

Shadow Report to the Committee on the Rights of Persons with Disabilities for the Review of Zambia

Report on the situation of persons with albinism in Zambia

A. SUBMITTING ORGANISATIONS

The shadow report is authored by the Africa Albinism Network (AAN) and the Albinism Multipurpose Organisation. These organizations have collaborated to provide a detailed examination of the human rights violations faced by persons with albinism in Zambia.

- **Africa Albinism Network**

The Africa Albinism Network (AAN) exists to promote the rights, well-being, and inclusivity of people with albinism in Africa through advocacy, capacity development, and collaboration.

Contact: info@africaalbinismnetwork.org

Website: www.africaalbinismnetwork.org

- **Albinism Multipurpose Organisation**

The Albinism Multipurpose Organisation aims to promote the economic, social, cultural, and environmental aspiration of people with albinism in Zambia and to facilitate their full inclusion in all aspects of life.

Contact Person: Gift Sakala

Position: Director

Contact: giftzambia@gmail.com

B. EXECUTIVE SUMMARY

In Zambia, persons with albinism face a myriad of challenges, including pervasive discrimination, stigma, and violence. These challenges which largely stem from prevalent myths and superstitions surrounding albinism hinder their access to education, employment, and social integration. Discrimination is particularly pronounced against women and children, who endure instances of name-calling, bullying, ritual attacks, and, in some cases, abandonment by their own family members.

While the government of Zambia has taken some steps to address these challenges, such as celebrating International Albinism Awareness Day to raise awareness on albinism and providing sunscreen, these efforts primarily benefit a few persons with albinism residing in urban centres, leaving those in remote regions behind. This report underscores the challenges faced by persons with albinism, particularly concerning

the enjoyment of their human rights, specifically outlined in Articles 5, 6, 7, 8, 10, 15, 24, 25, and 27. Additionally, the report poses several questions for the government and puts forth recommendations aimed at addressing these challenges and preventing further human rights violations.

QUESTIONS TO THE GOVERNMENT OF ZAMBIA

- What steps has the government of Zambia implemented to safeguard persons with albinism, who are susceptible to acts of violence, including heinous attacks that have resulted in fatalities, leaving them mutilated or instilling profound fear for their lives? Such occurrences directly and adversely affect their fundamental rights to life and personal security.
- Could the government of Zambia elaborate on the concrete actions it has implemented to expedite the legal proceedings and ensure conclusive judgments in cases pertaining to attacks against individuals with albinism? Particularly, when perpetrators have been apprehended, how is the government actively addressing these incidents as crimes that infringe upon the rights to life and security of the person?
- What concrete measures has the Government taken to provide remedies to persons who are victims of attack and their family members including access to justice, legal, medical, and socio-economic remedies?
- It is reported that violence and stigma aimed at people with albinism is still widespread due to general ignorance and myths associated with the condition. What has the Government done to develop and conduct sustained awareness-raising activities with the aim of increasing understanding of what albinism is and changing the societal misconceptions about albinism.?
- What measures has the Government taken to ensure that persons with disabilities have access to inclusive early childhood care and education, early development programmes, health care and other services, and ensure such services receive adequate human, technical and financial resources?
- What steps has the government of Zambia taken to adopt or domesticate the AU Plan of Action on Albinism to end attacks against persons with albinism among other human rights violations?

C. METHODOLOGY

This submission has been compiled by the Africa Albinism Network, drawing from insights provided by human rights defenders who serve as leaders within albinism groups and organizations. These dedicated individuals work towards advancing the rights and well-being of Persons with Albinism in Zambia. The inputs were gathered through one-on-one telephone interviews, internal research conducted by AAN, credible media reports, and pertinent information extracted from the state party

report submitted by the government of Zambia to the Committee on the Rights of Persons with disabilities.

