



Alternative Report on the Human Rights situations of Children with albinism in Ghana to the Committee on the Rights of Child (CRC Committee)

Africa Albinism Network (AAN)

The Africa Albinism Network promotes the rights, well-being, and inclusion of people with albinism in Africa through advocacy, capacity development, and collaboration.

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INTRODUCTION

This report is submitted to the Committee on the Rights of the Child (CRC) to provide an overview of the situation of children with albinism in Ghana, highlighting the unique challenges they face in realizing their rights under the Convention on the Rights of the Child. Despite significant legal and policy advancements aimed at promoting the rights of all children in Ghana, children with albinism continue to experience systemic discrimination, exclusion, and violations of their fundamental rights. These issues stem from deep-seated cultural beliefs, social stigma, and a lack of targeted interventions in existing frameworks designed to protect vulnerable children particularly children with albinism.

Children with albinism in Ghana are subject to various forms of discrimination and abuse, including social marginalization, barriers to accessing quality education, inadequate healthcare services, and limited participation in cultural and recreational activities. In some instances, they are victims of harmful cultural practices that perpetuate fear and superstition surrounding their condition as confirmed by Ghana report to the committee stating that violence against children still prevail in Ghana¹. These challenges are exacerbated by a lack of public awareness, insufficient support mechanisms, and the absence of specific provisions addressing the unique needs of children with albinism in national policies and programs.

This report provides a detailed examination of the current legal and policy frameworks, including the gaps in their implementation, and offer recommendations to ensure the protection and promotion of the rights of children with albinism in Ghana. It seeks to urge the Committee to engage with the Government of Ghana and other stakeholders to address the critical issues affecting this vulnerable group and to foster an inclusive environment where all children, regardless of their condition, can thrive.

This report has been compiled by the Africa Albinism Network, drawing on insights from various sources including, most notably, one-on-one interviews with persons with albinism

¹ Committee on the Rights of the Child: Combined sixth and seventh periodic reports submitted by Ghana under article 44 of the Convention, due in 2020. Para 45

across the 16 regions of Ghana. These interactions are in the process of being compiled into a "Situational Analysis Report on the Human Rights Situations of Persons with Albinism in Ghana". Other sources informing this report include draft report of the Commission on Human Rights and Administrative Justice (CHRAJ) on Systemic investigation report on alleged ritual banishment and stigmatization against persons with albinism (PWA) in Ghana, credible media reports, academic and journal articles, outcome statement issues by the African Committee on the Rights and Welfare of the Child on a day of general discussion held during their 43rd Ordinary Session as well as guiding note on reporting on children with albinism by member states of the African Union

1. Article 2: Non-Discrimination

Ghana's Constitution contains several provisions relevant to the rights of children with disabilities, including children with albinism. Article 17 prohibits discrimination on several grounds, such as gender, race, colour, ethnic origin, religion, creed, social, and economic status.² While the equality clause does not explicitly mention disability-based discrimination, Article 29 specifically addresses the "rights of disabled persons," stipulating that "disabled persons shall be protected from exploitation, regulation, and treatment of a discriminatory, abusive, or degrading nature."³

The Children's Act of Ghana reinforces the provisions of Article 17, explicitly stating in Section 3 that "No person shall discriminate against a child on the basis of gender, race, age, religion, disability, health status, custom, ethnic origin, rural or urban background, birth or other status, socio-economic status, or because the child is a refugee."⁴

² The 1992 Constitution of Ghana, Article 17

³ Article 29 reads:

"29. RIGHTS OF DISABLED PERSONS.

(1) Disabled persons have the right to live with their families or with foster parents and to participate in social, creative or recreational activities.

(2) A disabled person shall not be subjected to differential treatment in respect of his residence other than that required by his condition or by the improvement which he may derive from the treatment. (3) If the stay of a disabled person in a specialised establishment is indispensable, the environment and living conditions there shall be as close as possible to those of the normal life of a person of his age. (4) Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature. (5) In any judicial proceedings in which a disabled person is a party the legal procedure applied shall take his physical and mental condition into account. (6) As far as practicable, every place to which the public have access shall have appropriate facilities for disabled persons. (7) Special incentives shall be given to disabled persons engaged in business and also to business organisations that employ disabled persons in significant numbers. (8) Parliament shall enact such laws as are necessary to ensure the enforcement of the provisions of this article."

⁴ The Children's Act 1998, (ACT 560) Section 3

Furthermore, Section 32 of the Persons with Disability Bill of 2024 prohibits discrimination against persons with disabilities, including children with albinism,⁵ and Section 51 provides additional protection for the rights of children with disabilities including children with albinism.⁶

The government of Ghana have also put in place several policies to ensure the protection and promotion of human rights for all including children with disabilities. Some of these policies include the Inclusive Education Policy,⁷ National Health Insurance Policy,⁸ Livelihood Empowerment Against Poverty⁹ . Effective and efficient implementation of these policies remains a significant challenge, especially in terms of interventions targeting children with disabilities including children with albinism.

