# HUMAN RIGHTS
# SITUATION ANALYSIS REPORT OF
# PERSONS WITH ALBINISM IN GHANA

Africa
Albinism
Network

GAPA

# ACKNOWLEDGEMENTS

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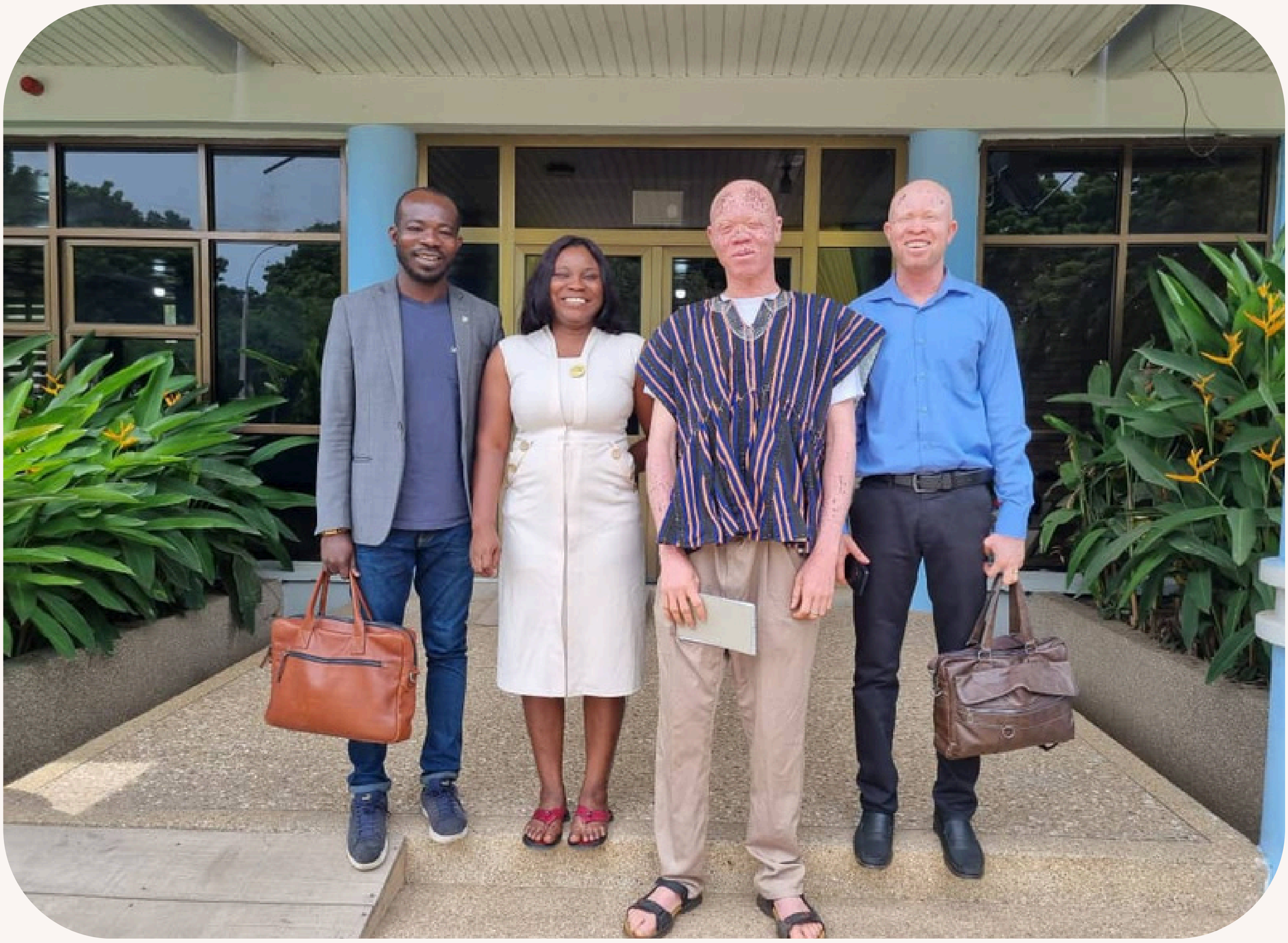
# DEDICATION

This report is dedicated to the memory of our esteemed colleague and Research Assistant, Abdul Wahab Adam, whose dedication was instrumental to this research project. He facilitated the regional consultations and arranged interviews with relevant institutions during the consultation process. His support was vital in ensuring a comprehensive and inclusive approach to this work. We honor his legacy with deep gratitude and remember him as a respected member of the albinism community in Ghana.



