



Alternative Report on the Human Rights situations of Persons with albinism in Ghana to the Committee on the Rights of Persons with Disabilities (CRPD 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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Submitted on 17th July 2024

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A. Introduction

Despite the State party report indicating that the Ghana Association of Persons with Albinism has been consulted in its development, Ghana's report makes only a single and generalised reference to persons with albinism.¹ The Government's more recent reply to the Committee's list of issues includes not even one reference to the implementation of CRPD provisions in respect of the enjoyment of the rights of persons with albinism, despite the Committee's explicit and directed questions in the List of Issues in respect of violence; awareness raising, torture or inhuman and degrading treatment; and exploitation and abuse.

This submission seeks to fill this gap by providing specific and detailed information relating to the experiences of persons with albinism in Ghana. It 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 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", a draft of which has been provided alongside this submission.

It is, overall, of significant concern that the Persons with Disabilities Act provides for an impairment-based definition of disability.² The Act, which was introduced before Ghana's ratification of the CRPD is out of step with Ghana's CRPD obligations in this and several other respects, including its failure to explicitly define discrimination against persons with disabilities as including the denial of reasonable accommodation.³

¹ Government's initial report to the CRPD Committee, paragraph 239.

² It reads:

““person with disability” means an individual with a physical, mental or sensory impairment including a visual, hearing or speech functional disability which gives rise to physical, cultural or social barriers that substantially limits one or more of the major life activities of that individual””

³ Instead, section 36 of the Act includes a right to reasonable accommodation. But this right also does not imply that failure to provide such accommodations amounts to discrimination. Read with section 4 of the Act:

“Section 4—Exploitation of and discrimination against a person with disability

(1) A person shall not discriminate against, exploit or subject a person with disability to abusive or degrading treatment.

(2) An employer shall not discriminate against a prospective employee or an employee on grounds of disability unless the disability is in respect of the relevant employment.”

There is a lengthy and ongoing process for the amendment of the Act. Indeed, a large range of the Government of Ghana's replies to the List of Issues produced by the Committee merely quote a 2024 version of the Bill intended to amend the Act without providing any further information.

Though the most recently available version of the Bill resolves some of the problems caused by the Act, including with respect to the definition of disability, some concern is warranted with respect to the Bill's failure to directly address core issues that are critical to the enjoyment of human rights by persons with albinism.

Finally, the Government of Ghana has not yet taken a range of steps which would, overall, improve the situation of persons with albinism:

- The adoption of a National Action Plan, in consultation with persons with albinism, pertaining to the protection of their rights.⁴
- The full implementation of the Pan African Parliament's Guidelines on Accusations of Witchcraft and Ritual Attacks;⁵
- The ratification of the Africa Disability Protocol; and
- The ratification of the Optional Protocol to the CRPD

Proposed Recommendations

- 1. Expedited Review and Amendment of the Persons with Disabilities Act 715:** The Government of Ghana should expedite and fast-track the lengthy review and amendment process of the Persons with Disabilities Act 715. This review should consider the specific recommendations outlined in each section of this submission to ensure that the rights and welfare of persons with albinism are adequately promoted and protected by the Act particularly with respect to banishment and harmful practices targeting persons with albinism in Ghana. This will strengthen the legal framework and address the unique challenges faced by persons with albinism in Ghana.

⁴ <https://www.ohchr.org/sites/default/files/documents/issues/albinism/AU-Plan-of-Action-EN.pdf>

⁵ https://www.ohchr.org/sites/default/files/2022-12/PAP-Guidelines-EN_0.pdf

2. **Adoption of a National Action Plan on Albinism in Ghana:** The Government of Ghana should develop and adopt a National Action Plan on albinism. This plan should be created in consultation with persons with albinism and be aligned with the African Union's Plan of Action on Eliminating Harmful Practices and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021 – 2031). The adopted Plan should include a dedicated budget and be implemented by the National Council for Persons with Disabilities in collaboration with the Ghana Association of Persons with Albinism. This collaborative approach will ensure that the needs and rights of persons with albinism are adequately addressed and protected.
3. **Adoption and Implementation of Pan African Parliament Guidelines on Witchcraft Accusations and Ritual Attacks:** The Government of Ghana, through the Parliament of Ghana, should adopt and implement the Pan African Parliament Guidelines on Accusation of Witchcraft and Ritual Attacks. These guidelines aim to eliminate harmful practices and other human rights violations. The adoption and implementation of these guidelines will provide a structured approach for parliamentarians to address and mitigate these issues, thereby enhancing the protection of vulnerable populations.
4. **Ratification of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities.** The Government of Ghana should expedite the processes leading to the ratification of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities. Ratifying this Protocol will enhance the legal and policy framework for protecting and promoting the rights of persons with disabilities in Ghana, ensuring alignment with regional human rights standards.
5. **Ratification of the Optional Protocol to the Convention on the Rights of Persons with Disabilities.** The Government of Ghana should ratify the Optional Protocol to the Convention on the Rights of Persons with Disabilities. This ratification will strengthen the country's commitment to upholding the rights of persons with disabilities by providing them with additional mechanisms to seek justice and ensuring adherence to international standards.