Overall, it is noteworthy that none of these legal and policy frameworks specifically mention albinism or recognise it as a form of disability to be protected. This creates a gap and should be considered as a form of systemic discrimination against children with albinism in Ghana. Due to this systemic discrimination and gaps in explicit legal protection, children with albinism face serious challenges when attempting to access or

⁵ Section 32 reads

Right to equality and non-discrimination

(1). A person with disability is entitled to recognition before the law on an equal basis with others in the social, cultural, economic, civil and political aspects of life. (2). The Commission shall take effective and appropriate measures to guarantee protection against discrimination for (a) a person with disability; (b) a caregiver or a guide for a person with disability; and (c) a parent of a person with disability within the family and the community. (3). A person who provides goods or services to the public shall put in place the necessary facilities that make the goods or services available and accessible to a person with disability. (4). A person with disability is entitled to affirmative action measures that are intended

To (a) accelerate or achieve the equal treatment of the person with disability; **and** (b) eliminate discrimination against a person with disability.

⁶ Section 51 reads

Rights of children with disabilities

(1). Every child with disability has a right and freedom on an equal basis with other children with respect to (a) a name and registration immediately after birth; (b) right to paternity including the right to be cared for and maintained by the father; (c) right to live with the family, regardless of the disability; (d) right to participate in sports, social and recreational activities; (e) protection from abuse, exploitation and neglect; (f) right to life, human development of their physical and mental potential; (g) access to social protection programs; (h) evolving capacities and identity and to enjoy a full and decent life, in conditions which promote and ensure dignity, self-reliance and independence; (i) freedom to express the views of that person on all matters affecting the person; and (j) age appropriate assistance to realize the rights of that person.

(2) A parent, guardian or caretaker of a child with disability who: (a) confines, abandons or neglects a child with a disability; or (b) fails to provide the necessities of life including maintenance; or (c) violates the rights of a child with disability: commits an offence and is liable on summary conviction to a fine of not less than five hundred penalty units and not more than five thousand penalty units or to a term of imprisonment of not less than three months and not more than one year or to both.

⁷ <https://sapghana.com/data/documents/Inclusive-Education-Policy-official-document.pdf>

⁸ <https://www.moh.gov.gh/wp-content/uploads/2016/02/National-Health-Insurance-Policy-framework.pdf>

⁹ <https://www.mogcsp.gov.gh/projects/livelihood-empowerment-against-poverty-leap/>

benefit from government interventions such as the 5% District Assemblies Common Fund dedicated to persons with disabilities including children with disabilities.¹⁰

Furthermore, persons with albinism, particularly children with albinism continue to face severe forms of discrimination in access to education, health care, leisure and recreation and more generally in day-to-day social life in Ghana. Attempts to hold perpetrators to account through criminal prosecution are uncommon and often unsuccessful, in part due to a lack of confidence in the justice system including the police force. This is worsened by persistent discrimination, stigma and stereotypes, fear of reprisal and attacks as well as low educational attainment, low economic status, and inadequate knowledge of their legal rights on the part of children with albinism as well as lack of representation. Even where individuals do attempt to take legal recourse, access to legal aid and to lawyers more generally is uncommon and unaffordable

Proposed Recommendations

1. **Provision of Legal Aid Assistance:** The Government of Ghana through the Legal Aid Commission should enhance the provision of free legal aid assistance to children with albinism and their representatives including organisation representing the interest of children with albinism.
2. **Judicial Training on Albinism:** Judges in Ghana should receive comprehensive judicial training programs focused on albinism. These training programs, which should involve the direct participation of persons with albinism, and may be facilitated through Ghana's Judicial Training Institute,¹¹ should aim to educate judges, magistrates, and other court staff, on the unique challenges and human rights violations faced by persons with albinism including children.

2. Article 6. Rights to life, survival and development

¹⁰<https://rodra.co.za/images/countries/ghana/policy/Guidelines%20for%20Disbursement%20of%20District%20Assembly%20Common%20Fund.pdf>

¹¹ <https://www.jtighana.org/>

The right to life of persons with albinism, particularly children with albinism has come under threat within the African region due to misconceptions and myths that their body parts, when used in ritual potions, have the power to bring wealth or good luck. These beliefs have led to numerous physical attacks on persons with albinism, resulting in the loss of lives and body parts across the region.

As of January 2023, Ghana has recorded four attacks on the lives of persons with albinism, including one killing and three survivors.¹² On January 1, 2023, an attempted abduction of a 16-year-old boy with albinism was reported in Garu, Upper East Region. While playing football with his teammates, the boy was approached by a man on a motorbike who asked him to retrieve a bicycle from a nearby neighbourhood. The boy agreed, but the perpetrator continued driving past the destination despite the boy's protests. Sensing danger, the boy jumped off the bike and sought help from a nearby woman, unaware that she was part of the abduction syndicate. Through the advocacy intervention of the Ghana Association of Persons with Albinism (GAPA), the two culprits were apprehended and charged with the crime. The accused have appeared in court twice, but the case seems to have stalled. GAPA has struggled to get updates from the relevant authorities.

Persons with albinism contacted expressed that while harmful practices such as infanticide are rare, they used to happen in the past, and there is no reason to believe they have completely ceased, even if they occur in very limited instances. One participant recounted the following experience:

"When I was born, my father rejected me. My mother told me that he gave me poison to drink, but I vomited it out and survived. I was then forced to serve a fetish priest, whom I had to accompany and serve anytime they were in a trance."

