

THE SITUATION OF CHILDREN WITH ALBINISM IN THE GAMBIA

A Report to the Committee on the Rights of the Child

Joint Submission by:



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- This report was prepared jointly by Under the Same Sun (UTSS), and the Association of Gambia Albinos (AGA) the organizations which both at the core are committed to promote social inclusion and end discrimination against people with albinism (PWA). The report is based on information from media reports; partners on the ground in The Gambia such as the aforementioned the AGA as well as UTSS own internal research.

Questions for the Government of The Gambia

- What measures has the Government taken to implement the recommendation issued by this committee during the last review regarding acceleration of the development and adoption of the national child protection strategy?¹
- What measures has the Government taken to establish an independent institution for monitoring human rights, including a specific mechanism for monitoring children's rights that is able to receive, investigate and address complaints by children in a child-sensitive manner² with specific reference to children with albinism?
- What has the Government done to strengthen awareness-raising programmes, including campaigns, for the community at large, aimed at combating the high level of discrimination against, and stigmatization of, children with disabilities³ such as children with albinism who are highly discriminated and stigmatized in the society?
- In order to encourage the inclusion of children with disabilities in society and in the mainstream educational system, including by making schools more accessible to children with albinism, what assistive devices are available to assist them to read taking into consideration that people with albinism are born with visual impairment?
- What deliberate efforts has been taken to provide training for professional staff working with children with disabilities with specific reference to those who have been left most behind among them such as children with albinism? These include measures targeting teachers, medical professionals and social workers, in order to understand the needs of children with albinism and accommodate their needs accordingly?

¹https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC/C/GMB/CO/2-3%20&Lang=En para 10

² Ibid para 18

³ Ibid para 59(a)

Situation in The Gambia

- There is no official statistics or study that has ever been conducted on persons with albinism in The Gambia, thus there is no official report on the number of persons with albinism in The Gambia. Though it can be opined that a considerable number of families have a person with albinism and the number seem to increase.⁴
- It is stated that persons with albinism in West Africa are not facing violent attacks seen in other parts of the continent, however they face grave and even life-threatening discrimination, lack adequate health care, face difficulties accessing education and employment as well as social marginalisation which lead many persons with albinism to live an extreme destitute life.
- There is high level of poverty in The Gambia with over 50% of the populace living in absolute poverty (2014 census). Given the often-reported correlation of disability in poverty,⁵ and the deep lack of information about albinism in the country and the widespread stigma the condition generates, the implication here is that persons with albinism are among the poorest of the poor in Gambia.
- The country's sahalian climate does not favour albinism, the extreme temperature and constant exposure to the sun, puts persons with albinism at high risk. The warm and sunny climate has a very detrimental effect on the skin and eyes of a person with albinism, constant exposure to the sun frequently causes blindness and skin cancer which can be fatal. One of the most effective protection for the skin is sunscreen with SPF 50+ which unfortunately is not being manufactured in the country and the cost for purchasing the same from normal shops is very high. Therefore, due to poverty, many persons with albinism and their families cannot afford sun screen lotions for their protection, thus skin cancer is a major health challenge for persons with albinism as the national health system is yet to undertake any policy decision or practical action to address this plight of persons with albinism. Although studies have not been

⁴ Jannah Gibairu, the Association of Gambian Albinos

⁵ <https://gsdrc.org/topic-guides/disability-inclusion/the-situation-of-people-with-disabilities/poverty-and-disability/>

conducted in Gambia, elsewhere in Africa, a majority of persons with albinism die before the age of 40 to this preventable condition.⁶

- In addition, sunglasses are very essential for protection of the eyes, these glasses are also not easily obtained. More importantly, prescription glasses which ought to form part of reasonable accommodation and adaptive devices for persons with albinism are highly expensive and therefore inaccessible, hampering their right to education.
- Beliefs and myths persist toward persons with albinism in The Gambia, most of the time they are excluded from the society from birth. Terminologies that are dehumanizing and with negative connotations are used to describe persons with albinism.
- While noting the efforts made by the government of the Republic of the Gambia as noted in the concluding observation of this Committee on the combined second and third periodic reports of the Gambia, including ratification of international and regional protocols, enactment of legislations including Domestic Violence Act 2013, Sexual Offences Act 2013, Women's Act 2010, Legal Aid Act 2008, Trafficking in Persons Act 2007, Children's Act 2005,⁷ 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.

