews.com/news/woman-kept-hidden-22-years-because-albinism.21698>

In 2019 during a public hearing on the situation of persons with albinism in Namibia conducted by the Office of the Ombudsman, it was revealed that persons with albinism, including children, are subjected to various forms of discrimination including being called names, spat at, mocked and avoided by their peers; being treated differently based on the color of their skin; abuse and violence, such as being beaten or cut to see if their blood is as different as their skin; and misconceptions and beliefs make people unwilling to share their food and clothing with persons with albinism. If persons with albinism touch someone or their belongings, they are often beaten or insulted.⁵ Because they are a minority and historically marginalized group in society, discrimination against them is simply overlooked and unreported.

Article 24: Right of the child to the enjoyment of the highest attainable standard of health

Skin cancer prevention and treatment:

In Namibia, children with albinism face a significant risk of ultraviolet-induced skin damage because their skin lacks melanin, which provides natural protection against the sun's harmful rays. Additionally, this age group tends to spend more time outdoors in the sun, increasing their exposure to harmful ultraviolet radiation. Consequently, they are highly susceptible to developing skin lesions that have both cosmetic and health complications, with a high risk of developing skin cancer in later years.⁶

Skin cancer is a primary cause of early death in most persons with albinism in Africa. The United Nations posits that most persons with albinism do not live past the age of 40 due to skin cancer-related illnesses. In Namibia, there are no official statistics about skin cancer-related deaths among persons with albinism, but research shows that harsh climatic conditions coupled with poor sun protective behavior increase skin cancer risks among this group.⁷

⁵ Office of the Ombudsman, Report on the public hearings on discrimination and other challenges faced by persons with albinism. 2022. Available here <https://africaalbinismnetwork.org/wp-content/uploads/2022/11/Namibia-Ombudsman-Albinism-Report-2022.pdf>

⁶ Lack of adequate sun protection for children with oculocutaneous albinism in South Africa <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>.

⁷ Lack of adequate sun protection for children with oculocutaneous albinism in South Africa <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>

According to reports, children with albinism are particularly vulnerable to skin cancer, with approximately seven of them requiring skin cancer-related treatment annually at Windhoek Central Hospital.⁸ Indeed, this data raises concerns about access to medical facilities for those residing in rural areas. It is plausible to assume that children with albinism in rural regions might face challenges in accessing specialized treatment facilities that are primarily concentrated in urban centers like the capital city.

The lack of healthcare infrastructure and medical resources in rural areas can hinder the timely diagnosis, treatment, and management of skin cancer cases among children with albinism. This disparity in access to medical facilities might result in delayed interventions and potentially poorer health outcomes for affected children living in remote regions.

Addressing this issue requires a comprehensive approach, including efforts to improve healthcare infrastructure in rural areas, raise awareness about albinism and its associated health risks, and establish outreach programs to ensure that all children with albinism have equitable access to medical care, regardless of their geographical location. Facilitating health awareness and training concerning people with albinism among government authorities, non-governmental organizations, and healthcare providers is vital to bridge the healthcare gap and provide the necessary support for children with albinism across the country.

Article 28: Right to education for children

According to the state party report submitted to the Committee on the Rights of the Child, the government of Namibia admitted that children with disabilities face many challenges including the lack of disability-friendly infrastructure in and around schools, classrooms, and hostels and lack of supporting technology. The Demographic and Health Survey of 2013 indicates that about 87% of children with disabilities between the ages of 0–4 years have never attended early childhood development (ECD) programs, whereas the proportion of children with disabilities aged 5 years and above that never attended school is also high, especially in the rural areas at 82.1%,

⁸ <https://neweralive.na/posts/cancer-not-discrimination-threatens-namibian-albinos>

and 17.9% in the urban areas, the report further stated.⁹ This suggests children with albinism are less likely to benefit from these interventions.

Children with albinism in Namibia are not provided with low vision support to maximize the use of their vision such as monoculars in particular (which makes the biggest difference in their access to education), special reading glasses, and large print reading materials. Low costs adaptations such as having the student sit at the front row in class and providing them with notes of material written on the blackboard are often overlooked. They are often excluded from physical education on the basis of their low vision without reasonable alternatives.

