

THE SITUATION OF CHILDREN WITH ALBINISM IN ZAMBIA

A Report to the Committee on the Rights of the Child

Joint Submission by:



**UNDER THE
SAME SUN**

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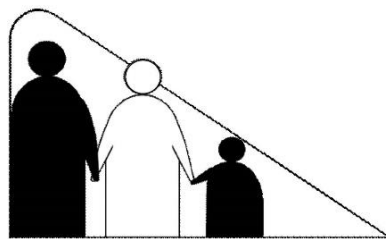
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"Breaking the silence on albinism"

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This report was prepared jointly by Under the Same Sun (UTSS) and Albinism Foundation of Zambia (AFZ). The report is based on information from media reports; partners on the ground in Zambia including AFZ as well as UTSS own internal research.

Questions for the Government of Zambia

- What measures has the Government taken to implement the recommendation issued by this committee during the last review regarding ensuring equal access to education, basic health care and other welfare services for all children¹ with specific reference to children with albinism?
- What intensified efforts has the Government taken to eliminate discrimination against the most vulnerable groups of children, such as girls and children with disabilities² including children with albinism?
- What measures has the Government taken to ensure that children 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 in compliance with the previous concluding observation;
- 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 awareness-raising activities with the aim of increasing understanding of what albinism and changing the societal misconceptions about albinism also eliminating stigmatization in the society?
- What deliberate efforts has been taken to provide training for professional staff working with children with disabilities with specific reference to children with albinism, such as teachers, medical, paramedical and related personnel and social workers, in order to understand the needs of children with albinism and accommodate their needs accordingly?
- What concrete measures has the Government taken to ensure that the perpetrators of the gruesome attacks against children with albinism have been brought to justice?
- What concrete measures has the Government taken to provide remedies to children who are victims of attack and their family members including access to justice, legal, medical and socio-economic remedies?

¹https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fZMB%2fCO%2f2-4&Lang=en accessed on 17/01/2020

² ibid

- How far does the National Plan of Action for 2015 youth Policy from the Ministry of Youth and Sport encompass Response Plan for threats or attacks that are faced by the Children with albinism?
- What measures have the government put in place to protect children with albinism who are vulnerable from violence including being subjected to gruesome attacks some of which have claimed their lives, Leaving them mutilated or living in extreme fear of their lives which directly and negatively impacts their rights to life and security of person.
- What legislative measures has the government put in place to fully protect the rights of children with albinism?
- What steps has the government of Zambia taken to adopt or domesticate the Regional Action Plan to end attacks against persons with albinism among other human rights violations as adopted by the African Union and which calls on countries to adopts the same.³ The same has been done in Malawi in the form of a national action plan.

Situation in Zambia

- In Zambia the population of persons with albinism may not be adequately captured. According to the 2010 Census on population and housing, the albino population at national level was 25,324. The population in rural areas was higher than urban areas at 16,937 and 8,387, respectively. Lusaka Province had the highest population of albinos at 3,495 while North-Western Province had the lowest at 1,387.⁴
- The first attack on person with albinism was recorded in March 2014 when an albino girl aged 12 from Kanyama compound of Lusaka was murdered and some body parts were removed from her. In June 2015 a woman from Lundazi eastern province was also attacked and killed for the same purpose. Her breasts and other body parts were removed. In January 2016 a young man with albinism aged 24 was also murdered in Mandevu compound of Lusaka whereas some body parts were also taken away.

³ Resolution 373 of the African Commission on Human and Peoples' Rights. Note also that the AU Specialized Technical Committee (STC) on Social Development, 1 to 5 April 2019, Addis Ababa, the STC endorsed the Regional Action Plan on albinism in Africa, recommending it the AU summit for total adoption as AU policy and decided to appoint an Envoy to implement the Plan (Prior to this Plan had only been endorsed by the African Commission on Human and Peoples' Rights).

⁴ John Chiti,2020, Situation of Persons With Albinism In Zambia, Executive Director/Music Activist Albinism Foundation of Zambia

These organised ritual killings kept increasing year by year from about 5 cases every year to now about 20 attacks. The latest records of 2019 has 5 reported cases from which 2 of them happened in the period of 2 weeks. The attacks have concentrated in the rural areas especially provinces/districts which share a boarder with other countries. So far eastern province (which share a boarder with Malawi) has the highest number of ritual attacks. It is suspected that these attacks also involve trafficking of body parts from one country to the other.⁵