B. Article 5 – Equality and Non-Discrimination

Ghana's Constitution contains several provisions relevant to the rights of persons with disabilities. Article 17 prohibits discrimination on various grounds, including gender, race, colour, ethnic origin, religion, creed, or social and economic status.⁶ While the equality clause does not make specific mention of disability-based discrimination, Article 29 makes specific provision for the "rights of a disabled person", which includes a provision that indicates that all "disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature".⁷ However, various aspects of this constitutional provision appear to be based on a medicalized understanding of disability and therefore fall short of the CRPD's requirements.

Nevertheless, a recent court decision of the Ghanaian Supreme Court appears to attempt to reconcile the gap between domestic and international law provisions relating to the rights of persons with disabilities. In *Rita Kriba vs Africa World Airlines [2023] GHACA 19*, the Court, citing Article 29 of the Constitution and provisions of the Persons with Disabilities Act confirms the unlawfulness of discrimination against persons with disabilities. Indeed, it goes further expressing the view that the Constitution and the Persons with Disabilities Act "subscribe to the [social theory or model of disability] that society has the power to harness the full potential of persons with disabilities through law and policy".⁸

⁶ The 1992 Constitution of Ghana, Article 17

⁷ 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."

⁸ <https://ghalii.org/akn/gh-hr-accra/judgment/ghaca/2023/19/eng@2023-03-02>, pages 18-21.

The Persons with Disability Act 715 of 2006 in section 4 also protects persons with disabilities against all forms of exploitation, discrimination, and abusive or degrading treatment.⁹ However, the Act does not provide for the operationalization of this prohibition, thereby limiting legal recourse for discrimination. In addition, and contrary to the CRPD, the Act does not define a failure to provide reasonable accommodations as constitutive of discrimination.

The government of Ghana have also put in place several policies to ensure the protection and promotion of human rights for all including persons with disabilities. Some of these policies include the Inclusive Education Policy,¹⁰ National Health Insurance Policy,¹¹ Livelihood Empowerment Against Poverty¹². Effective and efficient implementation of these policies remains a significant challenge, especially in terms of interventions targeting persons with disabilities including those 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 persons with albinism in Ghana. Due to this systemic discrimination and gaps in explicit legal protection, persons with albinism face serious challenges when attempting to access or benefit from government interventions such as the 5% District Assemblies Common Fund dedicated to persons with disabilities.¹³

Furthermore, persons with albinism continue to face severe forms of discrimination in access to education, health care, employment 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

⁹ Persons with Disabilities Act 715 of 2006, Section 4

¹⁰ <https://sapghana.com/data/documents/Inclusive-Education-Policy-official-document.pdf>

¹¹ <https://www.moh.gov.gh/wp-content/uploads/2016/02/National-Health-Insurance-Policy-framework.pdf>

¹² <https://www.mogcsp.gov.gh/projects/livelihood-empowerment-against-poverty-leap/>

¹³ <https://rodra.co.za/images/countries/ghana/policy/Guidelines%20for%20Disbursement%20of%20District%20Assembly%20Common%20Fund.pdf>

persons with albinism. 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. **Amendment of Section 4 of the Persons with Disabilities Act 715:**¹⁴ The Government of Ghana should amend Section 4 of the Persons with Disabilities Act 715 to include specific provisions defining what constitutes exploitation of or discrimination against persons with disabilities and make explicit that the denial of reasonable accommodation amounts to discrimination.
2. **Provision of Legal Aid Assistance:** The Government of Ghana through the Legal Aid Commission should enhance the provision of free legal aid assistance to persons with albinism.
3. **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,¹⁵ should aim to educate judges, magistrates, and other court staff, on the unique challenges and human rights violations faced by persons with albinism.