The incidents above leave children with albinism deeply traumatised and highlight the ongoing danger they face in Ghana. Such harmful practices targeting persons with

¹² https://www.underthesamesun.com/wp-content/uploads/2024/02/Attacks-of-PWA-2-page_13.02.2024.pdf

disabilities including children with albinism are confirmed by Ghana's report to the CRPD Committee which indicates that

“culturally and traditionally, instances of infanticide exist in some communities” in Ghana while, “some socio-cultural practices constitute violence against children and tend to affect their survival and development, especially children with disabilities”¹³

While not explicitly applying this statement to albinism, Ghana's report does also acknowledge elsewhere that:

“persons with disabilities such as those with Albinism are seen as a curse or bad omen (in certain communities) and are either banished from these communities or threatened with death”¹⁴

Several reports have documented that mothers who give birth to children with albinism in some communities in Ghana are forced to flee with their newborns due to fear of attacks and community-imposed prohibitions against persons with albinism. In some cases, community elders have explicitly stated that they cannot guarantee the safety of children with albinism, as local beliefs hold that such individuals are prohibited from residing in the community and may be targeted for ritualistic sacrifices.¹⁵ These harmful practices are rooted in entrenched socio-cultural beliefs and superstitions, as confirmed in Ghana's state party report, which acknowledges that negative attitudes toward persons with disabilities, including those with albinism, stem from deeply ingrained cultural norms and practices.¹⁶ The situation highlights the urgent need for targeted interventions to address these harmful beliefs and ensure the protection of children with albinism, particularly in rural and marginalized communities.

Proposed Recommendation

¹³ Government initial report (n 1 above) para 159 and 161

¹⁴ As above para 239

¹⁵ Ritual banishment and stigmatisation of persons with albinism in Ghana. <https://africaalbinismnetwork.org/wp-content/uploads/2022/09/1564577071633r4nvwrgc26e-1.pdf>

¹⁶ Combined sixth and seventh periodic reports submitted by Ghana under article 44 of the Convention, due in 2020. Para 92

1. **Prosecution of Crimes and Harmful Practices Targeting Persons with Albinism:** The Ministry of Justice and Attorney General should take all necessary measures to ensure that allegations of crimes against persons with albinism are fully investigated and expeditiously prosecuted. Courts should, where possible, expedite action on current cases involving such practices to ensure timely justice and reinforce the protection of persons with albinism.
2. **Provision of Counselling and Support Services for Persons with Albinism and their family members:** The Government of Ghana, through the Ministry of Gender, Children and Social Protection and its agencies, should provide free and regular counselling and support services to persons with albinism,¹⁷ particularly survivors of physical attacks and other harmful practices such as banishment, ostracism, infanticide, and discrimination.

3. Article 9; Rights to Family Life/parental care

In accordance with Article 9 of the Convention on the Rights of the Child (CRC), which stipulates that a child shall not be separated from their parents against their will unless it is in the best interest of the child. Section 5 of the Children’s Act of Ghana protects all children including children with albinism from being separated and to grow up with their parents.¹⁸ However, the rights of children with albinism in Ghana are frequently violated due to familial rejection, particularly by fathers. This rejection is often rooted in the belief that albinism does not exist within the family lineage, and that a child born with albinism is a result of shame or misfortune.¹⁹

¹⁷ CHRAJ, Systemic investigation report on alleged ritual banishment and stigmatisation against persons with albinism (PWA) in Ghana (2023) (Draft), on file with AAN. P 70

¹⁸ Section 5 of the Children’s Act reads
Right to Grow up with Parents.

No person shall deny a child the right to live with his parents and family and grow up in a caring and peaceful environment unless it is proved in court that living with his parents would— (a) lead to significant harm to the child; or (b) subject the child to serious abuse; or (c) not be in the best interest of the child.

¹⁹ Children with albinism and the right to family life.

<https://undocs.org/Home/Mobile?FinalSymbol=A%2F79%2F175&Language=E&DeviceType=Desktop&LangRequested=False> para 21. See also <https://www.youtube.com/watch?v=alu2g30CQKs>

In many cases, fathers abandon their children with albinism and their mothers, leading to family separation, which directly contravenes Article 9. This rejection not only harms the emotional and psychological well-being of the child but also places an undue burden on mothers, who are often forced to raise the child in hostile environments with little or no support. The fear of social stigma and rejection by the extended family further exacerbates this situation, contributing to the marginalization of children with albinism.

Proposed Recommendations

- 1. Public Education and Sensitization Campaigns:** The Government of Ghana, in collaboration with civil society organizations (CSOs), should initiate nationwide public education campaigns aimed at dispelling myths and misconceptions about albinism. These campaigns should target communities, especially in rural areas, to address the stigma and discrimination that lead to the rejection of children with albinism by their fathers and families. The campaigns should emphasize that albinism is a genetic condition and not a curse or sign of misfortune. Prominent community leaders, religious leaders, and traditional authorities should be involved to help change cultural beliefs and foster acceptance, in line with Article 9 of the CRC, ensuring that children with albinism are not separated from their families due to harmful superstitions.
- 2. Strengthening Family Support Systems:** The government, alongside CSOs, should establish and strengthen family support systems, including counselling services for parents of children with albinism. These programs should focus on providing emotional, psychological, and financial support to families to reduce instances of abandonment and separation. Fathers, in particular, should be encouraged to actively participate in parenting through outreach programs that challenge gender norms and emphasize the importance of parental responsibility regardless of the child's condition. Legal and social support mechanisms should be reinforced to protect children with albinism from family separation, ensuring their right to grow up within a loving and supportive family environment, as guaranteed under Article 9 of the CRC.

4. Article 23: The Rights of Children with Disabilities including children with albinism

Under Article 23 of the Convention on the Rights of the Child, Ghana is obligated to ensure that children with disabilities, including those with albinism, enjoy their full rights to dignity, self-reliance, and active participation in society. This article emphasizes the state's responsibility to prevent discrimination and ensure that children with disabilities including albinism have access to appropriate healthcare, education, and social services that cater to their specific needs. These rights are integral to fostering the development and inclusion of children with disabilities, allowing them to reach their fullest potential.