**Ghana Situational Analysis Field Research Trip (Accra, Ghana – August 21, 2023) L-R:** *Michael Gyan Nyarko (Human Rights Consultant), Ofosuhemaa Patience (Ghana Health Service),* ***Adam Abdul Wahab*** *(Disability Rights Consultant), Kwame Andrews Daklo (AAN).*

# TABLE OF CONTENTS

# I. LIST OF ACRONYMS

| | |
|---|---|
| **ACHPR** | African Charter on Human and Peoples’ Rights |
| **ACERWC** | African Charter on the Rights and Welfare of the Child |
| **ACHPR** | African Court on Human and Peoples’ Rights |
| **AU** | African Union |
| **CEDAW** | Convention on the Elimination of All Forms of Discrimination Against Women |
| **CHRAJ** | Commission on Human Rights and Administrative Justice |
| **CRC** | Convention on the Rights of the Child |
| **CRPD** | Convention on the Rights of Persons with Disabilities |
| **FCUBE** | Free, Compulsory, and Universal Basic Education |
| **DACF** | District Assemblies Common Fund |
| **GAPA** | Ghana Association of Persons with Albinism |
| **GFD** | Ghana Federation of Disability Organizations |
| **GSS** | Ghana Statistical Service |
| **HIV** | Human Immunodeficiency Virus |
| **IAAD** | International Albinism Awareness Day |
| **ICCPR** | International Covenant on Civil and Political Rights |
| **ICESCR** | International Covenant on Economic, Social, and Cultural Rights |
| **LAC** | Legal Aid Commission |
| **LEAP** | Livelihood Empowerment Against Poverty |
| **NAP** | National Action Plan |
| **NCCE** | National Council on Civic Education |
| **NCPD** | National Council for Persons with Disabilities |
| **NHIS** | National Health Insurance Scheme |
| **PAP** | Pan African Parliament |
| **PWA** | Person(s) with albinism |
| **PWD** | Person(s) with disability |
| **UN** | United Nations |

**Return to Table of Contents**

# II. DEFINITIONS

**Albinism**

Albinism is a relatively rare, non-contagious genetic condition found globally across all ethnicities and genders. It typically results in a lack of melanin in hair, skin, and eyes (oculocutaneous albinism), increasing vulnerability to sun exposure.[1]

**Discrimination**

Under Article 2 of the Convention on the Rights of Persons with Disabilities (CRPD), discrimination on the basis of disability refers to any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or other areas. This includes all forms of discrimination, such as the denial of reasonable accommodation.[2]

**Harmful Practices**

According to Amnesty International, harmful practice refers to longstanding values and beliefs within communities that harm specific groups, often persons with disability, children, women and the elderly, by limiting their autonomy, especially regarding control over their bodies. With regards to albinism, these harmful practices include beliefs that the use of the body parts of persons with albinism in witchcraft brings prosperity or luck; raping a woman or girl with albinism or the mother of a child with albinism cures HIV or other sexually transmitted infections; and the social exclusion and abandonment of children with albinism and their mothers.[3]

**Human Rights**

Human rights are fundamental rights inherent to all individuals, regardless of race, gender, disability, language, religion, or any other status[4]. They include rights such as life, freedom from slavery and torture, liberty, right to family life, freedom of expression, and right to adequate standard of living including food, water, clothing shelter, rights to health, work and education. Every person is entitled to these rights without distinction. International human rights law guarantees these rights and mandates States, as primary duty-bearers, to respect, protect, and execute the human rights and freedoms of all individuals and groups.

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**[1]** https://www.ohchr.org/en/special-procedures/ie-albinism/about-albinism-and-human-rights

**[2]** https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

**[3]** https://www.amnesty.org/en/wp-content/uploads/2021/07/AFR0338792021ENGLISH.pdf

**[4]** https://www.un.org/en/global-issues/human-rights

### Persons with Albinism

This term refers to individuals who have the condition of albinism. The term "albino," is now seen as inappropriate and potentially offensive, as it focuses solely on the condition rather that the person[5]. Likewise, "person living with albinism" is often viewed as misleading, implying the condition is acquired rather than innate. This report therefore uses "persons with albinism," an internationally accepted term endorsed by the United Nations (UN).

Persons with albinism are a distinct group whose human rights concerns have largely been overlooked for centuries, resulting in deep-rooted stigma, discrimination, and violence across numerous countries[6]. Due to the unique nature of albinism, their experiences intersect multiple human rights issues, including discriminations based on disability and color, specific needs for access to education, access to health, and the rights to life. This includes protection from harmful traditional practices, violence, ritual killings, trafficking for witchcraft purposes, as well as infanticide and child abandonment.

### Persons with Disabilities

Includes people with long-term physical, mental, intellectual, or sensory impairments, whose interaction with various barriers may limit their equal and full participation in the society.[7]

### Reasonable Accommodation

Refers to essential and appropriate modifications and adjustments, provided they do not impose an undue burden, to enable persons with disabilities to enjoy and exercise all human rights and fundamental freedoms on equal basis with others[8].

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**[5]** https://www.amnesty.org/en/wp content/uploads/2021/07/AFR0338792021ENGLISH.pdf
**[6]** https://www.ohchr.org/en/special-procedures/ie-albinism/about-albinism-and-human-rights
**[7]** https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities
**[8]** https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-2-definitions.html

Return to Table of Contents

# III. EXECUTIVE SUMMARY

Since establishing the Fourth Republic with the coming into force of 1992 Constitution on January 7, 1993, Ghana has made significant strides in democratic consolidation, respect for human rights, and the rule of law. However, despite Ghana's commitment to international and regional human rights treaties and its own constitutional and legislative protections, the lived experiences of persons with albinism reveal significant gaps between policy aspirations and reality.

