



A joint submission by the Africa Albinism Network, the Sierra Leone Association of Persons with Albinism (SLAPWA), the Sierra Leone Albinism Foundation (SLAFo), and the Albinism Royal Foundation to the 74 Pre-Sessional Working Group Session of the Committee on Economic Social and Cultural Rights (CESCR) on the enjoyment of human rights by persons with albinism in Sierra Leone.

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Africa Albinism Network: The mission of the Africa Albinism Network (AAN) is to promote the rights, well-being, and inclusivity of people with albinism in Africa through advocacy, capacity development, and collaboration. The AAN is guided by the AU Plan of Action on albinism (2021-2031) as its main strategy and we adopt a human rights-based approach to achieve our mission.

Sierra Leone Association of Persons with Albinism (SLAPWA) is an advocacy group in Sierra Leone with the mission to influence the recognition of people with albinism in national laws, policies, and developmental programs through advocacy, partnership, and empowerment for the equalization of rights and well-being.

Sierra Leone Albinism Foundation (SLAFo): The vision of SLAFo encompasses the creation of inclusive societies where individuals with albinism actively participate in the national development discourse. The mission is to advocate for and safeguard the human rights and well-being of persons with albinism in Sierra Leone.

Albinism Royal Foundation: The mission of the Albinism Royal Foundation is to ensure that every person with Albinism has the opportunity to achieve and fulfill their dreams, as bestowed by the creator. We are dedicated to empowering individuals with Albinism, fostering their productivity, and enhancing their overall well-being.

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A. Questions for the Government of Sierra Leone

- What specific actions is the government of Sierra Leone undertaking to guarantee the realization of the highest attainable standard of health for persons with albinism, with a particular focus on ensuring access to essential provisions such as sunscreens, regular skin cancer screening, and appropriate treatment within the healthcare system?
- What concrete and specific initiatives has the government of Sierra Leone implemented to guarantee that individuals with albinism enjoy equitable access to high-quality education, with a particular emphasis on reasonable accommodation such as securing access to large print reading materials, assistive technology, and requisite reasonable accommodations within the educational infrastructure?
- What concrete measures has the government of Sierra Leone instituted to ensure the equitable employment of individuals with albinism? Specifically, how is the government actively promoting inclusive workplace environments and providing necessary accommodations to facilitate the meaningful integration of persons with albinism into the workforce?
- To what extent has the government of Sierra Leone implemented concrete measures to combat discrimination against persons with albinism and foster gender equality within this specific demographic? Specifically, what initiatives and policies are in place to eradicate harmful practices, discriminatory practices, promote equal opportunities, and ensure the active inclusion and participation of individuals with albinism, particularly women, in diverse facets of societal engagement and advancement?

B. Introduction

The 2015 population and housing census of the country put the population of persons with albinism at 501 representing 0.5% of the population. Just as elsewhere in Africa, albinism is highly misunderstood in Sierra Leone making the condition shrouded in misery and misconceptions. Persons with albinism in Sierra Leone face constant marginalization, stigma and discrimination on daily basis making them vulnerable to the risks of attacks skin cancer and other socioeconomic challenges. This submission delves into each specific economic, social and cultural rights of persons with albinism in Sierra Leone

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 Sierra Leone. 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 Sierra Leone to the Committee on Economic, Social, and Cultural Rights (CESCR).

D. COMPLIANCE WITH THE PROVISIONS OF THE INTERNATIONAL CONVENTION ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ICESCR)

1. Article 3: Gender Equality and Non-Discrimination

The government of Sierra Leone recognizes gender equality and women's empowerment as integral components for achieving sustainable peace, social development, and economic progress in the country. Notable efforts have been made, including the establishment of a dedicated ministry overseeing gender and women's affairs, along with the amendment of the Sexual Offences Act in 2019.¹ However, despite these initiatives, the effective implementation of gender equality measures remains a formidable challenge, resulting in the marginalization of certain segments of the population, particularly persons with albinism.