Ghana, as a signatory to the CRC, is required to implement policies that provide children with albinism the same opportunities as their peers, free from discrimination. This includes ensuring that children with albinism are not excluded from mainstream education, that they have access to specialized healthcare and support services, and that their families receive the necessary guidance and assistance to care for them. These obligations should manifest in legal protections, policies, and programs aimed at reducing disparities and ensuring equal access for all children, regardless of their disability status.

Despite these clear obligations, children with albinism in Ghana continue to face significant challenges in accessing their rights under Article 23 of the CRC. One of the most pressing issues is the lack of inclusive education. Many schools in Ghana are not equipped to cater to the specific needs of children with albinism, particularly those related to vision impairments. As a result, these children often lack access to necessary educational resources such as large-print materials, assistive devices, and specialized support from trained staff. This exclusion not only limits their academic potential but also their ability to fully integrate into the school environment, leaving them at a significant disadvantage compared to their peers. More detail on this gaps and challenge provided under article 28 and 29 of this report.

The healthcare system in Ghana also poses major barriers to children with albinism. While these children require specialized care, particularly in dermatology and

ophthalmology, access to such services is severely limited. Essential products like sunscreen, which are critical for protecting their skin from the sun's harmful rays, are not covered under Ghana's National Health Insurance Scheme (NHIS). As a result, many children with albinism suffer from preventable conditions like skin cancer due to the lack of affordable protective measures. Furthermore, regular eye care, which is necessary for managing the vision impairments commonly associated with albinism, is often unavailable or inaccessible to these children. Refer to article 24 below for further details.

In addition to the challenges in education and healthcare, children with albinism are subject to deep-seated cultural stigma. Harmful beliefs, practices and myths about albinism persist in many communities, where children with this condition are often seen as a curse or a sign of bad luck. This stigma leads to widespread social rejection, and in some extreme cases, even violent practices such as ritual killings. Some communities openly reject children with albinism, and reports have documented situations where community leaders refuse to guarantee their safety, claiming that they are prohibited from residing in the community. These harmful practices leave children with albinism isolated, vulnerable, and unable to participate fully in social and community life, thus violating their right to inclusion and protection under Article 23 of the CRC.

The lack of targeted legal and social protection for children with albinism further exacerbates their vulnerability. Existing frameworks in Ghana do not specifically address the needs of these children, leaving them without adequate protection from discrimination, violence, and exclusion. This absence of targeted support systems highlights the gap between Ghana's obligations under the CRC and the actual experiences of children with albinism in the country.

Proposed Recommendations:

- 1. Legal Protections:** Amend the Children's Act and the Persons with Disabilities Act to explicitly include the rights of children with albinism, ensuring protections against discrimination and harmful cultural practices. Establish stricter sanctions for perpetrators of violence against children with albinism.

- 2. Inclusive Education:** Ensure that all schools are equipped with the necessary tools and trained staff to provide inclusive education for children with albinism. This includes large-print materials, assistive devices, and personalized learning support to accommodate their vision impairments.
- 3. Healthcare Access:** Expand the National Health Insurance Scheme to cover essential healthcare needs for children with albinism, such as sunscreen, dermatological care, and regular eye check-ups.
- 4. Awareness Campaigns:** Implement national campaigns aimed at dispelling myths and addressing stigma related to albinism. Engage community leaders, religious figures, and schools to educate the public on the rights and dignity of persons with albinism.

5. Article 24 Rights to health

Section 8 of the Children’s Act of 1998 (Act 560) states that (1) No person shall deprive a child access to education, immunisation, adequate diet, clothing, shelter, medical attention or any other thing required for his development. (2) No person shall deny a child medical treatment by reason of religious or other beliefs.²⁰ However, the act failed to mention disability as one of the grounds of denial of services to children hence creating a gap and systemic discrimination violating the rights to health of children with disabilities including albinism.

Similarly, the Persons with Disabilities Act deals with healthcare for persons with disabilities including children with albinism in an incomplete and confusing manner. It requires the provision of specialist healthcare services to “persons with total disability”,²¹ which it does not define.²² This approach excludes the provision of necessary specialised services to a wide range of other persons with disabilities considered to not be “total” and also discriminatorily adopts a medicalised approach to what is considered a total

²⁰ The Children’s Act of 1998 (Act 560), Section 8

²¹ Persons with Disabilities Act 715, section 31.

²² Daklo A.K, Access to healthcare for persons with albinism in Ghana: A human rights approach. <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 35.

disability.²³ To some extent, the Persons with Disability Bill of 2024 seems to correct some of this abnormality in section 35 (1) and (2)²⁴

The Act also requires the training of health professionals on “disability and disability-related issues”,²⁵ although in reality, such training is minimal. As one interviewee indicated:

“The curriculum for health professionals has a topic on disability but is not detailed and is usually rushed through... health professionals should have full modules on disability and difference in their curriculum so that they can provide better care for persons with albinism.”