This report documents how legislative and policy incoherence, stigma, discrimination, and societal misconceptions about albinism hinder the realization of the rights of persons with albinism. Stigma and discrimination restrict access to education, health, employment, and social participation. Key findings highlight a need for more public awareness about albinism and the rights of persons with albinism. National institutions have yet to undertake specific awareness campaigns, resulting in persistent discrimination and misunderstandings.

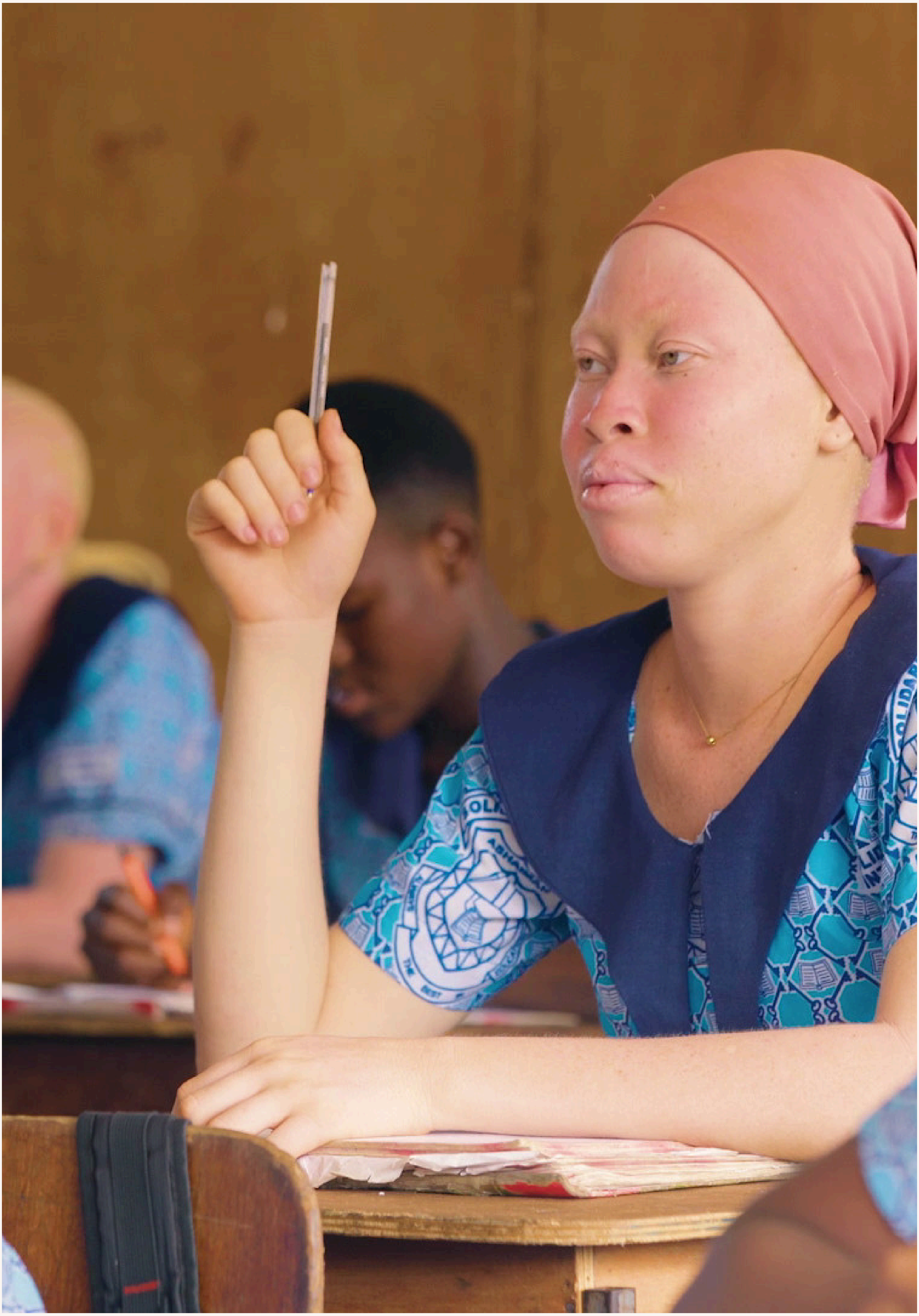
Healthcare professionals have limited awareness, and the National Health Insurance Scheme (NHIS) does not cover essential services. The non-availability of assistive devices and reasonable accommodation hinders education. Persons with albinism face physical violence due to harmful myths about albinism. The absence of comprehensive social protection programs further marginalizes them compared to other disability groups.

The findings of this report underscore the need for Ghana to adopt and implement specific and concrete measures such as a National Action Plan (NAP) on albinism aligned with the African Union’s Plan of Action to End Attacks and Other Human Rights Violations targeting Persons with Albinism in Africa (2021-2031). This plan should create a more inclusive society where persons with albinism can fully enjoy their human rights. Legislative reform, stakeholder capacity development, and robust public awareness campaigns are crucial to realize this.