D. COMPLIANCE WITH SPECIFIC ARTICLES OF THE CONVENTION

- **Article 5 – Equality and non-discrimination**

In Zambia, the issue of equality and non-discrimination for persons with albinism remains a significant challenge. This is despite the existence of legal provisions that prohibit discrimination on the basis of disability. Article 23 (3) of Zambia’s Constitution prohibits discriminating against persons with disabilities. The Persons with Disabilities Act, No. 6 of 2012 which gives effect to this provision and also domesticates the CRPD also prohibits discrimination of persons with disabilities including those with albinism. While information policies, such as the Access to Information Act 2023, have taken steps to accommodate persons with albinism, the implementation of comprehensive policies to address their specific needs has been limited. Unfortunately, the lack of substantial policy initiatives has left persons with albinism, struggling to overcome various obstacles.

Persons with albinism in Zambia face pervasive discrimination and stigma in various forms, rooted in misconceptions about their skin condition. This discrimination is evident in many societal interactions. Derogatory names are often hurled at persons with albinism, particularly when they are walking in public spaces. Companies, unfortunately, contribute to this discrimination by refusing to provide reasonable accommodations, mistakenly perceiving persons with albinism as no different from others in terms of working conditions and reasonable accommodation at work.

- **Article 6 – Women with disabilities**

The plight of women with albinism in Zambia, is a distressing tale of marginalization, discrimination, and heightened vulnerability. These women face intersecting forms of discrimination due to their gender and albinism, creating a complex web of challenges.

Tragically, women with albinism are targets of heinous attacks for ritual purposes. Disturbing incidents, such as the brutal chopping off the arms of a pregnant lady with albinism, highlight the extreme violence and danger they face.¹ Additionally, the unsettling revelation of a planned attack orchestrated by the partner of a lady with albinism, in collusion with others, underscores the extent of the threat they endure from within their own relationships.

Instances of exploitation and objectification are also not uncommon. One disturbing account involves a man expressing interest in marriage with a young lady with

¹ <https://allafrica.com/stories/201801110565.html>

albinism solely for financial gain, insinuating that having a wife with albinism would somehow bring more wealth into the household.²

The pervasive belief that persons with albinism are associated with wealth further exacerbates their vulnerability. Males have been known to seek relationships with women with albinism solely for financial gain and perpetuate harmful stereotypes, contributing to their social isolation. Unfortunately, this rejection is not limited to romantic relationships; women with albinism often face familial and community rejection, compounding their struggles.

- **Article 7 - Children with disabilities**

The challenges faced by children with albinism in Zambia, paint a disheartening picture of discrimination, bullying, and abandonment. These children encounter prejudice and name-calling both at home and in schools, where they are often subjected to bullying by their peers. Tragically, some fathers choose to abandon their children with albinism, compounding the emotional toll on these vulnerable youngsters.

For instance, on March 12, 2015, the Times of Zambia reported that an infant with albinism was abandoned for 2 weeks by both parents in Lusaka Kalundu Township, Zambia. The father, J.C, was arrested and charged with child negligence and failing to render and provide necessities for the child. While he has been detained by police, the mother was still at large.³

A distressing trend involves parents opting to send their children with albinism to live with grandparents, a decision often rooted in societal stigmatization and the fear of potential harm. In some instances, these children are denied access to education, a fundamental right, solely based on their albinism. The fear of attacks by ritualists further exacerbates the challenges faced by these children, as parents worry about their safety while traveling to and from school.

The vulnerability of children with albinism to attacks cannot be overstated. The prevailing misconception that body parts of persons with albinism hold mystical properties has led to an alarming number of ritualistic attacks targeting these innocent children. Such attacks not only endanger their lives but also perpetuate a cycle of fear and marginalization.

- **Article 8 - Awareness-raising**

We express our appreciation to the government of Zambia for observing the International Albinism Awareness Day through the Zambian Agency for Persons with Disabilities (ZAPD) and in collaboration with albinism groups. Furthermore, we

² Lived Experience of a health worker with albinism

³ Times of Zambia - <http://www.times.co.zm/?p=52873>

extend our commendation to the current president for endorsing and attending the launch of the albinism-themed movie, 'Can You See Us.' While these initiatives contribute significantly to raising awareness about albinism, it is imperative to acknowledge that a considerable portion of the population, particularly in rural areas where instances of crimes, discrimination, and stigma are prevalent, may not have access to or benefit from these awareness campaigns.

The absence of consistent and sustained awareness efforts, particularly through community engagement, creates a fertile ground for the proliferation of myths and harmful practices, such as the ritualistic killing and mutilation of persons with albinism. Examples of these attacks against persons with albinism are stated below under article 10 and 15.