Reports from albinism advocacy groups in Sierra Leone reveal that persons with albinism encounter discrimination, stigma, and prejudices within both family and community settings. A 2018 survey conducted by OSIWA supports these claims, indicating that 78.87 percent of persons with albinism surveyed acknowledged experiencing discrimination, with 70.79 percent being aware of multiple instances of discrimination against them.²

The plight of women impacted by albinism is particularly distressing, as reported cases include instances of sexual abuse. Some individuals harbour the misguided belief that engaging in a sexual relationship with a woman with albinism can cure HIV/AIDS, while others hold the erroneous notion that such encounters are more pleasurable than those with individuals without albinism. Consequently, many young women with albinism find themselves abandoned by their partners or victims of sexual assault, leading to instances of single motherhood due to unfounded beliefs. For instance, a 17 years old girl with albinism was sexually abused by her step father and eventually got her pregnant.

In some instances, children with albinism experience heartbreaking rejection and abandonment by their parents solely due to their skin colour. Disturbing reports from albinism advocacy groups reveal instances where a woman with albinism was deserted by her own mother, solely on the basis of her albinism. Another poignant account details a mother who, after giving birth to a boy with albinism, felt compelled to conceal the child within the confines of a room for approximately six months due to societal stigma and rejection by the father.

Addressing the unique challenges faced by women and persons with albinism necessitates a comprehensive approach that includes education, awareness campaigns, and legal frameworks to counter discrimination and false beliefs. Efforts

¹ Initial report submitted by Sierra Leone under articles 16 and 17 of the Covenant, due in 1998* to the Committee on Economic, Social and Cultural Rights. Para 35

² Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone, P 46

should be intensified to ensure that gender equality measures are not only enacted but effectively implemented, fostering an environment where all individuals, regardless of their characteristics, can thrive free from discrimination and prejudice.

2. Article 6: Right to Work

The employment landscape for persons with albinism in Sierra Leone presents a formidable challenge, with a significant portion facing unemployment, largely attributed to both the prevailing high rate of unemployment in the country and, to some extent, discrimination by potential employers. According to a study conducted by OSIWA, a mere 26.79% of participants with albinism were employed, while a staggering 73.21% remained unemployed. Within this demographic, 60.23% had never applied for a job, and 22.73% of those who did apply received no invitation for a job interview or placement.³

Discrimination, social stigma, low confidence and self-esteem, inadequate qualifications stemming from limited educational opportunities, and pervasive myths surrounding albinism constitute significant barriers to accessing job opportunities for persons with albinism in Sierra Leone. Reports from albinism advocacy groups in the country emphasize instances where qualified individuals with albinism are rejected during job placement processes solely based on their skin color and prevailing misconceptions related to their condition.

Regrettably, those who manage to secure employment often find themselves confronted with discrimination and stigma within the workplace. A distressing example involves a teacher with albinism who, upon being promoted to head a school, experienced bullying from both students and colleagues, accompanied by baseless accusations of inadequacy for the position. This distressing reality underscores the urgent need for comprehensive measures to combat discrimination, dispel myths, and foster inclusive workplace environments that provide equal opportunities and necessary accommodations for individuals with albinism in Sierra Leone.

3. Article 12: The Right of Everyone to the Enjoyment of the Highest Attainable Standards of Physical and Mental Health

Melanin deficiency in persons with albinism poses a significant public health concern across Africa.⁴ This is because the condition predisposes them to health risks such as visual and skin problems, including skin cancer,⁵ bowel and lung, diseases and excessive bleeding common in Hermansky-Padlak Syndrome (HPS) – a rare type of albinism. Research indicates that, in Sub-Saharan Africa, 90% of persons with albinism

³ As above p 29

⁴ ES Hong, H Zeeb and M Repacholi, 'Albinism in Africa as a public health issue' (2006) 6 BMC Public Health 212 DOI: 10.1186/1471-2458-6-212. 115. 4.