Specific recommendations made include making healthcare services accessible and sensitive to the needs of persons with albinism, providing inclusive education with adaptive learning assistive devices, ensuring non-discriminatory hiring practices, and offering sustainable livelihood opportunities. Sensitization should target both the demand and supply sides of access to justice. Affirmative action policies are needed to ensure political participation.

By implementing these recommendations, Ghana can ensure that persons with albinism are protected, respected, and empowered to lead fulfilling and dignified lives.

**Return to Table of Contents**

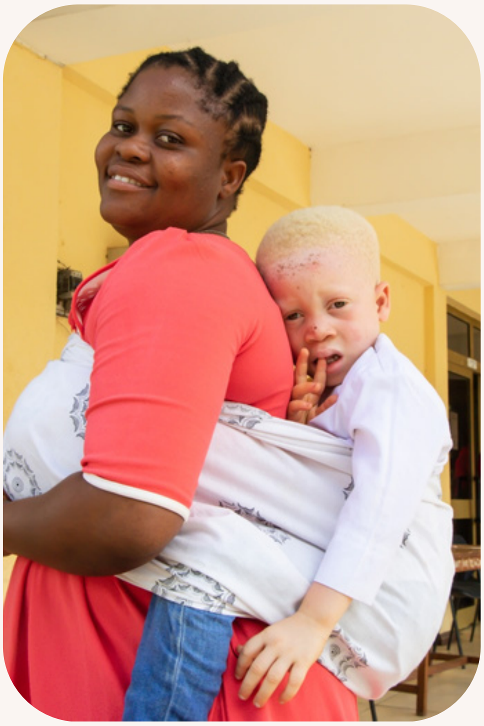


Return to Table of Contents

# 1 INTRODUCTION

Albinism is a rare, non-contagious genetically inherited condition resulting in a lack of pigmentation in the skin, hair, and eyes, affecting individuals from all races and cultures across the globe.[9] Except for 'ocular albinism [affecting only the eyes], which is passed on from mother to son,' all other types of albinism result from both parents being carriers of the gene, even if they themselves are not persons with albinism.[10] The reduction or absence of melanin makes persons with albinism vulnerable to the sun and bright light, resulting in visual impairment in most persons with albinism and making them prone to developing skin cancer.[11] The United Nations General Assembly acknowledges that persons with albinism across the globe are likely to experiencesocial exclusion and poverty because of the discrimination and other barriers they face, which restricts their participation in society on an equal basis with others.[12]

In Ghana,[13] as in many parts of Africa,[14] persons with albinism face significant challenges that impede the enjoyment of their human rights. This study examines the multifaceted hurdles confronting individuals with albinism in Ghana, ranging from social stigma and discrimination to health-related issues that result in the violation of their human rights. The study draws upon literature reviews, legal frameworks, qualitative interviews, and focus group discussions. It examines the Ghanaian government's approach to safeguarding the rights of persons with albinism. It further explores the role of international human rights norms, local advocacy, and policy interventions to foster inclusion and protection for this marginalized group.



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**[9]** Report of the Independent Expert on the enjoyment of all rights by persons with albinism, Albinism Worldwide, A/74/190, 18 July 2019, para 5.

**[10]** Office of the High Commissioner for Human Rights (OHCHR) 'Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights' (2013), A/HRC/24/57, para 10.

**[11]** OHCHR (as above), para 11.

**[12]** United Nations General Assembly 'Social development challenges faced by persons with albinism: Report of the Secretary-General' (2017), A/72/169.

**[13]** See F Benyah 'Equally able, differently looking: Discrimination and physical violence against persons with albinism in Ghana' (2017) 30 Journal for the Study of Religion 161.

**[14]** See E Durojaye & S Nabaneh 'Human rights and access to healthcare for persons with albinism in Africa' (2019) 7 African Disability Rights Yearbook 35; M Mswela 'Violent attacks against persons with albinism in South Africa: A human rights perspective' (2017) 17 African Human Rights Law Journal 114.

Return to Table of Contents

While a few studies already document some of the challenges facing persons with albinism in Ghana,[15] this study was necessitated by the need to have more comprehensive information derived through nationwide consultation with persons with albinism, their representative organizations, and national departments and agencies responsible for the promotion, protection, and fulfilment of the rights of persons with albinism.

### Aims and Objectives

The principal aim of the study is to provide information to support and form the basis for the drafting of a National Action Plan (NAP) on the rights of persons with albinism in Ghana to implement the African Union (AU) Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa – 2021-2031 (Plan of Action).

Consequently, at its core, **the study has three main objectives:**

- First, it seeks to highlight Ghana's regional and international human rights obligations towards persons with albinism and the national constitutional, legislative, and policy frameworks that have been adopted to implement these obligations for the benefit of persons with albinism.

- Second, it seeks to highlight some of the lived realities of persons with albinism in Ghana, emphasizing stigma, discrimination, and violation of the rights of persons with albinism in society, as well as the failure of relevant state institutions to respond to these violations.