- UTSS and Action on Albinism has recorded 16 attacks which were reported of which Seven (7) are killings, Seven (7) are Survivors and Two (2) are grave robberies. The recorded attacks took place between June 2018 and October 2019.⁶
- These attacks are extremely violent, cruel and inhuman mostly on children. Of the seven (7) killings recorded three of them were of children as young as seven, ten and seventeen years old.⁷
- The Albino Foundation of Zambia (AFZ) has been advocating for the equal treatment of people living with albinism. The organization has also been campaigning to debunk and stop the misconceptions that body parts of people with albinism can bring wealth or luck.⁸ In addition, the organization also has registered over 100 children with albinism from different parts of the country who were rejected by their fathers or those whose fathers' have denied responsibility because they were born with albinism. Most families don't understand what albinism is and how it happens. Therefore, families break and couple's divorce whenever albino children are born. Because these children are rejected by their fathers and stay with their single parents/mother who can't afford to take them to school, most children with albinism need educational and health support.
- In addition, violence and stigma aimed at people with albinism is widespread due to general ignorance and myths associated with the

⁵ ibid

⁶ <https://actiononalbinism.org/page/myitb7kjinia8i6ihn5sfko6r> accessed on 13/01/2020

⁷ <https://spaces.hightail.com/space/68BnVjGPEJ/files/fi-a79f0e4d-b16d-40f4-a260-e7b8d683977c/fv-c34aede529d-4e03-a324-fa5b582101a7/All%20Zambia%20Attacks%20reported.docx>

accessed on 13/01/2020

⁸ file:///F:/LOCAL%20DISK/UTSS/Zambia_%20Criminals%20in%20Kitwe%20hack%20off%20the%20hand%20of%207%20year-old%20girl%20with%20albinism.html accessed on

14/01/2020

condition, resulting in discrimination, dehumanisation and isolation. Some communities believe that people living with albinism are “ghosts” or have magical powers; that they are the result of incest or a curse. People living with albinism are therefore often victims of hate crimes such as beheading as their body parts are used in witchcraft rituals. This stems from the superstition that they can bring riches, success, power or sexual conquest. Children are especially vulnerable to these crimes.

- While noting the efforts made by the government of the Republic of Zambia as noted in the concluding observation of this Committee in the combined second and fourth periodic report of Zambia⁹, including ratification of international conventions and protocol, enactment of legislations including Persons with Disability Act No. 6 of 2012, Anti- Gender Based Violence Act No. 1 of 2011 as well as adoption of institutional and policy measures such as Revised National Plan of Action and National Child Policy of 2009, we wish to submit as follows;

Regarding Article 4 of the Convention on the Rights of the Child (CRC) which provides that: States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention.

- As it was noted in the concluding observation¹⁰, the Government of Zambia had adopted National Child Policy, further the statement of the Attorney General of the Republic of Zambia at the 71st Session of the Committee on the Right of the Child, stated that the Government is reviewing the draft legislation to be referred to as Children’s Code Bill which will consolidate in a comprehensive manner the laws providing for the rights and welfare of Children. He noted further that the bill when enacted will domesticate the provisions of the Convention on the Rights of the Child¹¹. This same pending bill has been referred to on other avenues by the Zambia Law Development Commission as a more comprehensive domestication of the

⁹https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fZMB%2fCO%2f2-4&Lang=en

¹⁰ Supra

¹¹https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZMB/INT_CRC_STA_ZM_B_22813_E.pdf

Convention on the Rights of the Child¹². However, to date the said bill is yet passed.

Regarding Article 6 of the CRC providing that: State Parties recognize that every child has the inherent right to life and that State Parties shall ensure to the maximum extent possible the survival and development of the child

- Children with Albinism in Zambia Children with albinism are marginalized and highly segregated against hence not fully enjoying their rights, peace or protection which ought to be provided by the mainly due to the misunderstanding of albinism which often takes the form of myths as the main reason for discrimination which influence social behavior towards children with Albinism they mainly have safety concerns, stemming from social prejudice driven by harmful traditional beliefs, and connected to the trafficking of human body parts to nearby countries.¹³
- Also there are myths associated with the belief that the body part of a child with Albinism brings good fortune, wealth or riches. The innocence of children with albinism and the alleged superpower of their body parts makes then a preferred target of attacks.
- The following are a sample of incidents recorded which threatened the inherent right to life of the child as well as threatened the child's survival.
 - i. **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 little Dorothy'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 so far, adding that investigations continue. Dorothy's parents have appealed for

¹²<https://bettercarenetwork.org/sites/default/files/Presentation%20on%20Laws%20Relating%20Children%20Zambia.pdf>

¹³ <https://actiononalbinism.org/page/myitb7kjni8j6ihn5sfko6r> accessed on 14/01/2020

support requesting to be assisted to relocate to another place for fear of safety of their daughter¹⁴.