- **Articles 10 and 15: Right to Life and Freedom from torture or cruel, inhuman or degrading treatment or punishment**

Safety concerns are prevalent among persons with albinism. The safety of persons with albinism is threatened by harmful traditional beliefs and myths around albinism., Pervasive myths circulate in Zambian society falsely attributing good fortune, wealth, and riches to body parts of persons with albinism. These unfounded beliefs in the superpowers of their body parts make persons with albinism susceptible to attacks resulting in the loss of lives of persons with albinism. Recent reported incidents in Zambia underscore this grim reality resulting in 28 reported attacks against persons with albinism.

The following are examples of the most recent incidents that led to the loss of lives of persons with albinism or threatened their inherent right to life;

1. **On June 3, 2023**, 4 men (two of whom are the same men who attempted to traffic the 41-year-old man with albinism below) attempted to traffic a 16-year-old boy with albinism between 16:00 and 18:00 hours in Mawire compound in Kalomo District of Southern Province. The five accused persons are all in custody and will appear in court soon in Kalomo District. Police have charged and arrested the two additional suspects for two counts of human trafficking. The other two were already charged with the attempted kidnapping of the 41-year-old man with albinism. A total of 5 suspects were charged and arrested.
2. **On June 3, 2023**, three men attempted to traffic a 41-year-old man from Mwandu District for the price of 500,000 ZMK (\$25 USD) at a guest house in Kalomo District (Southern Province). All three suspects have been charged and arrested with two counts of human trafficking.
3. **On July 18, 2023**, at around 9 am, Mr. C. B, aged 47 years old man with albinism, was at Mr. T. P's house (his brother-in-law) in the village of Nkungulu in the District of Katete (Eastern Province). Later on, Mr. K. P. B.

came by the house to pick up Mr. C. B. to give him some sweet potatoes that he had promised him. That was the last time he was seen. On July 22, 2023, the Katete Police Station received information that someone was in possession of the human body parts of a person with albinism and that the seller was in a town called Chadiza at the Chanida border in the Eastern Province. A follow-up was made by a combined team of Police Officers from Katete and Chadiza whereby one of the police officers posed as an interested buyer. Mr. K. P. B, aged 20 years old, from the village of Chongololo in the District of Katete was approached by the buyers and from his bag, he produced what was suspected to be human hair. He later took the “buyer” to where the body was located along the Musadwe stream near Nkungulu village in the District of Katete. The body was later retrieved by a team of police officers and upon physical inspection, the deceased’s neck was bruised and swollen and part of the head was shaved. The victim was identified as Mr. C. B. His relatives, who were not aware of the incident, were later informed. K P B was arrested for the murder of C.B. Mr. Kelvin P. B appeared in court before Magistrate Musongole who said the case could not be further heard by the subordinate court because it had no jurisdiction and would be referred to the high court upon the Director of Public Prosecutions’s (DPP) instructions. She said she was adjourning the case pending the DPP’s instructions to refer the case to the high court, saying the accused would remain in custody and appear for another mention on 5th September, 2023.

4. **On June 25th, 2022** between 9 am and 10 am in the Chilomo area, three men, one which was identified by Police Spokesperson Rae Hamoonga as Kendrick of Mkushi and two other unknown perpetrators cut the forefinger of the young survivor's left hand using a sharp instrument. The victim was left home with his fellow minors in the Chilomo area after his parents went to church. Whilst at church the parents received information about the incident and they rushed home where they found their boy crying and his forefinger of the left hand missing. He told his father that Kendrick and the two other perpetrators came to their home and told the young boy to come close to them and that's when the other two perpetrators held him down and cut off his forefinger using a big sharp scissors and knife. The three suspects ran away with the survivor's finger. Later the survivor was rushed to Mkushi District Hospital where he was admitted.
5. **On 30th April 2022**, a boy with albinism called B.C went to a marketplace called Njomwana in Central Province at around 16 pm on Saturday April 30, 2022. He was accompanied by his older sister who also has albinism. While at the market, he was called over by a man who started to interrogate him on his whereabouts i.e., where he lives, with whom etc. The stranger told his friend “I

am asking these questions because he is money” (according to the boy’s testimony). When B.C went back home, he told his father and his father went to the market, found the man, and took him to the police station around 17 pm for further questioning. At the police station, the man kept on apologizing and didn't deny the allegations made against him.