- Thirdly, it makes policy recommendations designed to enhance the recognition, protection, and realization of the rights of persons with albinism in Ghana.

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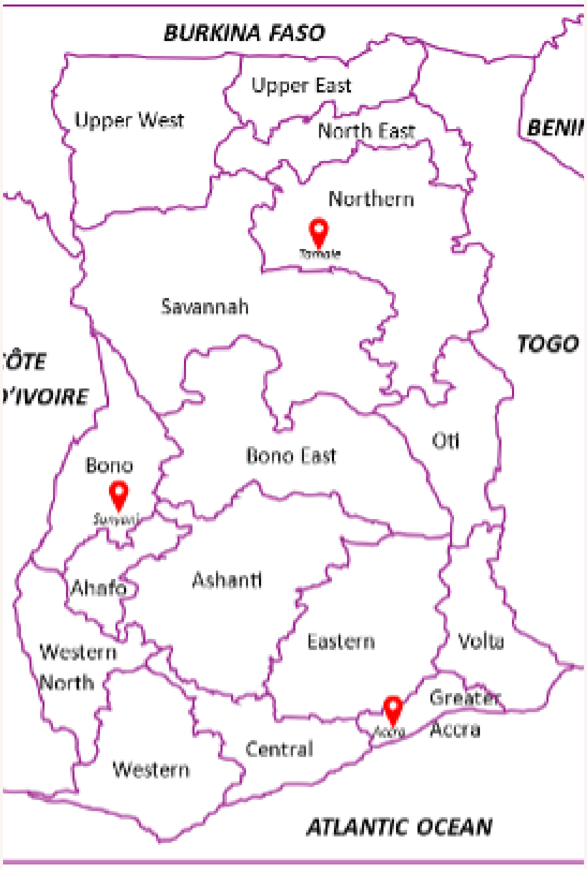
**[15]** See for instance FEK Benya 'Are albinos people like us? Albinism and social exclusion in Ghana' in AA Alemanji, CM Meijer, M Kwazema & FEK Benyah (eds) Contemporary discourses in social exclusion (2022) 143; AA Affram, E Teye-Kwadjo & AA Gyasi-Gyamerah 'Influence of social stigma on subjective well-being of persons with albinism in Ghana' (2019) 39 Journal of Community and Applied Social Psychology 323; F Benyah 'Equally able, differently looking: Discrimination and physical violence against persons with albinism in Ghana' (2017) 30 Journal for the Study of Religion 161.

**Return to Table of Contents**

# 2 METHODOLOGY AND DATA COLLECTION

The study was conducted based on both desk and field research. Desk research was conducted to highlight the legal and policy framework that underpins the enjoyment of human rights by persons with albinism as contained in international and regional human rights treaties, national legislation, and policy frameworks. This was supplemented with field research utilizing focus group discussions and interviews with persons with albinism, their representative organizations, other civil society organizations that provide services to persons with albinism, government departments responsible for social protection, and other stakeholders to further appreciate the lived realities of persons with albinism in Ghana. The focused group discussions and interviews were conducted in person except in a few instances where interviews through online platforms were utilized because of the physical unavailability of the relevant interlocutor. Participants in interviews and focused group discussions were briefed about the aims and objectives of the study. They were then asked to indicate whether they consented to recording their interview during the focus group discussion and for the information to be used for this report, which they freely did. Interlocutors were assured that their data would be kept confidential and complete anonymity would be observed. They were also told they would not be individually identified or quoted in the report to ensure they could provide truthful and complete responses.



Three regional convenings were held in:

- Tamale from 7-8 August 2023 for the northern belt,
- Sunyani from 11-12 August 2023 for the central belt, and;
- Accra from 14-18 August 2023 for the southern belt.

These three locations were chosen for the regional convenings to provide a central point of meeting in each of the country's northern, central, and southern belts due to limited resources, making it impossible to visit each of the 16 administrative regions of Ghana. In Tamale, participants were drawn from the Northern, Upper East, Upper West, Savannah, and Northeast regions, while in Sunyani, participants were drawn from Bono East, Bono, Ahafo, Ashanti, and Western North regions.

The convening in Accra drew participants from the Oti, Volta, Eastern, Central, Western, and Great Accra regions. About 126 participants were consulted during these convenings, the predominant majority of whom were persons with albinism. Research participants were therefore drawn from all the 16 administrative regions of Ghana to ensure that the data obtained is nationally representative.

The persons with albinism consulted came from diverse demographic, economic, and geographic settings and reflect different experiences. They came from various professional backgrounds, ranging from accountants, school teachers, activists, farmers, business persons, artisans, students in tertiary institutions and high schools, and persons who were unemployed at the time of interaction. Experiences shared included personal experiences as well as information that had been relayed to some participants by their parents, who, though not persons with albinism, had been subjected to various forms of associated discrimination and stigmatization as a result of their being parents of children with albinism.