- ii. **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, Jacob Chilembo, 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 is still at large. Their 2-year-old son is currently at a shelter for safety. The case was reported by some neighbors to Lusaka's Ng'ombe Clinic where staff decided to report the matter to the police.¹⁵

Regarding Article 28 of the CRC which provides that: States Parties recognize the right of the child to education

- The literacy rate for the albino population was 66.1 percent. In Zambia, the majority of the children with albinism attend segregated schools for children with visual impairments. This is as a result of two reasons:
 - i. They face a lot of stigma and bullying when they are in mainstream schools;
 - ii. They are believed to completely lose sight as they grow because of their visual impairment, thus they are introduced to Braille in the first grade of primary school.

Due to these reasons persons with albinism feel more confident and safer when socially interacting with persons with visual impairments.¹⁶

- In addition, there are no proper statistics on the number of persons with albinism in tertiary education. 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 male albinos than female albinos in 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 albino population that was currently not attending school was slightly higher than those currently attending school at 37.5 and 37.3 percent, respectively. The proportion of the albino population that had never

¹⁴ <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/>

¹⁵ Times of Zambia - <http://www.times.co.zm/?p=52873>

¹⁶ John Chiti, Executive Director, Albinism Foundation of Zambia

attended school was 25.3 percent. The highest level of education attained by most of the albino population 25 years and older was primary education at 48.3 percent.¹⁷

- Children with albinism are marginalized and highly segregated against. There have been no deliberate national programs to promote education of albino children at either primary or secondary levels. They have been left out in all social activities. Albino children cannot go out to play like any other child in the sun, they need special protective wear to enable them walk in the sun. Stigma and superstitious beliefs has played a great part.
- Further, most parents of children with albinism cannot afford to buy protective clothing, as a result, these children find it difficult to attend school, thus enters adulthood with little information on HIV, reproductive health, Entrepreneurship skills yet they are more prone to HIV /AIDS due to poverty level. Therefore there is need to combine and step up efforts in order to achieve Millennium Development Goals number 2, that all children must be considered with no regards to race, religion, background or disability¹⁸
- 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 performance of rituals or witchcraft. An example is the incident that took place on **March of 2017**, a 16-year-old boy with albinism by the name of Gift narrowly escaped abduction and possible death near his home in Matero, Lusaka, Zambia.
- Gift narrates that his own uncle, Bwalya Musonda paid him a visit. It had been a long time since they had seen each other and his uncle asked Gift to accompany him to Matero Shoprite because he wanted to buy him some new shoes. Gift went with him. After getting off a bus and walking towards the Shoprite store, the uncle received a call and spoke in Swahili. Gift 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

¹⁷ ibid

¹⁸ ibid

was later released on police bond although Gift's mother suspected corruption. Gift stated that he lived in fear and he was stopped from going to school for a period of time and the year the attempt was reported he was preparing to go to school however he was still worried about his safety.

Right to health

Specific Measures are necessary to implement legal provisions pursuant to Article 4 of the CRC

- According to the Albino Foundation of Zambia, a great challenge facing more Zambians with albinism is over-exposure to sunlight,¹⁹ which makes a persons with albinism susceptible to skin cancer due to their skin condition which does not protect them from ultra-violet light from the sun. In order to protect themselves from this cancer vulnerability they need to apply to their skin sun-screen cream. These creams are expensive in private pharmacies. The creams are rarely found in public clinics where they should be dispensed freely.²⁰
- In schools or colleges, the children are required to put on dark glasses to protect them from the sun rays. Some schools that are not aware stop them from doing so thus exposing them to damage of their eyes. In order to improve the situation of persons with albinism deliberate interventions are required by the state and non-state actors.²¹ The Government had “committed to procure sun cream lotions for people living with albinism”²² however more is still needed to be done to reach more children especially in rural areas.
- The situation of children with albinism in Zambia requires concrete measures. Legislation alone is insufficient to tackle the situation of persons with albinism whose context is cultural and a condition mired in ignorance. It is for this reason that the regional action plan on albinism has been adopted at the AU level and countries called to adopt measures contained therein.

¹⁹ <https://actiononalbinism.org/page/myitb7kjinia8j6ihn5sfko6r> accessed on 17/01/2020

²⁰ John Chiti, *Supra*

²¹ *ibid*

²² <https://actiononalbinism.org/en/entity/8drfujlksp4bggvmwhyskxm6r?page=1>

- The regional action plan contains prevention, protection, non-discrimination and accountability measures which are specific to the situation of persons with albinism. These include support structures for homes of persons with albinism and providing sunscreen to prevent skin cancer.
- It is worthy of note that in addition to the CRC, both the CRPD and CERD which apply to the situation of children with albinism call for specific measures to advance substantive equality and protect those who are most in need of protection. The same is echoed through the central pledge of the SDGs which is to leave no one behind beginning with the furthest first.

