Response to a Call for Input: Report of the Independent Expert on albinism to the 80th session of the United Nations General Assembly focusing on Skin Health and skin cancer among persons with albinism

By

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Introduction

This submission is led by the Africa Albinism Network (AAN) in collaboration with Engage Now Africa (ENA) and the Ghana Association of Persons with Albinism (GAPA). It provides information on the state of access to healthcare and the realization of the right to health for persons with albinism in Ghana.

Due to the limited time between the publication of the call and the submission deadline, coinciding with major events that significantly engaged the attention and capacity of AAN's small team, this report is focused exclusively on Ghana. Nonetheless, it draws on the expertise and lived experiences of national stakeholders actively working to improve the lives of persons with albinism and offers insight into the policy frameworks, barriers, and good practices relevant to the health and well-being of this community.

Methodology

This submission is compiled by Africa Albinism Network based on inputs received from human rights defenders, all of whom are leaders of albinism groups and organisations working to promote the rights and welfare of Persons with Albinism in their respective countries in Africa. These inputs were collated through one-on-one phone interviews as well as written submissions using the questionnaire provided by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on Persons with Albinism and the rights to education

Response from Ghana

Policy Framework

1. **Please provide information on the international and regional frameworks that your government has ratified or committed to in the effort to ensure the enjoyment of the right to health with persons with albinism/persons with disabilities.**

   Ans: Ghana has ratified key human rights treaties relevant to health and disability, including:

- Convention on the Rights of Persons with Disabilities (CRPD) – ratified in 2012.
- African Charter on Human and Peoples' Rights and its Protocol on the Rights of Persons with Disabilities in Africa – signed but not yet ratified.
- International Covenant on Economic, Social and Cultural Rights (ICESCR)

2. **Please provide information on efforts made by your government to provide access to quality healthcare services and products in both the public and private health system.**

   Ans: Ghana has a National Health Insurance Scheme (NHIS) aimed at improving access to basic health services. It includes coverage for consultations, laboratory investigations, treatment for common diseases, and maternal health. The Ministry of Health also supports public-private partnerships to extend healthcare coverage, though rural areas remain underserved.

3. **Please share information on any efforts, policies and programs by the government to provide access to sunscreen lotion and protective clothing to persons with albinism in your country?**

   Ans: There are no government-led programs specifically targeting access to sunscreen and protective clothing for persons with albinism. Most support comes from NGOs such as Engage Now Africa (ENA), which distributes sunscreen, hats, and long-sleeved clothing during outreach programs.

4. **Is sunscreen lotion part of the national essential medicines list in your country? If yes, please cite the relevant law or policy.**

   Ans: No, sunscreen lotion is not currently listed on Ghana's national essential medicines list. There have been advocacy efforts to include it, particularly by local civil society organizations and international partners including the Ghana Association of Persons with Albinism (GAPA) and Engage Now Africa.

5. **Is sunscreen lotion imported tax free in your country?**

   Ans: Sunscreen is not currently imported tax-free in Ghana. Import duties contribute to its high cost, making it unaffordable for many persons with albinism.

6. **Have there been initiatives or programs implemented by the government or other stakeholders to raise awareness and educate the public on skin health for persons with albinism?**

   Ans: Awareness campaigns have been carried out by Engage Now Africa, the Ghana Association of Persons with Albinism (GAPA), and the Africa Albinism Network. These programs are not yet nationwide or government-led.

Human Rights Challenges or barriers to the enjoyment of the Right to Health

7. **Please provide information on human rights concerns or barriers affecting the right to health of persons with albinism in your country.**

   Ans:

   - Lack of recognition of albinism-specific needs in national health policies: Ghana's key health-related legal and policy frameworks, including the National Health Insurance Act and the Persons with Disability Act, do not explicitly address the specific healthcare needs of persons with albinism. Critical services such as provision of sunscreen, regular dermatological and ophthalmological screenings, and access to skin cancer treatment are not recognized or prioritized, resulting in significant gaps in care and protection for this vulnerable population.
   - Limited availability and high cost of sunscreen and visual aids: The Government of Ghana does not currently provide or subsidize sunscreen or visual aids for persons with albinism. As

a result, sunscreen products are rarely available in government health facilities and are mainly found in supermarkets or cosmetic stores at prohibitively high prices due to import taxes and lack of regulation. Similarly, visual aids such as prescription spectacles and magnifiers, essential for managing albinism-related visual impairments, remain largely inaccessible to most individuals due to cost and supply issues.