The Act also provides for the “periodic” screening of children to “detect, prevent and manage disability”,²⁶ as well as the establishment of assessment centres to “provide early diagnostic medical attention to mothers and infants to determine the existence or onset of disability.”²⁷

The National Health Insurance Act creates a national health insurance scheme. The contributions required for users of the health system are supposed to be predicated on their ability to pay. Section 29 of the Act therefore sets out various groups of persons “exempted from the payment of contributions”.²⁸ This list includes “categories of differently-abled persons determined by the Minister responsible for Social Welfare”.²⁹ Despite this, persons with albinism appear not to benefit from exemptions on these

²³ As above, p 36.

²⁴ The Persons with Disability Bill 2024 Section 35 (1 and 2) reads

Right to medical care (1) A person shall not deprive a person with disability of access to medical care on the grounds of the disability of the person with disability. (2) A person with disability is entitled to: (a) appropriate medical care and treatment in line with the condition of the person with disability; (b) medical assessment reports for purposes of registration, employment or compensation; and obtain medical care and treatment with respect and dignity.

²⁵ Persons with Disabilities Act 715, section 32.

²⁶ Persons with Disabilities Act 715, section 33.

²⁷ Persons with Disabilities Act 715, section 34.

²⁸ It reads in full:

“Exemptions to contributions 29. The categories of persons exempted from the payment of contributions under the Scheme include (a) a child; (b) a person in need of ante-natal, delivery and post-natal healthcare services; (c) a person with mental disorder; (d) a person classified by the Minister responsible for Social Welfare as an indigent; (e) categories of differently-abled persons determined by the Minister responsible for Social Welfare; (f) pensioners of the Social Security and National Insurance Trust; (g) contributors to the Social Security and National Insurance Trust; (h) a person above seventy years of age; and (i) other categories prescribed by the Minister .

²⁹ Persons with Disabilities Act 715, section 29(e).

grounds.³⁰ Moreover, the Government's report suggests that a mere 3800 persons with disabilities in total have been registered for free allowing them "access medical care at no cost".³¹

Access to adequate healthcare for persons with albinism is crucial to their survival, especially in Ghana, where daily sunshine ranges between six to seven hours. Due to the lack of melanin in their skin and eyes, persons with albinism are predisposed to the harmful effects of ultraviolet (UV) rays from the sun which is exacerbated by the increasing change in climate. This exposure increases susceptibility to skin damage and eye problems.

Excessive sun exposure results in sunburns, rashes, premature photo-aging, wrinkling, and skin lesions. If left untreated, skin lesions can develop into skin cancer among persons with albinism especially children with albinism who in most cases play outdoor in the sun. Moreover, research has revealed that skin cancer is the primary cause of morbidity and mortality among persons with albinism in Africa.³² Though there is a dearth of research data on the prevalence rate of skin cancer among persons with albinism in Ghana, a recent study in neighbouring Togo indicated a 95.2 per cent rate of skin lesions among persons with albinism with an 11.8 per cent incidence rate of skin cancer.³³

Because skin cancer kills more persons with albinism than ritual attacks and murders, adequate sun protection measures must be followed strictly to reduce the impact of skin cancer on this population in Ghana. To achieve this, persons with albinism need a range of things including: long sleeve shirts; wide-brimmed hats; UV protection sunglasses; and sunscreen lotions. In addition, the availability, accessibility and affordability of well-resourced public healthcare facilities, goods and services and health-related

³⁰ <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 37.

³¹ Government initial report (n1 above), para 398. Studies seem to confirm that most persons with disabilities pay contributions for healthcare:

<https://www.tandfonline.com/doi/epdf/10.1080/2331205X.2021.1901379?needAccess=true>.

³² PM Lund, 'Lack of adequate sun protection for children with oculocutaneous albinism in South Africa,' (2008) 2

³³ Saka et al, 'Skin cancers in people with albinism in Togo in 2019: results of two rounds of national mobile skin care clinics,' BMC Cancer (2021) 21:26 <https://doi.org/10.1186/s12885-020-07747-8>

programmes, including adequate information on albinism and health needs associated with it, is essential to the health needs of children with albinism.

Persons with albinism including children also need access to specialist healthcare services such as dermatological and eye care services for regular skin screening, early detection and treatment of skin problems, including skin cancer and eye-related problems. Currently, approximately 25 dermatologists are serving the entire population of over 30 million people, and most of them are located in urban areas such as Accra and Kumasi.³⁴ This means access to dermatological services by persons with albinism remains challenging, especially for those in remote areas whose daily survival needs depend on farming and other outdoor activities such as children with albinism walking to and from school.

Furthermore, Ghana has only three cancer treatment facilities – Korle-Bu and Komfo Anokye Teaching Hospitals and a privately owned Sweden-Ghana Medical Center.³⁵ These three facilities are located in Accra and Kumasi, with a heavy backlog of patients waiting to be treated. Therefore, accessing these facilities becomes challenging for persons with albinism due to travel time, financial resources and waiting time to receive treatment. In the first place, most families of children with albinism cannot afford the cost of long-distance travel to Accra or Kumasi and the cost of the treatment. Secondly, those who can afford these expenses have to wait for a long time to get treated, resulting in further spreading or growth of the cancer tumours.

One of the individuals interviewed relayed information about a 16-year-old boy with advanced-stage forehead cancer who had to be transported from the Savannah region to Accra (about 660km or 13 hours of travel time). This happened because there is no treatment facility within that part of the country.

³⁴ E Smith-Asante' Only 23 dermatologists in Ghana; Rabito plans a rescue' Graphic Online, 16/10/2018, <https://www.graphic.com.gh/news/health/only-23-dermatologists-in-ghana-rabito-plans-a-rescue.html> (accessed 11 November 2021); <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10280237/#ref11>.