⁵ PT Lekalakala and others, 'Oculocutaneous Albinism and Squamous Cell Carcinoma of the Skin of the Head and Neck in Sub-Saharan Africa' [2015] Journal of Skin Cancer. 2015; 2015:167847. Epub 2015 Aug 12. PMID: 26347819; PMCID: PMC4549604.

die before the age of 40 due to skin cancer,⁶ and almost all persons with albinism have varying degrees of visual impairment.⁷

The mental health and well-being of persons with albinism is significantly impacted by persistent discrimination, stigma, and a lack of societal support. The continuous experience of these challenges exacerbates the emotional strain on individuals with albinism, contributing to heightened mental health issues. The prevalence of discrimination and stigma not only affects their self-esteem but also creates a hostile environment that can lead to anxiety, depression, and other mental health challenges.

According to the Independent Expert on the enjoyment of human rights by persons with albinism, persons with albinism need access to appropriate gender-sensitive healthcare services tailored to the condition of albinism and close to their communities.⁸ These services are essential to women and girls with albinism because of their vulnerability to intersecting forms of gender-based discrimination. The Independent Expert further notes that persons with albinism require health professionals to provide appropriate healthcare services equal to the quality provided to others, noting that these services be devoid of discrimination based on colour or disability. For persons with albinism to enjoy the highest attainable standard of physical and mental health, information on the condition must be provided by state parties to promote understanding and provide adequate healthcare services commensurate to their needs. Information on skin cancer prevention, sunscreens, protective clothing, psychosocial support and eye care services should be readily available, accessible and good quality.

It is disheartening to acknowledge that persons with albinism in Sierra Leone encounter formidable obstacles when seeking healthcare, driven by factors such as discrimination, pervasive stigma, insufficient understanding of their condition by healthcare professionals, and inadequate infrastructure to cater to their unique health needs. Reports from albinism advocacy groups in Sierra Leone have brought to light instances where individuals with albinism were denied access to healthcare services by service providers.

The absence of specialized healthcare services, particularly in dermatology and skin cancer treatment, contributes significantly to the high prevalence of skin cancer among persons with albinism in the country. Additionally, the lack of government provision of essential protective gear, such as sunscreens, further compounds the challenges faced by this vulnerable population, leaving the responsibility solely to private organizations. Research findings reveal that 22.78 percent of surveyed persons with albinism sought primary healthcare services primarily due to skin itching.⁹

Disturbingly, women affected by albinism encounter intrusive questioning when attempting to access sexual and reproductive health rights. An alarming incident

⁶ Human Rights Council (HRC), 'Preliminary study on the situation of human rights of persons with albinism' (2014) A/HRC/AC/13/CRP.1 paras 10-12. para 22.

⁷ As above, para 5.

⁸ Human Rights Council, 'Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism' (2017) A/72/131 Para 52

⁹ Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone, P19

involves a pregnant woman with albinism facing inappropriate scrutiny from a nurse who questioned her ability to conceive. Instances of prolonged waiting times, leading to agitation among persons with albinism seeking healthcare, have also been reported by albinism advocacy groups.

Despite the provisions of the Sierra Leone Disability Act, which mandates free healthcare for persons with disabilities, including albinism, there is a significant disconnect, as many healthcare service providers do not recognize albinism as a form of disability. Consequently, individuals with albinism are often denied their rightful access to healthcare services. In certain cases, leaders of albinism advocacy groups have had to intervene on behalf of their members to ensure they receive the healthcare they require. Addressing these systemic challenges is imperative to ensure that persons with albinism can access healthcare without facing discrimination, stigma, or undue obstacles.

4. Article 13: Right to Education

According to the committee on Economic, Social and Cultural Right, “education is both a human right in itself and an indispensable means of realizing other human rights.”¹⁰ Education has the potential to lift economically and socially marginalised individuals such as persons with albinism from poverty and can also enable them to participate fully in their communities.