- Stigma and misinformation within the healthcare system, especially in rural areas: In many parts of Ghana, particularly rural communities, healthcare professionals lack adequate training and awareness on albinism. This often leads to misdiagnosis of skin lesions in persons with albinism, including mistaken identification of cancerous growths. Furthermore, entrenched stigma and discriminatory attitudes among some health workers result in persons with albinism receiving substandard or dismissive care, discouraging them from seeking timely medical attention.

8. **Please share any social protection programs provided by the government to enable persons with albinism to access healthcare services and products?**

   Ans: The NHIS is the main scheme available, but it does not cover sunscreen, visual aids, or specialist dermatological care. Persons with albinism must pay out-of-pocket for many essential products and services related to their condition.

9. **When persons with albinism visit public health facilities (clinics or hospitals) do they receive the necessary treatment for the ailment they are suffering from?**

   Ans: Persons with albinism generally receive treatment for common ailments, but there is limited specialized care for albinism-related conditions like skin damage or visual impairment.

10. **Are there any incidents of discrimination in public health services? If yes, please explain further?**

Ans: There are anecdotal reports of discrimination, such as stigmatizing comments or poor prioritization. However, such incidents are underreported and not systematically documented.

11. **Do persons with albinism have free or affordable and regular access to the following health services:**

Service	Access	Notes
a. Skin cancer screening	Limited	Available in some urban centers
b. Skin checks (6 months)	No	Not a standard service
c. Dermatologists	Limited	Only in major hospitals
d. GP/Doctor	Yes	Through NHIS
e. Skin cancer treatment	Very limited	Requires referrals
f. Oncologists	Very limited	Only in teaching hospitals
g. Visual aids	No	Expensive and not covered by NHIS
h. Ophthalmologists	Limited	Access varies by region
i. Optometrists	Some access	In urban centers
j. General wellness checkups	Basic	Through NHIS
k. Respiratory/bleeding specialists	Rare	Not commonly available

12. Is the sunscreen lotion available in your country easily accessible? Please explain what makes sunscreen accessible or inaccessible for persons with albinism?

Ans: Sunscreen is not easily accessible. It is expensive, not stocked in many pharmacies, and often unaffordable for low-income families. Distribution by NGOs helps but is not sustainable or comprehensive.

13. Please indicate the places persons with albinism can source sunscreen in your country:

Ans:

a) ☑ Private pharmacies/chemists and some Cosmetic shops
b) ❌ Government pharmacies
c) ❌ Public hospitals
d) ☑ Supermarkets (expensive)
e) ☑ NGO events (free but infrequent)

14. Is the sunscreen lotion available in your country suited to the local climatic conditions and needs of persons with albinism? If no, what challenges exist with the sunscreen lotion that is available?

Ans: Many sunscreens available are not well-suited to Ghana's hot, humid climate. They may lack adequate SPF or be oily and uncomfortable. Better-suited, dermatologically approved options are expensive. Many persons with albinism complain of itchy eyes skin irritation when they use the sunscreen. Engage Now Africa used to produce sunscreen locally but in small quantity for free distribution. Many persons with albinism who used the product liked it since it is produced with Shea butter as the base and feel gentler and more comfortable when applied. However, production stalled due to funding challenges

15. Are education and awareness raising campaigns on skin health accessible to persons with albinism and caregivers of children with albinism in all areas of the country? (rural and urban) Explain.

Ans: Education and awareness raising campaigns are mostly urban-centered and in most case through the radio or TV interviews. Rural outreach is sporadic and largely driven by Engage Now Africa. There is no national, inclusive strategy to ensure consistent education in all regions.

16. Do individuals with albinism in your country have access to genetic testing to identify their specific type and related concerns?

Ans: There is no routine access to genetic testing for albinism in Ghana. Only a few urban-based private or research institutions may offer such testing, which is expensive and uncommon.

GOOD PRACTICES

17. Are there any good practices that have been implemented to ensure access to quality healthcare services and products for persons with albinism/persons with disabilities?

Ans:

- Health screening including skin and eye screening exercise by Engage Now Africa help to identify health concern and, in some instances, support the treatment of skin cancer and provision of prescription eye glasses and sunglasses to persons with albinism
- Engage Now Africa (ENA) runs a Mobile Outreach Program distributing sunscreen and educating communities.
- Community training and awareness activities by Engage Now Africa help reduce stigma and improve care-seeking behavior.