¹⁴ Section 4 of the Persons with Disabilities Act 715 reads

Section 4—Exploitation of and discrimination against a person with disability

(1) A person shall not discriminate against, exploit or subject a person with disability to abusive or degrading treatment.

(2) An employer shall not discriminate against a prospective employee or an employee on grounds of disability unless the disability is in respect of the relevant employment

¹⁵ <https://www.jtighana.org/>

C. Article 6 – Women with disabilities

The Persons with Disabilities Act 715 does not contain a specific provision relating to women with disabilities¹⁶ and more generally does not adopt an intersectional and gendered perspective to disability rights. A 2020 report on the rights of women with disabilities in Ghana provides context on the discrimination against them.¹⁷ Unfortunately, however, the report makes only one specific reference to issues particular to women with albinism, generally noting the stigma faced by them.¹⁸

Women with albinism face several challenges particularly because they are women and also because they are persons with albinism. Such intersectional discrimination was confirmed in the consultations for the situational analysis produced by AAN. Particularly severe examples were expressed with respect to challenges faced by women with albinism while attempting to access sexual and reproductive health services.

Many healthcare professionals especially nurses and midwives generally believe the myths and misconceptions about albinism. One participant shared a harrowing story of how she had two stillbirths because of the refusal by nurses to attend to her when she was in labour. Other participants expressed how they were ridiculed by nurses and midwives who were generally aggressive to them while they were in labour and often suggested that they should be asexual or refrain from having children.¹⁹

In addition, it is widely believed that sexual intercourse with a woman with albinism cures HIV/AIDS. These beliefs and myths subject many women with albinism to sexual violence, including rape.²⁰

¹⁶<https://rodra.co.za/images/countries/ghana/research/GENDER%20BASED%20VIOLENCE%20AGAINST%20WOMEN%20WITH%20DISABILITIES%20GHA> ; <https://globaldisability.org/2016/04/28/ghana-disability-act>; <https://gcap.global/wp-content/uploads/2021/02/LNWB-Ghana-Country-Report-1.pdf>

¹⁷ <https://gcap.global/wp-content/uploads/2021/02/LNWB-Ghana-Country-Report-1.pdf>

¹⁸ Government initial report (n1 above), p11.

¹⁹ Africa Albinism Network, Persons with albinism in Ghana: A situational Analysis Report (2024) (Draft on file) p 35-36

²⁰ <https://www.ghanaweb.com/GhanaHomePage/NewsArchive/We-are-not-carriers-of-coronavirus-stop-tagging-us-Person-with-Albinism-979582>

Some others believe that marrying a woman with albinism brings wealth or good opportunities. For instance, in the northern part of Ghana, traditional healers, popularly called Mallams, believe that having a woman with albinism as a wife enhances their healing powers. A woman with albinism narrated how she was harassed by a Mallam as a result of this belief.²¹

The Government's report to the CRPD Committee indicates that:

“there seem to be no efforts to train social service providers, healthcare providers, and law enforcement officers on how to recognize and respond to violence against women with disabilities.”²²

This reality, for which the Government is responsible in terms of its CRPD obligations, was affirmed by women with albinism in Ghana with respect to the challenges confronting them.

Proposed Recommendations

- 1. Review and Amendment of the Persons with Disabilities Act 715 to include a specific section on women with disabilities in Line with CRPD Article 6:** The Government should review and amend the Persons with Disabilities Act 715 to include a specific section on women with disabilities, including women with albinism, in accordance with CRPD Article 6. This section should recognise the rights of women with albinism to social, economic, political, and reproductive healthcare, as well as other rights related to women and should also prohibit discrimination and other harmful practices targeting women with albinism.
- 2. Training of Healthcare Professionals on the Care of Women with Disabilities, Including Women with Albinism:** The Government of Ghana, through the Ministry of Health and its agencies and educational institutions such as the Ghana Health Services, nursing schools, medical training institutions, and allied health training institutions, should train healthcare professionals,

²¹ Africa Albinism Network (n 17 above) p 28

²² Government initial report (n1 above) para 11

including nurses, midwives, doctors, and other health service providers such as traditional birth attendants, herbalists, and specialised health personnel including dermatologists, optometrists, and ophthalmologists, on how to care for women with disabilities, including women with albinism. This training should encompass various health services, including reproductive healthcare, skin and eye care, and other services related to their disabilities.