³⁵ EW. Fiagbedzi et al, 'Radiotherapy in cancer treatment in Ghana: from the past to present' Available at https://humanhealth.iaea.org/HHW/RadiationOncology/ICARO2/E-Posters/04_FIAGBEDZI.pdf (accessed 11 November 2021)

“Further engagements with the boy’s family indicated that he has been undergoing treatment in a Polyclinic at Nalerigu. However, his wound was treated as a common skin problem without any lab investigation leading to further cancer growth.”

Indeed, the knowledge of albinism is so limited, and the healthcare advice provided so lacking, that persons with albinism may die without their families knowing the cause:

“My uncle had a child with albinism who developed skin cancer but because of ignorance, the community believed that my uncle had used his child for money rituals and that is why he had a sore on his forehead. It was only later in life that I learned that my cousin had skin cancer because of exposure to the sun and I told same to my mother and family members.”

In another instance, another patient with albinism had to delay his skin cancer treatment because of pressure on health facilities across the country because of the COVID-19 pandemic. As a result, his situation worsened, and the cancer spread further to his internal organs, reducing his chances of surviving the treatment. He was initially diagnosed to receive radiotherapy, but due to the delay that led to the disease's spreading, chemotherapy was added to the treatment plan, increasing the cost of treatment, while leaving him with a slim chance of survival.

Making matters worse, skin cancer treatment is explicitly excluded from coverage on the National Health Insurance Scheme, which excludes all cancer treatment “other than cervical and breast cancer”.³⁶ The Scheme also excludes products required to prevent skin cancer, such as sunscreen.³⁷

Sunscreen in Ghana, as elsewhere, is treated as a luxury and can only be purchased in supermarkets and malls, at what for most individuals with albinism are exorbitant prices.

³⁶ National Health Insurance Scheme, ‘Benefit Package’ available at <http://www.nhis.gov.gh/benefits.aspx> (accessed 1/9/2021)

³⁷ <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 56.

In health facilities, no provision is made for it as they are generally considered as a cosmetic product.³⁸

Similarly, eye care services, such as access to optometrists and ophthalmologists is significantly limited both by their limited number and the cost of accessing such services.³⁹ Interviewees also expressed general dissatisfaction with the services they receive from healthcare centres including for their eye care. They complained about a lack of urgency from optometrists and ophthalmologists, as well as a complete lack of knowledge in respect of eye conditions impacting persons with albinism disproportionately. This results in a risk of misdiagnoses and inadequate treatment.

The government's report to the CRPD Committee acknowledges more generally the "unprofessional attitudes of health professionals towards persons with disabilities ... in the delivery of services in the health sector",⁴⁰ a reality reflected by interviewees consistently.

The prejudicial responses of health professionals to children with albinism have also been reported to have an impact on parents' reactions to their children. For example, one woman indicated that after a nurse mocked her child, her husband subsequently abandoned her and she would not breastfeed her child:⁴¹

"My husband because of the incident subsequently abandoned me and the baby because of the skin colour of the boy. I refused to breastfeed him for some days due to the nurses' reactions."

Finally, the impact of social stigma and discrimination has a major impact on the mental health of persons with albinism.⁴² As documented in this submission, negative impacts on mental health may emanate from family, religious leaders, school teachers, health

³⁸ W Thompson-Hernández 'The Albino Community in Ghana: 'I'm Motivated to Believe That I Can Survive' The New York Times 9 June 2018 <https://www.nytimes.com/2018/06/09/world/africa/living-with-albinism-in-ghana.html>. (Accessed 12 November 2021).

³⁹ <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 57.

⁴⁰ Government initial report (n1 above) para 404

⁴¹ Adonai StudiosGH 'Albinism in Ghana' <https://www.youtube.com/watch?v=FO4o3mRb55g>

⁴² <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 22-4.

professionals or any other member of society. Persons with albinism are therefore at high risk of developing issues relating to their mental health.⁴³ Access to mental health services is poor throughout Ghana,⁴⁴ particularly community-based services that respect the rights of health system users.⁴⁵

Proposed Recommendation

- 1. Inclusion of Sunscreens in the NHIS Medicines List:** The Government of Ghana, through the National Health Insurance Authority, should add sunscreens with SPF 30 and above to the National Health Insurance Scheme (NHIS) Medicines List and ensure their availability in pharmacies across the country.
- 2. Inclusion of Skin Cancer Treatment in the NHIS Benefit Package:** The Government of Ghana through the National Health Insurance Authority should consider adding skin cancer treatment to the benefit package of the National Health Insurance Scheme (NHIS).
- 3. Training of Healthcare Professionals on the Care of persons with Disabilities, including persons with Albinism:** The Government of Ghana, through the Ministry of Health and its agencies and educational institutions such as the Ghana Health Services, nurses training schools, medical training institutions, and allied health training institutions, should train healthcare professionals, including nurses, midwives, doctors, and other health services providers such as traditional birth attendants, herbalists, and specialised healthcare personnel including dermatologists, optometrists, and ophthalmologists, on how to care for persons with albinism. This training should encompass various health services, including access to reproductive healthcare, skin and eye care, and other services related to their disabilities.

⁴³ <https://onlinelibrary.wiley.com/doi/10.1002/casp.2403>;
<https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 23.