6. **On March 25, 2020**, the mutilated body of an unidentified male with albinism was recovered in a maize field at Yamene farms along the Chipata/Lundazi Road, in the Eastern Province of Zambia. It is believed that the victim was murdered for ritual purposes as he was discovered with missing eyes, tongue and both arms. On April 28, 2020, UTSS received additional information that the ZAF had facilitated a burial of an unidentified and unclaimed man who was a victim of a gruesome attack. Later on, ZAF found the family of the deceased who was identified as a 43-year-old man (E.P). He was survived by a wife, 3 children and extended family. E.P was an accomplished carpenter who lived in Navutika compound in Chipata, Eastern Province, Zambia. He had accepted a custom job in another part of Chipata and told his family he would be back in 2 weeks, but he failed to return home. The family became concerned and frantically started a search which finally led to a mortuary with Chipata police where they confirmed it was E.P by recognizing his clothes, shoes and pictures of the body. Police have since then arrested the customer as a suspect and the investigation is ongoing.⁴
7. **On November 6, 2019**, a 7-year-old girl with albinism by the name of D.M. survived a brutal machete attack at her family home near the village of Mutupa, Kitwe District of the Copperbelt Province in Zambia. It is reported that three Unknown assailants broke into the young girl’s bedroom, dragged her to a nearby bush and chopped off her left arm above the elbow and pulled out her hair as her mother, who ran to her rescue, watched helplessly. Copperbelt Commissioner of Police, Charity Katanga had reported during the time of the incident that no arrests were made, adding that investigations continue. the young girl’s parents have appealed for support requesting to be assisted to relocate to another place for fear of safety of their daughter⁵.

- **Article 24 - Education**

⁴ Information received by UTSS from Zambia Albino Foundation, in April 28, 2020 https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version_0.pdf /Zambia

⁵ <https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf> <https://thisisafrica.me/politics-and-society/zambia-criminals-in-kitwe-hack-off-the-hand-of-7-year-old-girl-with-albinism/>

In Zambia, the majority of the persons with albinism attend segregated schools for persons with visual impairments. This is due to two reasons: They face a lot of stigma and bullying when they are in mainstream schools. There is a perception therefore that they are safer and will experience less exclusion when learning with students with visual impairments. They are erroneously believed to completely lose sight as they grow and therefore need to be taught braille.

Barriers to the inclusion of children with albinism in mainstream schools extend to the inadequacy of assistive devices within these educational settings. The absence of necessary tools, such as magnifiers, screen readers, or specialized lighting in mainstream schools, poses a significant challenge for these students with albinism. This deficit in assistive technologies hinders their ability to fully participate in the learning process, access educational materials, and engage in classroom activities.

According to the 2010 census the literacy rate for males was 69.2 percent compared with 63.0 percent for females. There were more literate males with albinism than females in both rural and urban areas at 61.9 and 54.6 percent for rural areas and 82.8 and 79.7 percent for urban areas, respectively.

The proportion of the population of persons with albinism of school-going age that is currently not attending school was slightly higher than those currently attending school at 37.5 and 37.3 percent, respectively. The proportion of the population of persons with albinism who had never attended school was 25.3 percent. The highest level of education attained by most persons with albinism 25 years and older was primary education at 48.3 percent. ⁶In addition, there are no proper statistics on the number of persons with albinism in tertiary education.

Due to their sensitivity to the sun, children with albinism need protective clothing as well as sunscreen lotion to enable them to take part in school activities conducted outside the classroom. Many parents of children with albinism who live in poverty cannot afford to buy protective clothing and sunscreen, as a result, these children find it difficult to fully participate in school activities.