D. Article 8 – Awareness Raising

Persons with albinism in Ghana face a range of challenges rooted in legislative and policy incoherence, as well as pervasive stigma and discrimination due to a lack of adequate information and awareness on the condition. Some of the myths and superstitions about persons albinism in Ghana include:²³

- A belief that they are a curse or a bad omen;²⁴
- Description using derogatory language such as *gesoshi* (“fallen from the sky”) in reference to their perceived supernatural means of being incomplete or *ofri/ofridjato* (“scorched or marked person or borrowed person” or *gbungu* (“supernatural”);
- A belief that persons with albinism are ghosts;
- A belief that persons with albinism do not excrete on Fridays;
- A belief that the feet of persons with albinism turn into fire at night;
- A belief that persons with albinism cannot see during the day;
- A belief that a person who marries a person with albinism will become poor and also a belief that a person who marries a person with albinism will become rich;
- A belief that pregnant women should not be exposed to persons with albinism because albinism will be spiritually transferred to the unborn child;
- A belief that a child is born with albinism because of a pregnant mother's contact with a mythical creature;
- A belief that a child is born with albinism because it was conceived through an adulterous relationship.
- A belief that coming into contact with a person with albinism in the morning means bad luck for the rest of the day;
- A belief that sex with a person with albinism can cure HIV/AIDs or will otherwise bring wealth;
- A belief that persons with albinism ultimately do not die, but simply vanish.

²³ Africa Albinism Network (n 17 above).

²⁴ Government initial report (n1 above), para 239.

These are some specific examples which mask a larger discriminatory environment which leads to overall scapegoating of persons with albinism for anything negative that occurs around them. A typical example of discrimination and stigmatisation against persons with albinism as narrated by a person with albinism,

“...even on my way from my town to Accra for this consultation, no one sat next to me in the vehicle until it was almost full’. Even with children, sometimes whenever anything bad happens, it is the child with albinism who is blamed.”²⁵

The remainder of this report highlights some of the harmful consequences contributed to by these and other false beliefs about albinism in Ghana. In the worst cases, these beliefs are key contributors to harmful practices as severe as banishment, societal ostracism and even violence.

Although national institutions are mandated to engage in public awareness about various human rights issues, they have not undertaken specific programming or awareness-raising campaigns focused on albinism. Such institutions include the Commission on Human Rights and Administrative Justice²⁶ and the National Commission on Civic Education.²⁷

In the absence of targeted efforts has resulted in persistent discrimination and societal misconceptions about albinism, further marginalizing persons with albinism and restricting their access to education, healthcare, employment, and social participation. The stigma and myths surrounding albinism exacerbate these issues, leading to exclusion even within disability groups.

Indeed, many persons with albinism themselves lack self-awareness regarding their condition, contributing to their inability to protect themselves against environmental

²⁵ Africa Albinism Network (n 17 above)

²⁶ Commission of Human Rights and Administrative Justice Act: <https://chraj.gov.gh/wp-content/uploads/2018/09/ACT-456.pdf>.

²⁷ The National Commission for Civic Education Act: <https://ir.parliament.gh/bitstream/handle/123456789/1902/NATIONAL%20COMMISSION%20FOR%20CIVIC%20EDUCATION%20ACT%2C%201993%20%28ACT%20452%29.pdf?sequence=1&isAllowed=y>

risks and access state services and societal accommodations. This situation is worsened by public ridicule. As one person with albinism explained:

“Growing up as a child and walking to school, people begin to chant names and look at you in a weird way as though you are not a human being, which made us very uncomfortable... It really affected some of us who were already struggling to accept ourselves.”²⁸

This situation is further compounded by insufficient awareness among healthcare professionals, leading to the denial of basic healthcare services and the non-coverage of essential healthcare services and consumables under the National Health Insurance Scheme (NHIS). The same is true in the educational environment in respect of teachers and other school staff.

Proposed Recommendations

- 1. Review and Amendment of the Persons with Disabilities Act 715 for disability awareness raising including albinism:** The Government of Ghana should review and amend the Persons with Disabilities Act 715 to include a specific provision mandating the government and its agencies, such as the National Council for Persons with Disabilities (NCPD), National Commission for Civic Education (NCCE), the Commission on Human Rights and Administrative Justice (CHRAJ), the Ghana Health Service (GHS), and the Ghana Education Service (GES), to adopt appropriate measures to raise awareness about albinism in Ghana.
- 2. Intensive public education and awareness raising about albinism in Ghana:** The Government, through its agencies such as the National Council for Persons with Disabilities, National Commission for Civic Education (NCCE) and the Commission on Human Rights and Administrative Justice (CHRAJ), should conduct nationwide sensitisation campaigns on the rights of persons with albinism. These campaigns should target community leaders, including chiefs, opinion leaders, market women and men, religious bodies, educational

²⁸ Africa Albinism Network (n 17 above)

institutions, organised groups, social services providers, persons with albinism, and their families. This effort should aim to demystify albinism, reduce or eliminate misconceptions associated with the condition, and promote a more inclusive and respectful society, especially for persons with albinism.