⁴⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10194950/>

⁴⁵ <https://www.hrw.org/news/2023/12/04/ghana-invest-more-mental-health-services>

4. Inclusion of Albinism in Public Health Sensitization and Community

Engagement: The Ghana Health Service should include albinism in its public health sensitisation and community engagement interventions. These interventions should target persons with albinism and their relatives, religious bodies, school children, opinion leaders, community members, and organised groups.

6. Article 28 and 29: Education

Under the Convention on the Rights of the Child, particularly Article 28, every child is entitled to education without discrimination, including on the basis of disability. In Ghana, however, despite legal protections, children with disabilities including those with albinism, continue to face significant barriers to accessing quality education, constituting a violation of this right.

While Section 8 (1) of Ghana's Children's Act guarantees the right to education for all children, including those with disabilities and albinism, it falls short in specifying the nature and scope of this education.⁴⁶ The Act does not clarify whether education should be inclusive, thereby failing to address the unique learning needs of children with disabilities. Similarly, Section 10(2) of the Act guarantees the right of children with disabilities to special care and education but does so in vague terms without defining what constitutes "special care" or how educational systems should accommodate diverse disabilities.⁴⁷

Similarly, both the Persons with Disabilities Act and the Education Act contain specific provisions relating to the education of children with disabilities. Section 5 of the Education Act, titled "Inclusive Education",⁴⁸ which it defines as a "value system... which holds that

⁴⁶ Section 8(1) of the Children's Act of Ghana (Act 560) reads
Right to Education and Well-being.

(1) No person shall deprive a child access to education, immunisation, adequate diet, clothing, shelter, medical attention or any other thing required for his development.

⁴⁷ Section 10(2) reads

Treatment of the Disabled Child.

(2) A disabled child has a right to special care, education and training wherever possible to develop his maximum potential and be self-reliant.

⁴⁸ Education Act of 2008, section 5 reads:

all persons who attend an educational institution are entitled to equal access to learning, achievement and the pursuit of excellence in all aspects of their education”.

The Persons with Disabilities Act provides more detail on education for children with disabilities, empowering the Minister of Education to “designate” schools “which shall provide the necessary facilities and equipment that will enable persons with disability to fully benefit from the school or institution”.⁴⁹ It also provides for “free education” for persons with disabilities.⁵⁰ However, the Act, in contravention of the CRPD, appears to consider certain children with disabilities incapable of enrolment “in formal schools” on account of their disability,⁵¹ and explicitly empowers schools to refuse admission to children with disabilities if it has been determined that such a child “clearly requires to be in a special school”.⁵²

These laws should be read with the Inclusive Education Policy, published in 2015, which acknowledges that “regular schools with an inclusive orientation are the most effective means of combating discrimination, building an inclusive society and achieving education for all”.⁵³ The policy itself appears to be in some tension with the Persons with Disabilities Act and the Education Act. The direction of the policy, which is in the process of being reviewed and updated, is contradicted by the realities of challenges faced by children with disabilities in accessing school.

This legislative vagueness contradicts Ghana's obligations under the CRC, particularly Article 23, which mandates that states ensure children with disabilities receive the support needed to maximize their development and integration into society. The failure to specify inclusive education models or ensure the provision of reasonable accommodations such

“5. (1) The District Assemblies and heads of institutions shall ensure that designs for schools are user-friendly for children with special needs. (2) Institutions that deliver education to children with special needs shall improve upon the existing infrastructure and provide for additional facilities where necessary. (3) A parent or guardian shall take advantage of the inclusive education facilities to send the child with special needs to the appropriate education facility, or subject to the availability of resources, make a request for the provision of the appropriate education facility. (4) For the purposes of this section, “inclusive education” means: the value system which holds that all persons who attend an educational institution are entitled to equal access to learning, achievement and the pursuit of excellence in all aspects of their education; and which transcends the idea of physical location but incorporates the basic values that promote participation, friendship and interaction.”

⁴⁹ Persons with Disabilities Act 715, section 17.

⁵⁰ As above, section 18(a).

⁵¹ As above, section 18(b).

⁵² As above, section 20(1).

⁵³ Inclusive Education Policy, page 5.

as assistive devices, tailored learning materials, or trained support staff leaves children with albinism in Ghana without the necessary tools to thrive academically.

Children with albinism face significant challenges in accessing education, especially at the primary and secondary levels. These challenges span the entire educational process, from enrolment to examination. During consultations, participants indicated that while enrolment forms at the tertiary level typically allow learners to indicate if they have any disabilities that require accommodations on account of disabilities, this provision is generally unavailable at the primary and secondary school levels. As a result, the needs of learners are not individually assessed, making the provision of reasonable accommodations unlikely if not impossible.

Additionally, persons with albinism noted that registration for the Basic Education Certificate Examination (B.E.C.E.), administered by the West African Examination Council, asks learners to indicate if they are blind to allow it to provide exam questions in braille. This singular measure is insufficient in ensuring equal access to education for children with albinism.

Due to the varying degrees of low vision among children with albinism, it is imperative that they receive reasonable accommodations, including assistive devices and technologies, in all their classrooms daily. Such accommodations vary depending on the specific individual and may include:

- the provision of large font textbooks and other learning materials;
- the provision of binoculars or monoculars, prescription lenses;
- the provision of computers, and other assistive technologies to enhance their learning;
- allowing Children with albinism to sit at the front of classrooms and be allowed to move, whenever necessary, while still being close to the chalkboard or marker board.

Persons with albinism in Ghana complain that these and other reasonable accommodations are typically not provided in the ordinary, mainstream, community schools thus making such schools non-inclusive. Such devices and materials are typically only provided to persons with albinism who attend special schools, particularly special schools for the blind learners.