The study adopted a human rights-based approach utilizing international, regional, and national human rights norms as a framework to highlight and analyze the discrimination and other forms of human rights violations suffered by persons with albinism in Ghana. A human rights-based approach emphasizes the universality, indivisibility, interdependence, and inter-relatedness of rights, as well as equality, non-discrimination, participation, and inclusion of affected persons or communities and the accountability of states and other duty bearers.[16] A human rights-based approach ensures that vulnerable and marginalized groups can participate in decision-making processes and hold duty-bearers accountable for human rights violations.

## Limitations to the research

While significant efforts were made to obtain the views of relevant government departments and institutions, these efforts were unsuccessful in many instances. Consequently, the study, as it stands, predominantly reflects the views of persons with albinism and civil society organizations with limited input from state actors. We intend to include the views of such state actors in subsequent reviews of the report.

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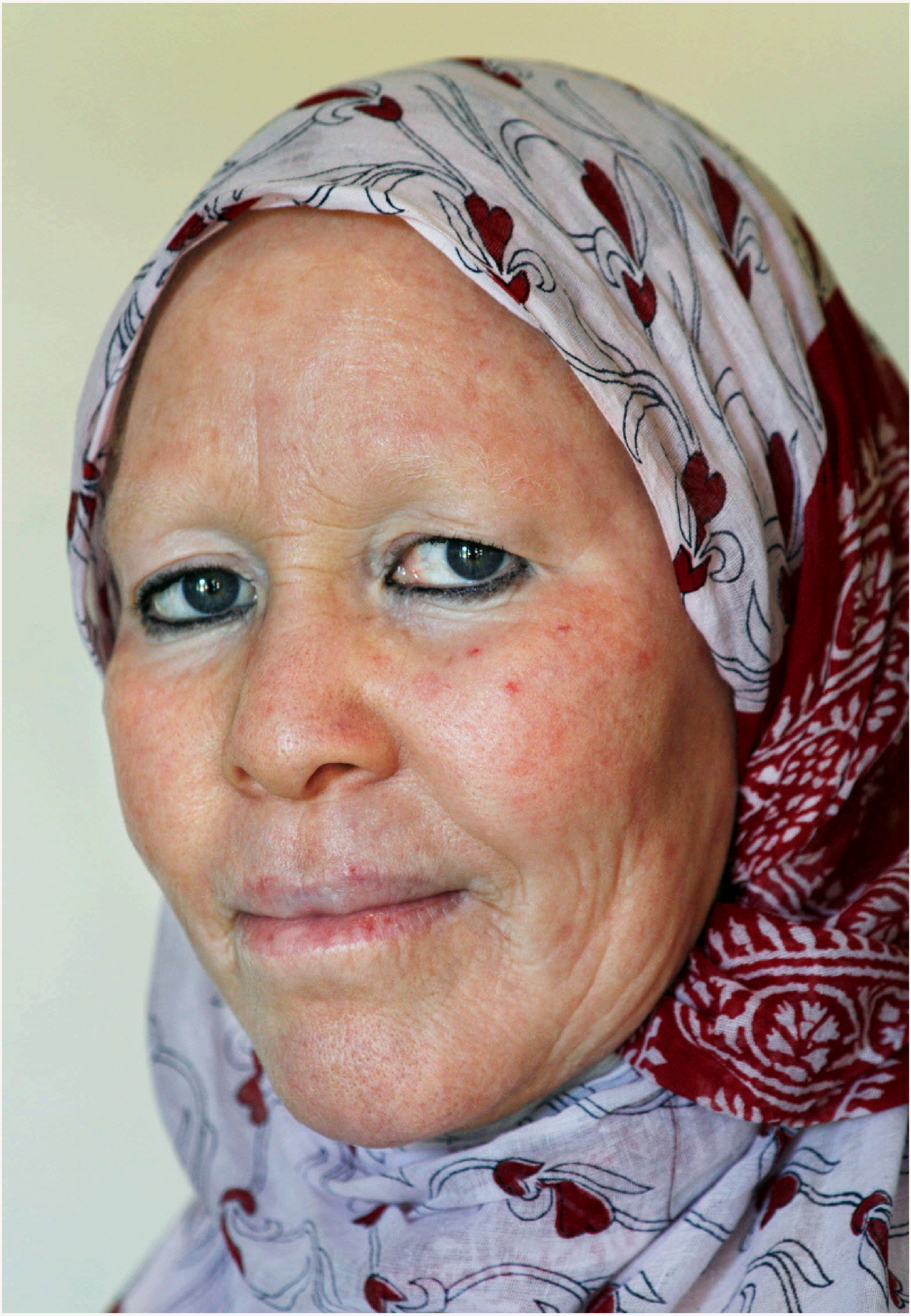
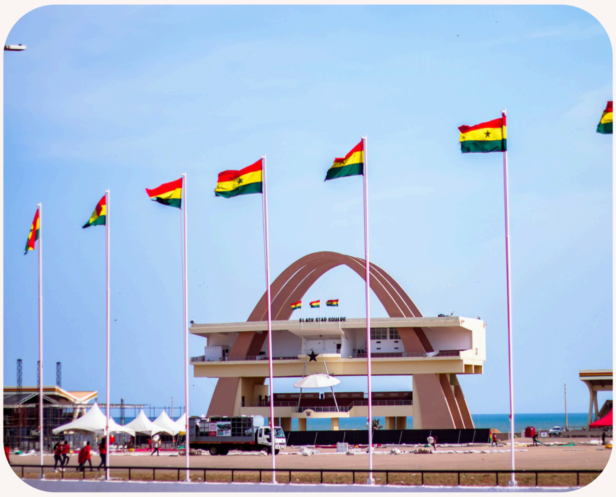
[16] M Broberg & H Sano ‘Strengths and weaknesses in a human rights-based approach to international development– an analysis of a rights-based approach to development assistance based on practical experiences’ (2018) 22 International Journal of Human Rights 664.