These awareness interventions should take various forms including community engagement, seminars and conferences, workshops, television and radio talk shows featuring persons with albinism and short films highlighting the capacities of persons with albinism.

- 3. Adoption of International Albinism Awareness Day and National Albinism Awareness Month:** The Government through the NCPD should adopt and recognise June 13th as a national day to mark International Albinism Awareness Day. On this day, the government, through the National Council for Persons with Disabilities, should organise conferences and other awareness-raising activities. This will serve as a national platform to discuss issues related to albinism and foster a national discourse on finding solutions to the challenges faced by the albinism community. Additionally, the government should adopt National Albinism Awareness Month. This month-long awareness campaign can include a series of activities such as radio and TV discussions, community engagements, public seminars, and local conferences.

E. Articles 10 and 15: Right to Life and Freedom from torture or cruel, inhuman or degrading treatment or punishment

The right to life of persons 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.²⁹ The most recent attack resulting in death occurred on February 17, 2015, when the deceased body of Kofi Yeboah, a person with albinism, was found in Amanase-Boketey near Suhum in the Eastern Region. It is suspected that he was killed by a local pastor. Initially, the local police were lethargic in their response to the crime, and it took public and media pressure for the homicide unit at the national police headquarters in Accra to take over the investigation.³⁰

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.

Several participants shared their experiences with attempted abductions or near encounters with physical harm for ritual purposes. One participant shared his personal experience of being targeted for ritual sacrifice. He recounted being informed that

²⁹ https://www.underthesamesun.com/wp-content/uploads/2024/02/Attacks-of-PWA-2-page_13.02.2024.pdf

³⁰ https://ccprcentre.org/files/documents/Ghanians_with_Albinism.pdf

individuals from the chief's palace in his community wanted to capture him and take him to a fetish priest. Fortunately, a person at the palace when the decision was made notified him. Fearing for his safety, he quickly fled the town.³¹

Persons with albinism 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 persons with albinism deeply traumatised and highlight the ongoing danger they face in Ghana.

Such harmful practices targeting persons with disabilities 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"*³²

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"*³³

³¹ <https://www.businessghana.com/site/news/general/141797/Albinos-still-live-in-fear> See also Africa Albinism Network (N 17 above) p 31

³² Government initial report (n 1 above) para 159 and 161

³³ As above para 239

Proposed Recommendation

- 1. Review and Amendment of Act 715 to include specific provisions on the Right to Life:**³⁴ The Government of Ghana should review and amend the Persons with Disabilities Act 715 to include a section on the right to life of persons with disabilities, in line with Article 10 of the CRPD. This amendment should explicitly protect the right to life of all persons with disabilities, including those with albinism, ensuring their safety and well-being and affirming their inherent dignity and value as equal members of society.
- 2. 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.
- 3. Provision of Counselling and Support Services for Persons with Albinism:** 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,³⁵ particularly survivors of physical attacks and other harmful practices such as banishment, ostracism, infanticide, and discrimination.

³⁴ The persons with Disabilities Act have no section on rights to life for persons with disabilities.

³⁵ 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

F. Articles 18, 19 – Freedom of Movement and Right to Live in the Community

Many persons with albinism are forced to make choices to move away from their communities, fearing for their safety because of threats of violence or other discrimination. These choices are not freely made, therefore amounting to violations of their right to “freedom to choose their residence ... on an equal basis with others, including by ensuring that persons with disabilities”.³⁶

Sometimes such choices to leave communities are explicitly forced due to varying forms of “cultural banishment” still practised and applied to persons with albinism. For example, one person with albinism indicated that:

“Cultural banishment happens in places like Akwamufie and Kwahu Bukuruwa, where persons with albinism are not allowed to live in the community. We were once told of a woman from Kwahu Bukuruwa who gave birth to a child with albinism. She had to leave the community to raise the child outside that community.”