- The Government of the Gambia enacted Children's Act, 2005, however still voices from the ground are rising on the unavailability of learning materials for students with disabilities including students with albinism in mainstream schools.

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

⁶ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/007/00/PDF/G1600700.pdf?OpenElement>

⁷ https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC/C/GMB/CO/2-3%20&Lang=En

- Children with Albinism in the Gambia are marginalized and highly segregated against hence not fully enjoying their rights, in the society mainly due to the widespread misunderstanding of albinism which often takes the form of myths as the main reason for discrimination which influence social behavior towards children with albinism. This includes derogatory name-calling which affects the perception of equality of the child and also affects the ability of the child to attain substantive equality on an equal basis with others.
- The right to life of persons with albinism is also negatively impacted by their right to health which is deeply compromised as explained below.

Right to health

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

- According to the Association of Gambian Albinos (AGA), a great challenge facing people with Albinism is over-exposure to sunlight, which makes a person 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, they need to apply sun-screen and ought to have access to health education including on use of alternative measures to sunscreen. However, there is no public health education in this regard and sunscreens are expensive and tend to be available only in private pharmacies. The creams are rarely found in public clinics where they should be dispensed freely.

“Specific Measures”

- In light of the call from the Office of High Commissioner for Human Rights⁸ and the Independent Expert on albinism⁹ that State parties ought to take specific measures which are necessary¹⁰ to respond to the situation of persons with albinism, the authors of this report affirm that Legislation alone (Children’s Act 2005) is insufficient to tackle the situation of persons with albinism whose context is cultural and a

⁸ Report of the Office of the United Nations High Commissioner for Human Rights on the attacks and discrimination against persons with albinism, 2013

⁹ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N18/229/16/PDF/N1822916.pdf?OpenElement>

¹⁰ Article 5(4) of the Convention on the Rights of Persons with Disabilities

condition mired in ignorance. It is for this reason that we call on the Government of the Gambia to implement the regional action plan on albinism which was adopted at the African Union level.

- The regional action plan on albinism contains prevention, protection, non-discrimination and accountability measures which are specific to the situation of persons with albinism.¹¹ These include support structures for homes of persons with albinism and providing sunscreen to prevent skin cancer.¹²
- 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. The measures of the regional action plan are linked to the SDGs and also the AU Agenda 2063.¹³

Recommendations to the Government of Zambia

• Specific Measures

- As called upon by the African Commission on Human and Peoples' Rights, the Gambia should in consultation and cooperation with relevant stakeholders, should implement measures in the regional action plan.¹⁴ They could do this by putting in place a national action plan and to ascribe a particular budget for it as has been done in Kenya and Malawi. This should be done in addition to passing protective legislation if Gambia is to leave no one behind as they have pledged to do in the SDGs.

• Data

- There is an urgent need to conduct a census on persons with albinism in The Gambia to determine their number, identify their specific needs and understand the condition of albinism. This is essential to ensure that policy and support efforts are informed by

¹¹ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/363/74/PDF/G1736374.pdf?OpenElement>

¹² <https://actiononalbinism.org/en/page/sfj6gs7s8kid5f6c6zyhw7b9>

¹³ <https://actiononalbinism.org/page/ufyuvxx23z>

¹⁴ <https://www.achpr.org/index.php?url=sessions/resolutions&id=415>

evidence and that they are deliberately targeted to the ones in desperate need.

- **Representation and Participation**

- 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 visual impairment of students with albinism in their care. Several guides out of Tanzania and Malawi offer best practices that ought to be incorporated in teacher-training on issues of disability and reasonable accommodation.
- Ensure that resources are at the disposal of mainstream schools to meet the specific or particular needs of children with albinism, notably by providing for textbooks and exams with larger fonts and adaptive as well as assistive devices for low vision to read the blackboard in

- **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 Gambians about its nature, challenges and possible solutions.

- **Health:**

- Sunscreen lotion should be provided freely to the children with albinism mostly those from very poor family and from rural area as a matter of reasonable accommodation as well as the right of the highest attainable standard of health.
- The Government should subsidize costs of 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 when 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 to cooperate with the Special Procedures branch including 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 1,000.¹⁵ There are no up-to-date reliable statistics on the number of persons with albinism.
- In the Gambia, the society in general do not know much about albinism and therefore people have put many myths, beliefs and misconceptions on the condition which causes high level of stigma and discrimination in the society.
- 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 the Gambia, persons with albinism are 1,000 more prone to skin cancer than their 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.

¹⁵ 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