The safety of children with albinism in schools or on their way to school is still a challenge, as they are faced with threats of either being attacked or even killed by those looking for body parts of a person with albinism to be used in the performance of rituals or witchcraft. An example is the incident that took place in March of 2017, a 16-year-old boy with albinism named G narrowly escaped abduction and possible death near his home in Matero, Lusaka, Zambia. G narrates that his own uncle, B.M paid him a visit. It had been a long time since they had seen each other and his uncle asked G to accompany him to Matero Shoprite because he wanted to buy him some

⁶ As above (n 4)

new shoes. G went with him. After getting off a bus and walking towards the Shoprite store, the uncle received a call and spoke in Swahili. G didn't understand the conversation, but a person walking close behind did and quickly interrupted saying "I know Swahili"! He accused the uncle of plans to sell the child. The stranger then reported the uncle to the police who was finally placed in holding at central police for a month. The uncle was later released on police bond although G's mother suspected corruption. G stated that he lived in fear and his mother had stopped him from going to school for a period. The attempted trafficking happened whilst he was preparing to go to school and now, he worries about his safety when he goes to school.⁷

- **Article 25 - Health**

According to Albinism groups in Zambia, the health situation for individuals with albinism in the country is concerning, particularly due to the heightened risk of skin cancer exacerbated by high sun exposure and increasing temperatures linked to climate change. Although the government supplies sunscreen to persons with albinism through government hospitals, its distribution is not reaching everyone, especially in remote and rural areas which are characterized by limited basic services. The absence of regular skin and eye screening programs further compounds the risks, as early detection is crucial for managing potential health issues. Financial barriers, include the high cost of traveling to the only cancer disease hospital in Lusaka.

Limited availability of skin cancer treatment facilities as well as dermatologists particularly in rural areas, further exposes this population to health risks. It is also noteworthy to state that the National Health Insurance does not make adequate provisions for the specific health needs of persons with albinism such as sunglasses and other protective clothing.

- **Article 27 - Work and employment**

Albinism groups in Zambia reported that persons with albinism often encounter significant challenges in securing employment opportunities, primarily due to prevalent societal misconceptions and discrimination. This issue is exemplified by a disheartening incident involving a qualified man with albinism who faced discrimination during a job interview at a hospital. Despite possessing the necessary qualifications for the position, he was denied employment on the basis of his albinism. During the interview, he was asked about the potential impact of his condition on people's willingness to visit the hospital.⁸

Regrettably, such instances reflect broader issues related to the employment prospects of persons with albinism in the country. Discriminatory attitudes rooted in cultural

⁷ Report of attack from UTSS Attack database.

⁸ Lived Experience of a man with albinism shared by a human rights defender with albinism.

beliefs and lack of awareness contribute to the perpetuation of stereotypes surrounding albinism. This, in turn, hampers access to education and professional development for individuals with albinism, limiting their opportunities to acquire the skills necessary for gainful employment.

One noteworthy aspect is the placement of persons with albinism in potentially harmful environments to work. There have been cases where persons with albinism have been sent to locations known for attacks against them, emphasizing a critical need for protective measures and awareness among employers and policymakers.

The broader issue, however, extends beyond workplace challenges.

E. RECOMMENDATIONS

Considering the rights violations described above we suggest the government of Zambia adopts the following measures and hope that the CRPD Committee will consider including these recommendations in its review and Concluding Observations to Zambia:

- **Policy:** We highly recommend that the Zambian government collaborates closely with key stakeholders including albinism groups to develop, adopt and implement a comprehensive national action plan on albinism. It would be beneficial to allocate a dedicated budget to ensure the successful implementation of this plan. The proposed measures within the action plan should align with the high standards set in the AU Plan of Action on Albinism in Africa.
- **Access to Justice:** It is imperative for Zambia to swiftly conduct immediate and impartial investigations into attacks targeting persons with albinism. To ensure justice, court cases related to such attacks should be expedited. In the pursuit of fairness, victims must be granted pro-bono legal representation. Additionally, the government should actively endorse and support civil society organizations addressing concerns related to persons with albinism. Furthermore, there is a pressing need for the government to assist persons with albinism in raising awareness about their rights, including informing them about national mechanisms available for their protection. This holistic approach will contribute to fostering a society that values and safeguards the rights of persons with albinism.
- **Access to Quality Education:** It is essential to provide comprehensive education for teachers and educators regarding albinism, emphasizing proper protection and accommodation strategies for students with this condition under their care. Valuable insights can be drawn from exemplary guides originating from Tanzania and Malawi, which offer best practices in this

regard. To facilitate effective learning environments, schools should be equipped with the necessary resources to meet the specific needs of individuals with albinism. This includes ensuring the availability of textbooks and exams with larger fonts, as well as providing assistive devices for students with low vision to read from the blackboard. It is advisable to move away from the practice of mandating students with albinism to use Braille and instead focus on tailored resources that enhance their learning experience within mainstream educational settings. This approach promotes inclusivity and empowers students with albinism to thrive academically.