Various experiences were documented in AAN's interviews with persons with albinism. One respondent indicated that they failed their exams because the questions placed on the board were not visible:

"I was supposed to write an examination in primary 6 for promotion to Junior High School, but because I couldn't see from the board and wasn't placed at the front of the class, I failed the exams."

Another indicated that stigma and discrimination from family and at school was prevalent:

"When I went to school, there were many comments from my family suggesting that educating me would be useless as I had no useful purpose in life. I also faced a lot of teasing at school, which led me to quit."

The experience of bullying and marginalisation at schools is common:

"When I finished Junior High School, I had the opportunity to go to Senior High School, but on my first day, I almost quit. I was given to the girl's prefect to accompany me to the dormitory, and before we got there, I heard loud screams and people running, some almost falling from the top. Even the senior house mistress heard it from her bungalow. I was so embarrassed and felt so sad. The senior house mistress had to come in and calm the other students down before I was taken to the dormitory."

Such bullying is worsened by teacher's attitudes, sometimes resulting in corporal punishment, as these examples illustrate:

“I had the experience of a teacher who took joy in lashing me because he had heard that my skin would become red when he lashed me. So, he constantly lashed me and would then ask me to lift my dress so that he could see if indeed my skin would turn red”.

“My economics teacher used to throw a marker at me every day because I had difficulty seeing the board and every time, I would strain my eyes to try to see what was on the board, he thought I was sleeping. I had to physically fight with the teacher at some point after which the teacher was moved to another class”.

Overall, this environment is demoralising and results in severe strain on children with albinism, some of whom may give up on their effort to go to school. Those who remain report the difficulty involved in doing so:

“I had become reserved and uninterested in class sometimes because of the bullying and stigmatisation. At some point I would not contribute to discussions in class because of the stigmatisation”.

Persons with albinism interviewed expressed their general support for the Inclusive Education Policy but bemoaned the circumstances detailed above also highlighting the apparent inadequacy of training of teachers on disabilities and albinism in particular. One study confirms this situation indicating that teachers are not, in their training “given enough opportunity to reflect on their values, beliefs, biases, and attitudes toward learners with disabilities to develop appreciation of learners with disabilities and to be sensitive toward them”.⁵⁴

Proposed Recommendation

1. Review and Amendment of Sections 8 and 10 of the Children’s Act of Ghana:

The Government of Ghana should review and amend Sections 8 and 10 of the Children’s Act to explicitly expand the type and scope of education provided to children with disabilities, including children with albinism. While the current provisions guarantee the right to education and special care for children with

⁵⁴ <https://www.frontiersin.org/journals/education/articles/10.3389/feduc.2023.1056630/full>

disabilities, they fail to specify the nature of education required or to mandate inclusive educational practices that address the unique learning needs of these children.

2. Review and Amendment of the Persons with Disabilities Act 715 sections 17 and 18b for Inclusive Education:⁵⁵

The Government of Ghana should review and amend sections 17 and 18b of the Persons with Disabilities Act 715 in line with Article 24 of the CRPD to place greater emphasis on inclusive education. This amendment should mandate the provision of reasonable accommodations and assistive devices, such as:

- large font textbooks,
- accessible computers and computer programs,
- binoculars,
- magnifiers, and
- other assistive technologies.

3. Amendment of Section 5 of the Education Act 778: The Government of Ghana should amend Section 5 of the Education Act 778 to ensure the provision of fully inclusive education to all children with disabilities, including children with albinism, in compliance with Article 24 of the CRPD.

4. Implementation of the Inclusive Education Policy for Students with Albinism:

The Government of Ghana, through the Ministry of Education and the Ghana Education Service, should fully implement its Inclusive Education Policy. This implementation should ensure that reasonable accommodations and assistive devices, such as prescription lenses, computers, magnifying glasses, binoculars or monoculars, are provided to students with albinism in their classrooms. Additionally, accommodations should include large font textbooks and other

⁵⁵ Section 17 of The Persons with Disabilities Act 715 reads

The Minister of Education shall by Legislative Instrument designate schools or institutions in each region which shall provide the necessary facilities and equipment that will enable persons with disability to fully benefit from the school or institution.

Section 18b reads

(b) establish special schools for persons with disability who by reason of their disability cannot be enrolled in formal schools

reading materials, allowing children with albinism to sit at the front of the class, and permitting the wearing of long-sleeved shirts and wide-brimmed hats.

5. **Adequate Resourcing of the Ghana Education Service for Inclusive Education Policy Implementation:** The Government of Ghana should ensure that the Ministry of Education, the Ghana Education Services and the Special Education Unit are adequately resourced, including both financial and human resources to properly implement the Inclusive Education Policy at all levels of education.
6. **Collection of Disaggregated Data on Students with Albinism:** The Government of Ghana, through the Ghana Education Service, should gather disaggregated data on students with albinism at various levels of education across the country. This data collection effort aims to inform decision-making processes, particularly regarding the provision of reasonable accommodations and assistive devices for students with albinism. By understanding the specific needs and challenges faced by these students, the government can better allocate resources and support to ensure their educational success and inclusion.
7. **Provision of Accessible Textbooks and Reading Materials for Students with Albinism:** The Government of Ghana through the Ministry of Education and the Ghana Education Service should ensure the provision of textbooks and other reading materials in accessible formats, such as large font and audiobooks, to enhance the quality of education for students with albinism.