Students also experience bullying and stigmatization within the school setting which also increases dropout rates. A typical example is the story of the 34 years old woman who was kept away from society as a child with albinism and attended school only for a year in her entire life. Students with sunburn and second-stage squamous cell cancers experience greater stigma. The schools often do not provide avenues for the students to speak about the trauma, humiliation, and pain experienced and receive the necessary psychosocial support.¹⁰

Recommendations to the Government of Namibia

Preserving the right to life and upholding freedom from torture & inhuman and degrading treatment & punishments and ensuring access to justice:

- The government of Namibia should continue to strongly condemn the incidences of attacks and related forms of violence, including killings, mutilations against children and other persons with albinism in the country.
- As advised by the UN Expert on albinism, the government of Namibia is encouraged to, in consultation with persons with albinism, develop, adopt and implement a National Action Plan on Albinism based on the AU Plan of Action on Albinism to ensure the effective protection and promotion of the rights of persons with albinism with particular attention to children and

⁹ Combined fourth to sixth periodic reports submitted by Namibia under article 44 of the Convention, due in 2017* CRC/C/NAM/4-6 para 110 and 218

¹⁰ <https://www.nbcnews.com/news/woman-kept-hidden-22-years-because-albinism.21698>

members of their families. Namibia is urged to allocate dedicated budgets to ensure the implementation of this National Action Plan on Albinism and other program interventions on albinism and to develop robust monitoring and evaluation frameworks to track progress.

- The government of Namibia is called on to work with other SADC leaders to integrate existing regional strategies, and measures for the prevention, detection, investigation, prosecution, and punishment of cross-border crimes affecting persons with albinism in the region, notably trafficking of persons, children and body parts. To this end we specifically urge Namibia to strengthen cross-border police cooperation through bilateral and multilateral agreements and to allocate adequate resources to better tackle trafficking in persons and body parts of persons with albinism; Other recommendations in this regard are available in the PAN African Parliament Guidelines on Eliminating Harmful Practices Related to Accusation of Witchcraft and Ritual Attacks.

Public Awareness:

- The government of Namibia, civil society organizations and communities of people with albinism, and other key stakeholders should work together to address the root causes of discrimination and violence against people with albinism in Namibia and increase knowledge and awareness on albinism including by embarking on an intense nationwide public awareness raising campaign to debunk false myths and beliefs about albinism and its cause.
- Government should support civil society working on issues regarding persons with albinism and should assist persons with albinism in awareness-raising about their rights including national mechanisms available for their protection.

Education:

- Namibia should take all measures necessary to enhance access to inclusive, equitable, and quality education for children with albinism and to provide comprehensive reasonable accommodation at all levels of education, including in the form of low vision support to maximize the use of their vision;

- Teachers and educators should continue being educated on albinism and proper protection as well as accommodation of the visual impairment of students with albinism in their care;
- Ensure that resources are at the disposal of schools to meet the specifications needed of persons with albinism, notably by providing textbooks and exams with larger fonts and assistive devices for low vision to read the blackboard such as monoculars and specialized glasses with photoprotection from the sun and glare, sun protective uniforms such as long-sleeved shirts, sunglasses and wide-brimmed hats.

Health:

- Ensure access to health services and adaptive devices for reasonable accommodation such as visual aids as described above under education.
- Provide low-cost and barrier-free access to quality sunscreen with an appropriate protective spectrum for all persons with albinism particularly children in rural areas and with emphasis on skin cancer screening, prevention, and treatment.
- Provide available and low-cost, barrier-free access to specialist services for low vision and dermatological care including skin cancer treatment and prevention. Psychosocial support should also be made available to persons with albinism in their communities.
- Nurses and midwives should be trained on albinism and provision of counseling to parents when babies with albinism are born. This will reduce the chances of rejection and abandonment by mothers of children with albinism.

Data collection:

- We urgently request that Namibia systematically collect, disaggregate, and disseminate data on persons with albinism including children with albinism using the guidance note by the Washington Group.¹¹

¹¹ <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/>

Social protection:

- We urge Namibia to design, implement, and strengthen social safety net mechanisms and programs that are inclusive of children with albinism.

Cooperate with Special Procedures:

- We implore Namibia to cooperate fully with the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism and the AU Special Envoy on Albinism (once appointed) in the discharge of their mandates and to give serious consideration to implementing their recommendations, to provide the mandate holders with all necessary information relating to the mandate and to react promptly to their communications and urgent appeals in order to enable them to fulfil the mandate effectively.