In its commitment to guaranteeing the realization of the right to education, the government of Sierra Leone has undertaken various educational initiatives and policies. Notably, the Free Quality School Education (FQSE) was introduced in 2018, followed by the recent implementation of the Radical Inclusive Education policy.¹¹ Chapter 2 of the 1991 Constitution of Sierra Leone explicitly acknowledges education as a vital instrument for national development.¹² Furthermore, it mandates the government to ensure that education is universally accessible as an equal right for all citizens, emphasizing the prohibition of discrimination based on factors such as disability or social status.

Despite the commendable policy frameworks in place, it is regrettable to note that the effective implementation of these initiatives poses significant challenges, particularly for marginalized segments such as persons with albinism, who face distinct learning needs. While the government has taken steps to establish special schools nationwide to address these unique requirements, the availability of crucial assistive technologies, including magnifying lenses, binoculars, and large-font textbooks, remains insufficient even within these specialized institutions.

Reports from albinism advocacy groups in Sierra Leone highlight a multitude of challenges in the pursuit of quality education for persons with albinism. Instances of bullying, name-calling, and other forms of abuse, perpetrated by both educators and peers, persist. Furthermore, the absence of adequate accommodations in the classroom

¹⁰ General Comment No. 13: The right to education (article 13) (1999), Para 1

¹¹ Initial report submitted by Sierra Leone under articles 16 and 17 of the Covenant, due in 1998* to the Committee on Economic, Social and Cultural Rights. Para 174

¹² As above, Para 176

exacerbates difficulties, resulting in underperformance in academic endeavours. Tragically, this unfavourable learning environment contributes to a disproportionately high rate of school dropout among persons with albinism, with many unable to progress beyond basic education levels due to the adverse impact of insufficient accommodations on academic performance.¹³

The findings of a 2018 survey conducted by OSIWA reveal concerning statistics regarding the educational experiences of persons with albinism. According to the survey, 35 percent of respondents reported never having received special attention or support in the classroom,¹⁴ highlighting a significant gap in addressing the unique needs of this vulnerable group. Additionally, a substantial 57.29 percent indicated that they had not been provided with any assistive devices throughout their schooling years,¹⁵ further underscoring the challenges faced by persons with albinism in accessing essential tools for their education.

Regrettably, instances of teachers with albinism becoming victims of abuse, both from their students and fellow colleagues, have been reported. These incidents underscore the pressing need for heightened awareness, education, and advocacy to foster inclusivity and eliminate discrimination within educational settings. Efforts should be directed toward creating a supportive environment that upholds the rights and dignity of individuals with albinism, ensuring that educators, irrespective of their physical characteristics, can carry out their professional responsibilities free from harassment or discrimination. Addressing these challenges is crucial for cultivating a culture of respect, understanding, and equality within the educational community.

E. Recommendations

Promoting the economic, social, and cultural rights of persons with Albinism in Sierra Leone requires a comprehensive and multi-faceted approach. Here are some recommendations for the government:

1. Education and Awareness:

We recommend that the government of Sierra Leone take proactive measures to enhance the well-being of persons with Albinism by implementing comprehensive awareness campaigns aimed at educating the public about Albinism, dispelling prevalent myths and stereotypes. Additionally, it is crucial to integrate inclusive education policies within the national framework, ensuring that individuals with Albinism enjoy equal access to quality education, fostering a society that is informed, inclusive, and supportive of their unique needs. We commend the government in its effort in formulating the Radical Inclusion Education Policy aimed at ensuring every child enjoy accessible and quality education in the country. We want to reiterate the effective implementation of this policy to enhance quality education for all including persons with albinism.

2. Healthcare Support:

¹³ Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone, P22

¹⁴ As above, p23

¹⁵ As above p23

We strongly recommend the government to institute measures for the equitable healthcare of persons with Albinism by offering subsidized or free healthcare services that encompass essential provisions such as sunscreen, sunglasses, and bifocal glasses. Furthermore, there is a critical need to enhance the capacity of healthcare professionals through targeted training programs, enabling them to gain a comprehensive understanding of and effectively address the distinctive health requirements of individuals with Albinism. This proactive approach is pivotal in ensuring the holistic well-being and health equity for this specific demographic group.