In some extreme circumstances, such as in Akwamufie, Abease, and Atebubu, persons with albinism are simply not allowed to reside, purportedly due to cultural practices, beliefs, and the presence of gods in these communities that do not permit persons with albinism in their presence.³⁷ Responding to a complaint laid by the Ghana Association of Persons with Albinism about banishment of persons with albinism in 2019, the CHRAJ has produced a yet unpublished report on “ritual banishment and stigmatisation against persons with Albinism in Ghana”.³⁸ This report builds on a previous report produced by GAPA in 2019, which documents the banishment of persons with albinism in Ghana.³⁹ The

³⁶ Article 18(1) ; Article 19.

³⁷ Daklo, A. K., & Obadire, O. S. (2024). Exploring the experiences of persons living with albinism in Ghana. *Cogent Education*, 11(1). <https://doi.org/10.1080/2331186X.2024.2335792>

³⁸ CHRAJ, Systemic investigation report on alleged ritual banishment and stigmatisation against persons with albinism (PWA) in Ghana (2023) (Draft), on file with AAN.

³⁹ <https://africaalbinismnetwork.org/wp-content/uploads/2022/09/1564577071633r4nwvrgc26e-1.pdf>

CHRAJ's report confirms the prevalence in some communities in Ghana of the practice of banishment.

The practice of banishment applies to persons born in such areas, but also extends to individuals seeking to move to particular areas, often for work opportunities, thus also impinging on their right to work – particularly devastating given the significant barriers to persons with albinism accessing such opportunities for work more generally.

The CHRAJ's report, for example, documents the following experience, indicating how longstanding this practice is:

“I, together with a PWA (an accountant), was transferred from Akwapim in 1979 to work with a food processing company in Bokuruwa. Because we were strangers in the community, we needed to visit the Chief to inform him of our transfer to work here. The very moment we got to know that PWAs were not accepted in the community, He (the PWA) had to flee the community”.

AAN's situational report confirms that this practice is ongoing, with one respondent, for example, indicating the following:

“As a teacher in the Birem South District of the Eastern Region, I had to be posted to 4 or 5 schools within one school term without any explanation. When I finally settled in Kwae, it was resisted by the authorities and when I enquired from the authorities, including from CHRAJ, it was explained to me that the communities did not accept persons with albinism and therefore it would not be safe to be transferred to that community. The justification was that the communities around the Birem River consider it to be a taboo to have a person with albinism in their community.”

Proposed Recommendations

- 1. Amendment of the Persons with Disabilities Act to Prohibit Banishment and Harmful Practices targeting persons with disabilities including**

albinism:⁴⁰ The Government of Ghana should amend the Persons with Disabilities Act to include a specific section that prohibits banishment and other harmful practices such as infanticide, ostracism, and ritual killings targeting persons with disabilities, including those with albinism.

2. **Collaborative Efforts with CSOs and NGOs to Raise Awareness about Albinism:** The Government through its agencies such as the NCPD, NCCE and CHRAJ as well as the Information Services Department should work with civil society organisations (CSOs) and non-governmental organisations (NGOs) to raise awareness about albinism in communities where harmful practices violate the rights of persons with albinism. Specific attention should be given to communities such as Akwamufie, Abease, and Atebubu, where persons with albinism face banishment and threats of death if they visit these places.
3. **Cultural Reforms to Address Harmful Practices:** The National House of Chiefs should, as empowered by section 272(c) of the Constitution, “undertake an evaluation of traditional customs and usages to eliminate those customs and usages that are outmoded and socially harmful”.⁴¹ Such an evaluation should focus specifically on the harmful practices and beliefs that are prevalent with respect to persons with albinism. The Ministry of Chieftaincy and Religious Affairs should work with the National, Regional, Houses of Chiefs as well as Traditional and Divisional Councils to initiate cultural reform interventions in communities with practices that violate the rights of persons with albinism. Such interventions should include a public declaration to signify that all communities in Ghana accept and tolerate PWAs.⁴²

⁴⁰ The Persons with Disabilities Act 715 have no section on harmful practice and other cultural practice violating the rights of persons with albinism in particular and persons with disabilities in general. Some harmful practices here: <https://clcjbooks.rutgers.edu/books/spirit-children-illness-poverty-and-infanticide-in-northern-ghana/> See also <https://www.youtube.com/watch?v=5JXZocX4xns>

⁴¹ See also Chieftaincy Act 759 of 2008, section 3(1)(c) which requires the National House to “undertake an evaluation of traditional custom and usage with a view to eliminating custom and usage that is outmoded and socially harmful”.