Recommendations to the Government of Zambia

- **Policy:**
 - Zambia should in consultation and cooperation with relevant stakeholders, put in place a national action plan and to also ascribe a particular budget for it. All measures contained in the action plan should meet the standard in the regional action plan developed at the African Union.²³ The national action plan should reflect the following recommendations
- **Access to Justice:**
 - Immediate and impartial investigation of attacks against people with albinism should be thorough and court cases in that regard should be expedited. Victims of such attacks should be provided with pro-bono legal representation.
 - Government should support civil society working on issues regarding person with albinism and should assist persons with albinism in awareness-raising about their rights including national mechanisms available for their protection.
- **Education:**
 - Teachers and educators should be educated on albinism and proper protection as well as accommodation of the impairment of students with albinism in their care. Several guides out of Tanzania and Malawi offer best practices.

²³https://actiononalbinism.org/uploaded_documents/1532674430509telzfn73q65pbaawyld0wwmi.pdf

- Ensure that resources are at the disposal of schools to meet the specifications needed of children with albinism, notably by providing for textbooks and exams with larger fonts and assistive devices for low vision to read the blackboard instead of forcing students with albinism in specialized schools to use Braille.
- **Public Awareness:**

The Government should embark on an intense long-term (and not adhoc) nationwide public awareness raising campaign to debunk false myths about albinism, and educate Zambians about its nature, challenges and possible solutions.
- **Protection:** Local authorities should increase security for persons with albinism residing within their areas. Communities should be sensitized on raising alarm and immediately reporting attacks to the police. The police should also ensure the security and anonymity of whistleblowers.
- **Redress:** Victims of actual and attempted mutilation of body parts and dependents of murdered victims should be provided with redress including full medical care for injuries sustained, psychiatric counseling, monetary compensation, and where necessary, reallocation to safer areas of residence – in consultation with the victim and their family members.
- **Healthcare:** The Government should subsidize costs for accessing skin care and low vision health services for persons with albinism, as well as removing barriers to access to dermatologists and optometrists specialized in albinism. Skin cancer treatment should be strengthened. Nurses and midwives should be trained on albinism and provision of counseling to parents where babies with albinism are born. This will reduce chances of rejection and abandonment of mothers of children with albinism.
- **Cooperate with Special Procedures:** The Government should continue cooperate with The United Nations Independent Expert on the Enjoyment of Rights of people with albinism by consulting and updating her on issues pertaining to human rights of children with albinism.

APPENDIX

What is Albinism?

- Albinism is a relatively rare, non-contagious, genetically inherited condition characterized by a lack of pigmentation in the hair, skin and eyes. It occurs regardless of ethnicity or gender. Both parents must carry the gene for it to be passed on, even if neither have albinism themselves. In Africa, estimates on 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, where Gambia is located, it may be as high as 1 in 1,000.²⁴ There are no up-to-date reliable statistics on the number of persons with albinism.
- In Zambia, the society in general do not know much about albinism and therefore people have put many myths, beliefs and misconceptions on the condition. Most of these beliefs are negative and do affect albino people negatively. Some of the common beliefs are that; “Albino people don’t die but just disappear “ or “Spiting in your shirt whenever you see an albino to avoid having or becoming one yourself” or “Albino body parts can be used to cure certain diseases and make one rich” Such beliefs make persons with albinism to stand out and make them feel inferior to other people.
- The belief that one can cure diseases and make money if they use body parts of albino persons makes those who are looking for solutions to their poverty or cure to be on the lookout for albino body parts, thereby hunt and kill or mutilate persons with albinism and use their body parts for rituals/witchcraft. For this reason, different people with albinism, young and old have been murdered for their body parts across Africa.
- Nearly every person with albinism is born visually impaired and with little to no melanin or pigment for protection, such that their skin burns very quickly in the sun. In many tropical climates, including in Zambia, persons with albinism are 1,000 more prone to skin cancer than their

²⁴ 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_ENG.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

fellows without albinism. Many acquire dramatic visible skin damage at an early age. Persons with albinism often have disabilities mainly as a result of visual impairment and attitudinal barriers owing to their appearance and colouring. They have also been recognized as persons who face racial discrimination and stigmatization on the ground of colour. These intersecting factors have resulted in physical attacks, including killings in eastern, western, central, southern Africa, including Zambia²⁵.

²⁵ Ikponwosa Ero, Albinism Worldwide, report of the Independent Expert on the enjoyment of human rights by persons with albinism to the General Assembly, 18/07/2019 see <https://undocs.org/A/74/190>