3. Employment and Livelihood Opportunities:

We also strongly advise the government to initiate affirmative action policies aimed at fostering the inclusion and employment of persons with Albinism across diverse sectors. This proactive approach will not only promote diversity but also contribute to creating a more inclusive workforce. Additionally, there is a crucial need to implement skill development programs specifically tailored for individuals with Albinism, enhancing their employability and opening avenues for entrepreneurial endeavours. By championing these initiatives, the government can empower persons with Albinism to actively contribute to the workforce and cultivate a society that values and leverages the diverse talents of all its citizens.

4. Anti-Discrimination Legislation:

We strongly recommend that the government takes decisive action to safeguard the rights of persons with Albinism by enacting and rigorously enforcing anti-discrimination laws. These laws should be comprehensive, specifically targeting and protecting individuals with Albinism from discrimination across all facets of life, encompassing areas such as employment, education, and healthcare.

Furthermore, to demonstrate a commitment to regional initiatives, we encourage the government to actively engage with and adopt the African Union (AU) Plan of Action on Albinism. Implementation of this plan will not only reinforce national efforts but also contribute to a broader, collective strategy aimed at addressing the challenges faced by persons with Albinism. Embracing these measures will foster a society that upholds the principles of equality, justice, and inclusivity for all its citizens.

5. Community Engagement:

We strongly urge the government to champion community-based initiatives that actively promote inclusivity, understanding, and acceptance of persons with Albinism. By encouraging grassroots efforts, the government can facilitate the creation of a more compassionate and supportive social fabric.

Additionally, fostering community dialogues is crucial to address prevalent misconceptions surrounding Albinism. These dialogues provide a platform for open discussions, education, and the dispelling of myths, contributing to the cultivation of a supportive and informed environment. Through these concerted efforts, the government can play a pivotal role in fostering communities that embrace diversity and prioritize the well-being of all individuals, irrespective of their characteristics.

6. Access to Justice:

We strongly recommend that the government takes proactive steps to ensure that the legal system is equipped to promptly and effectively address cases of discrimination or violence against persons with Albinism. This includes the establishment of specialized mechanisms within the legal framework to handle cases related to the rights of persons with Albinism.

By enhancing the responsiveness of the legal system, the government can create a deterrent against discrimination and violence, providing a sense of security for individuals with Albinism. Specialized mechanisms will not only streamline the legal processes but also demonstrate a commitment to upholding the rights and dignity of this specific community. This approach is pivotal in fostering a just society where instances of discrimination and violence are swiftly addressed and mitigated.

7. International Collaboration:

We strongly recommend that Sierra Leone collaborates with international organizations and non-governmental organizations (NGOs) to share best practices and access resources for the betterment of persons with Albinism. Active participation in international forums is crucial to raise awareness about the unique challenges faced by individuals with Albinism and to advocate for their rights on a global scale.

Furthermore, we implore Sierra Leone to fully cooperate with the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism and the AU Special Envoy on Albinism (once appointed). This collaboration should include providing the mandate holders with all necessary information related to their mandates, implementing their recommendations, and reacting promptly to communications and urgent appeals. This level of cooperation is essential for the mandate holders to effectively fulfil their roles and contribute to the overall well-being and rights protection of persons with Albinism.

8. Data Collection and Research:

We strongly advise the government of Sierra Leone to initiate comprehensive research efforts aimed at gathering accurate and up-to-date data on the living conditions, challenges, and opportunities for persons with Albinism. This data serves as a foundational resource that can inform evidence-based policy development and implementation.

By conducting thorough research, the government can gain a deeper understanding of the specific needs and experiences of individuals with Albinism, enabling the formulation of targeted policies and programs to address challenges and enhance opportunities. This proactive approach aligns with the principles of informed decision-making and ensures that policies are tailored to the unique circumstances of the Albinism community, fostering a more inclusive and supportive environment.

By adopting these recommendations, the government of Sierra Leone can work towards creating an environment where persons with Albinism can fully enjoy their economic, social, and cultural rights on an equal basis with other.