⁴² CHRAJ (n 37 above) p 70

G. Article 24 – Education

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”,⁴³ which it defines as a “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”.

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”.⁴⁴ It also provides for “free education” for persons with disabilities.⁴⁵ 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,⁴⁶ 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”.⁴⁷

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”.⁴⁸ 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

⁴³ Education Act of 2008, section 5 reads:

“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.”

⁴⁴ Persons with Disabilities Act 715, section 17.

⁴⁵ As above, section 18(a).

⁴⁶ As above, section 18(b).

⁴⁷ As above, section 20(1).

⁴⁸ Inclusive Education Policy, page 5.

is in the process of being reviewed and updated, is contradicted by the realities of challenges faced by children with disabilities in accessing school.

Persons 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 persons with albinism.

Due to the varying degrees of low vision among persons 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 persons 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”.

Despite problems with the unavailability of accommodations being more severe at the primary and secondary levels, the same issues are also reportedly sometimes present at the tertiary level:

“When I was registering for the teacher training college the admission forms made provision for candidates to tick if they have any disabilities which we did but I wasn’t provided reasonable accommodation”.

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”.⁴⁹

⁴⁹ <https://www.frontiersin.org/journals/education/articles/10.3389/feduc.2023.1056630/full>

Proposed Recommendation

- 1. Review and Amendment of the Persons with Disabilities Act 715 sections 17 and 18b for Inclusive Education:**⁵⁰ 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.
- 2. 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.
- 3. 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 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.

⁵⁰ 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

4. **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.
5. **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.
6. **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.

H. Article 25 – Health

The Persons with Disabilities Act deals with healthcare for persons with disabilities in an incomplete and confusing manner. It requires the provision of specialist healthcare services to “persons with total disability”,⁵¹ which it does not define.⁵² 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 disability.⁵³

The Act also requires the training of health professionals on “disability and disability-related issues”,⁵⁴ 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”,⁵⁵ 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.”⁵⁶

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”.⁵⁷ This list includes “categories of

⁵¹ Persons with Disabilities Act 715, section 31.

⁵² <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 35.

⁵³ As above, p 36.

⁵⁴ Persons with Disabilities Act 715, section 32.

⁵⁵ Persons with Disabilities Act 715, section 33.

⁵⁶ Persons with Disabilities Act 715, section 34.

⁵⁷ 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

differently-abled persons determined by the Minister responsible for Social Welfare”.⁵⁸ Despite this, persons with albinism appear not to benefit from exemptions on these grounds.⁵⁹ 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”.⁶⁰

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. 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. Moreover, research has revealed that skin cancer is the primary cause of morbidity and mortality among persons with albinism in Africa.⁶¹ 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.⁶²

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

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 .

⁵⁸ Persons with Disabilities Act 715, section 29(e).

⁵⁹ <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 37.

⁶⁰ 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>.

⁶¹ PM Lund, ‘Lack of adequate sun protection for children with oculocutaneous albinism in South Africa,’ (2008) 2

⁶² 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>

affordability of well-resourced public healthcare facilities, goods and services and health-related programmes, including adequate information on albinism and health needs associated with it, is essential to the health needs of persons with albinism.

Persons with albinism therefore 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.⁶³ 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.

Furthermore, Ghana has only three cancer treatment facilities – Korle-Bu and Komfo Anokye Teaching Hospitals and a privately owned Sweden-Ghana Medical Center.⁶⁴ 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 persons 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.

“Further engagements with the boy’s family indicated that he has been undergoing treatment in a Polyclinic at Nalerigu. However, his wound was

⁶³ 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>.

⁶⁴ 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)

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”.⁶⁵ The Scheme also excludes products required to prevent skin cancer, such as sunscreen.⁶⁶

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. In health facilities, no provision is made for it as they are generally considered as a cosmetic product.⁶⁷

⁶⁵ National Health Insurance Scheme, 'Benefit Package' available at <http://www.nhis.gov.gh/benefits.aspx> (accessed 1/9/2021)

⁶⁶ <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 56.

⁶⁷ 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).

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.⁶⁸ 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 quality of healthcare from health professionals was a more generally expressed issue too. For instance, a 23-year-old man with albinism was left to die due to the “offensive odour” around him because of the advanced stage tumour of the head.⁶⁹ The government’s report to this Committee acknowledges more generally the “unprofessional attitudes of health professionals towards persons with disabilities ... in the delivery of services in the health sector”,⁷⁰ 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.⁷¹

“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.”