- **Public Awareness on Albinism:** The government is urged to initiate a comprehensive and sustained nationwide public awareness campaign, focusing on dispelling myths surrounding albinism. This effort should be deliberate and long-term rather than ad hoc, ensuring a consistent and impactful outreach. The campaign's primary objective should be to educate the public about the true nature of albinism, the challenges faced by individuals with this condition, and potential solutions.

By fostering a deeper understanding within the Zambian population, this initiative aims to dismantle misconceptions and promote a more inclusive and supportive environment for those with albinism. Investing in such an extensive awareness campaign is crucial for fostering empathy, eradicating stigma, and building a society that values and protects the rights of persons with albinism.

- **Protection:** Local authorities play a pivotal role in enhancing the security of individuals with albinism residing in their jurisdictions. It is imperative for these authorities to intensify security measures specifically tailored to the needs of persons with albinism. Community sensitization programs are crucial in empowering residents to raise alarms promptly and report any attacks against persons with albinism to the police. Furthermore, it is essential for law enforcement agencies to prioritize the security and anonymity of whistleblowers, fostering a safe environment for individuals to come forward with crucial information. By creating a collaborative and vigilant community, coupled with strong support from local authorities and law enforcement, we can work towards ensuring the safety and well-being of persons with albinism and actively combatting any threats they may face.
- **Redress:** Victims who have endured the harrowing experience of actual or attempted mutilation of body parts, as well as the dependents of those who have been tragically murdered, deserve comprehensive redress to facilitate their recovery. This support should encompass full medical care to address any physical injuries sustained, as well as access to psychiatric counselling to aid in the emotional healing process. Additionally, victims and their families should

be entitled to monetary compensation as a means of acknowledging the severity of the harm suffered.

In cases where the safety and well-being of the victims and their dependents are compromised, it is essential to consider reallocation to safer areas of residence. This relocation should be determined through consultation with the victim and their family members, taking into account their preferences and needs. By providing holistic redress, authorities can contribute significantly to the rehabilitation and reintegration of victims and their families, fostering a sense of justice and support in the aftermath of such traumatic events.

- **Access to Quality Healthcare:** To enhance the well-being of persons with albinism, the government is encouraged to subsidize the costs associated with accessing essential skincare and low-vision health services. Additionally, efforts should be made to eliminate barriers to access dermatologists and optometrists who specialize in albinism-related concerns. Strengthening skin cancer treatment services is crucial to address the specific health challenges faced by persons with albinism.

Moreover, it is essential to implement comprehensive training programs for nurses and midwives to ensure they are well-informed about albinism. This includes providing guidance on counselling parents when babies with albinism are born. Such training aims to reduce the likelihood of rejection and abandonment by fostering understanding and support from healthcare professionals. By addressing these healthcare needs and providing appropriate support, the government can significantly improve the quality of life for persons with albinism and promote inclusivity within the healthcare system.

- **Cooperate with Special Procedures:** It is highly recommended that the government maintains and strengthens its collaboration with the United Nations Independent Expert on the Enjoyment of Rights of people with albinism and the AU Envoy on Albinism when appointed. This can be achieved through regular consultation and timely updates on matters related to the human rights of persons with albinism. By actively engaging with the Independent Expert, the government can benefit from valuable insights, recommendations, and international best practices to enhance the protection and promotion of the rights of individuals with albinism. This collaborative effort will contribute to fostering a more inclusive and rights-based approach to addressing the unique challenges faced by persons with albinism within the national context.
- **Support for albinism organizations:** Directly support organizations of persons with albinism to undertake advocacy and programmatic activities in support of their rights.