Return to Table of Contents

# 3 BACKGROUND AND SOCIO-POLITICAL CONTEXT

Since independence, Ghana's political context of governance and human rights reflects a microcosm of the broader post-colonial African experience. It embodies the trials of establishing democratic governance structures in the wake of colonial rule and under the shadow of authoritarianism and military dictatorships. Ghana's journey is illustrative of the struggles and triumphs faced by emerging democracies worldwide.



That said, Ghana’s socio-political history since independence has been very checkered. Since gaining independence from British colonial rule in 1957 under the leadership of Kwame Nkrumah, Ghana has traversed various forms of governance ranging from democratic institutions to military dictatorships, which had significant negative impacts on governance and human rights.[17] The return to constitutional democracy in 1993, after decades of political instability due to recurring military coups, marked the beginning of the Fourth Republic and a new trajectory for governance and human rights in Ghana. This is also illustrated by the fact that Ghana has ratified most major international human rights treaties and accepts individual complaint procedures and inquiry procedures by several United Nations Treaty Bodies since the return to democracy in 1993.

**[17]** K Quashigah ‘The 1992 Constitution of Ghana’ (2013) http://www.icla.up.ac.za/images/country_reports/ghana_country_report.pdf (accessed 8 November 2023); HK Prempeh ‘Towards judicial independence and accountability in an emerging democracy: The courts and the consolidation of democracy in Ghana’ (1997) Institute for Economic Affairs occasional Papers Number 11, 23, available at http://ieagh.org/mdocs-posts/toward-judicial-independence-and-accountability-in-an-emerging-democracy-the-courts-and-the-consolidation-of-democracy-in-ghana/; AB Biney Kwame Nkrumah: An intellectual biography (2007); K Quashigah ‘Demystifying assumptions about the nature of power relations between the executive and judiciary: An overview of approaches to judicial and executive relations in Ghana’ in CM Fombad (ed) Separation of powers in African constitutionalism (2016) 226 229; MG Nyarko ‘The impact of the African Charter and Maputo Protocol in Ghana’ in VO Ayeni (ed) The impact of the African Charter and Maputo Protocol in selected African states (2016) 95; K Frimpong & K Agymeman-Budu ‘The rule of law and democracy in Ghana since independence: Uneasy bedfellows?’(2018) 18 African Human Rights Law Journal 244 251; J Haynes ‘Human rights and democracy in Ghana: The record of the Rawlings’ regime (1991) 90 African Affairs 407; M Oquaye ‘Human rights and the transition to democracy under the PNDC in Ghana (1995) 19 Human Rights Quarterly 556.

The Fourth Republic has been marked by an ongoing process of democratic consolidation characterized by competitive multiparty elections, peaceful transfers of power, and the strengthening of civil society.[18] Thus, governance in the Fourth Republic has seen significant advancements in human rights, underpinned by constitutional guarantees and the establishment of institutions such as the Commission on Human Rights and Administrative Justice (CHRAJ).

That said, the approach to the rights of persons with disabilities in Ghana since independence has been focused on ‘rehabilitation, skills training, and special education,’ aimed at moving away from ‘welfarism’ to empowerment to ensure that persons with disabilities can actively participate in development processes.[19] This policy approach resulted in the establishment of rehabilitation centers across the country, some of which are still in operation.[20] This rehabilitation model has been continued by successive governments ‘through community-based rehabilitation programmes, thereby expanding the capacities of special schools to provide formal education and training for children with disabilities’[21] until the recent introduction of the inclusive education policy in 2015. A more human rights-based understanding of disability rights in Ghana commenced in the 1980s with the proclamation of the United Nations Decade of Disabled Persons between 1983 and 1992.[22] This period saw the establishment of the Ghana Federation of Disability Organizations (GFD) as a national umbrella body for disability organizations to ensure that the voices of persons with disabilities are factored into governance processes.[23] Subsequent development of disability rights in Ghana includes express constitutional recognition and the enactment of disability-specific legislation, as more extensively discussed in section IV of this study.