Even where persons with albinism do access medical treatment and are prescribed medication by health professionals, they note that the labelling of the medication is often inaccessible due to small writing:

⁶⁸ <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 57.

⁶⁹ Daklo et al (n 34 above), p 8.

⁷⁰ Government initial report (n1 above) para 404

⁷¹ Adonai StudiosGH ‘Albinism in Ghana’ <https://www.youtube.com/watch?v=FO4o3mRb55g>

“Prescriptions from doctors and other healthcare professionals are often inaccessible to persons with albinism because the prescription is usually in handwriting that is not readable and the leaflet in medications are usually in very small font which is inaccessible to most people with albinism who have low vision.”

Finally, the impact of social stigma and discrimination has a major impact on the mental health of persons with albinism.⁷² As documented in this submission, negative impacts on mental health may emanate from family, religious leaders, school teachers, health professionals or any other member of society. Persons with albinism are therefore at high risk of developing issues relating to their mental health.⁷³ Access to mental health services is poor throughout Ghana,⁷⁴ particularly community-based services that respect the rights of health system users.⁷⁵

Proposed Recommendation

- 1. Review and Amendment of Section 31 of the Persons with Disabilities Act 715:**⁷⁶ The Government of Ghana should review and amend Section 31 of the Persons with Disabilities Act 715 in line with Article 25 of the CRPD. This amendment should ensure the provision of appropriate and specialised healthcare services that meet the specific healthcare needs of all **(partial and total)** persons with disabilities, including those with albinism.
- 2. 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.

⁷² <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>, p 22-4.

⁷³ <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.

⁷⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10194950/>

⁷⁵ <https://www.hrw.org/news/2023/12/04/ghana-invest-more-mental-health-services>

⁷⁶ Section 31 of the Persons with Disabilities Act 715 reads

The Ministry of Health in formulating health policies shall provide for free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons with **total** disability.

3. **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).
4. **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.
5. **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.

I. Article 31 - Statistics and data collection

The Government's report provides very little information on the disability prevalence in the country, citing 2010 estimates of a prevalence of 3%,⁷⁷ but omitting information from Ghana's Population and Housing Census conducted in 2021 which put the population of persons with disabilities at 2,098,138 representing 8% of the total population of the country.⁷⁸

No disaggregated data on the population of persons with albinism is available. GAPA reports a membership of 2,741 individuals with albinism in Ghana, while the NCPD estimated that there were 4,214 persons with albinism in Ghana as of 2017. While these may be conservative figures, they indicate that there are thousands of persons with albinism in Ghana. For instance, a study conducted in Abura, Asebu, Kwamankese district of the central region of Ghana projected the prevalence rate of albinism to one in 1,067 people in the district.⁷⁹ Also, Under the Same Sun (UTSS) estimated in 2015 that given the prevalence of albinism in Africa being between one in 5,000 and one in 15,000 and the population of Ghana at the time, which was at 27 million, the number of persons with albinism in Ghana at the time was between 1,800 and 5,400.⁸⁰ The 2021 population and housing census missed the opportunity to capture any data on the number of persons with albinism in the country

Proposed Recommendations

- 1. Inclusion of Albinism-Specific Questions in Data Collection by Ghana Statistical Service:** The Ghana Statistical Service should include albinism-specific questions in its data collection tools, utilising the Washington Group set of questions.
- 2. Collection of Disaggregated Data on Persons with Albinism through the Birth Registration System:** The Births and Deaths Registry should collect

⁷⁷ Government initial report (n1 above), para 21.

⁷⁸ <https://gna.org.gh/2022/11/persons-with-disability-and-ghanas-economy-today/#:~:text=According%20to%20the%202021%20Population,months%20ago%2C%20weighed%20on%20him>

⁷⁹ AK Daklo 'Access to healthcare for persons with albinism in Ghana: A human rights approach (2022). <https://repository.gchumanrights.org/server/api/core/bitstreams/eaf41460-896e-433e-bbb5-21d8309f08f5/content>

⁸⁰ https://ccprcentre.org/files/documents/Ghanians_with_Albinism.pdf

disaggregated data on persons with albinism from birth through the birth registration system

3. **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.
4. **Periodic Research on the Needs of Persons with Albinism:** The Government of Ghana, in collaboration with research institutions, should periodically conduct research on the needs of persons with albinism in the country. This research should target various aspects such as health, education, and other social needs. The findings will enable the government to determine the specific interventions required to support persons with albinism effectively, ensuring that policies and programs are responsive to their unique challenges and needs.