**[18]** A Sithole ‘Ghana: A beacon of hope in Africa’ (2012) 18 ACCORD Policy and Practice Brief https://www.files.ethz.ch/isn/154807/ACCORD-policy-practice-brief-18.pdf; E Graham, R Gyampo, P Faanu and E Yobo ‘The third peaceful transfer of power and democratic consolidation in Ghana’ (2017) 10 Journal of Pan African Studies 99; F Oduro, L Selvik & K Dupuy ‘Ghana: A Stagnated Democratic Trajectory’ in LR Arriola , L Rakner & N van de Walle (eds) Democratic Backsliding in Africa? Autocratization, Resilience, and Contention (2022) 112.

**[19]** M Fordjour ‘Country situational analysis of the rights of persons with disabilities in Ghana’ (2022) 11; JD Grischow ‘Disability and rehabilitation in late colonial Ghana’ (2011) available at https://ghanadisability.com/wp-content/uploads/2019/04/Grischow-2011-Disability-and-Rehabilitation-in-Late-Colonial-Ghana.pdf.

**[20]** Fordjour (as above).

**[21]** Fordjour (as above).

**[22]** As above.

**[23]** As above.

In terms of the socio-economic context, even though the return to democratic governance under the Fourth Republic has resulted in remarkable economic performance that helped reduce the poverty rate by more than half between 1991 and 2017,[24] a reported 6.8 million people in Ghana lived in poverty as of 2017, the majority of whom resided in rural areas.[25] Before the COVID-19 pandemic, UNICEF estimated that 3.65 million children in Ghana lived in poverty, at least 1.2 million of whom were living in extreme poverty with limited access to food.[26] Children with albinism were affected by this dire situation, which, from all indications, has worsened due to the impacts of the COVID-19 pandemic, economic challenges, and currency depreciation, among others.

The World Bank reports that 'Ghana's economy entered a full-blown crisis in 2022, after having rebounded from the COVID-19 slowdown in 2021'.[27] This, on top of 'currency depreciation, rising inflation [reaching as high as 54.1% in December 2022], and tumbling domestic investor's confidence resulting from unsustainable public debts, high public expenditure, and chronically low public revenues, compounded by difficult global conditions.[28] The currency depreciation and high inflation increased the cost of living and put many impoverished households under budgetary stress. Ghana's economic growth for 2023 was 3.1%.[29] These are in comparison to growth rates of 5.1% and 3.1% recorded in 2021 and 2022, respectively.[30] While economic growth for 2024 'exceeded expectations, reaching 5.7%',[31] high inflation and crippling depreciation of the Ghana cedi meant a significantly high cost of living which negatively affected the most vulnerable.

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**[24]** National Development Planning Commission 'Mul-Dimensional Child Poverty in Ghana' (2020) 16 https://www.unicef.org/ghana/media/2676/file/Multi-Dimensional%20Child%20Poverty%20Report.pdf (accessed 2 November 2023).

**[25]** Ghana Stascal Service (2018). Ghana Living Standards Survey Round 7 (GLSS 7). Poverty Trends in Ghana, 2005-2017.

**[26]** UNICEF 'Social policy and protection' https://www.unicef.org/ghana/social-policyand-protection (accessed 7 November 2023).

**[27]** World Bank Group '7th Ghana Economic Update – Price surge: Unraveling inflation's toll on poverty and food security' (2023) 1 https://documents1.worldbank.org/curated/en/099072023055014341/pdf/P177994046644e0e20b3dd057c81347c0ef.pdf (accessed 2 November 2023).

**[28]** World Bank Group (as above).

**[29]** BMI 'Economic growth in Ghana will pick up in 2024, following weak Q323' available at https://www.fitchsolutions.com/bmi/country-risk/economic-growth-ghana-will-pick-2024-following-weak-q323-21-12-2023?fSWebArticleValidation=true&mkt_tok=NzMyLUNLSC03NjcAAAGR3dub-CHDi5oGr4UG0bXRzGn0bMix0nOa1QFv6z43wTw7Y--GDXZbksIePFcR3OUVI3ZRvstGaAY55HSEjfdI1sxRLQFEOfBF5KNQBoLr1CcjUVbJaQ.

**[30]** https://www.worldbank.org/en/country/ghana/overview

**[31]** World Bank Group (as above).

On the back of these economic challenges, the World Bank estimates that nearly 850,000 Ghanaians were pushed into poverty in 2022 alone due to rising prices and loss in purchasing power, with at least a quarter of the population currently considered to be food insecure.[32] Climate change also poses a threat to food security in Ghana, especially in the northern parts of the country, which is heavily dependent on rain-fed agriculture that is impacted by changes in rainfall patterns, temperature increases, and extreme weather events that affect crop yields.

While the currency has exceeded expectations, appreciating against most global currencies and attaining reasonable stability during the first half of 2025,[33] unsustainably high public debt continues to have significant impact on government resource available for investment in the social sector.[34] The current economic challenges pose significant impediments to the ability of individuals and households to sustain their livelihoods and socio-economic needs and to the ability of the state to fulfil some of its most basic human rights obligations to the population. The World Bank projects that poverty is likely to increase, reaching 51.2% by 2027 with extreme poverty reaching 26.9% by 2027.[35] As persons with albinism remain some of the most vulnerable and marginalized groups, the economic challenges and increased poverty will have a significant impact on them.

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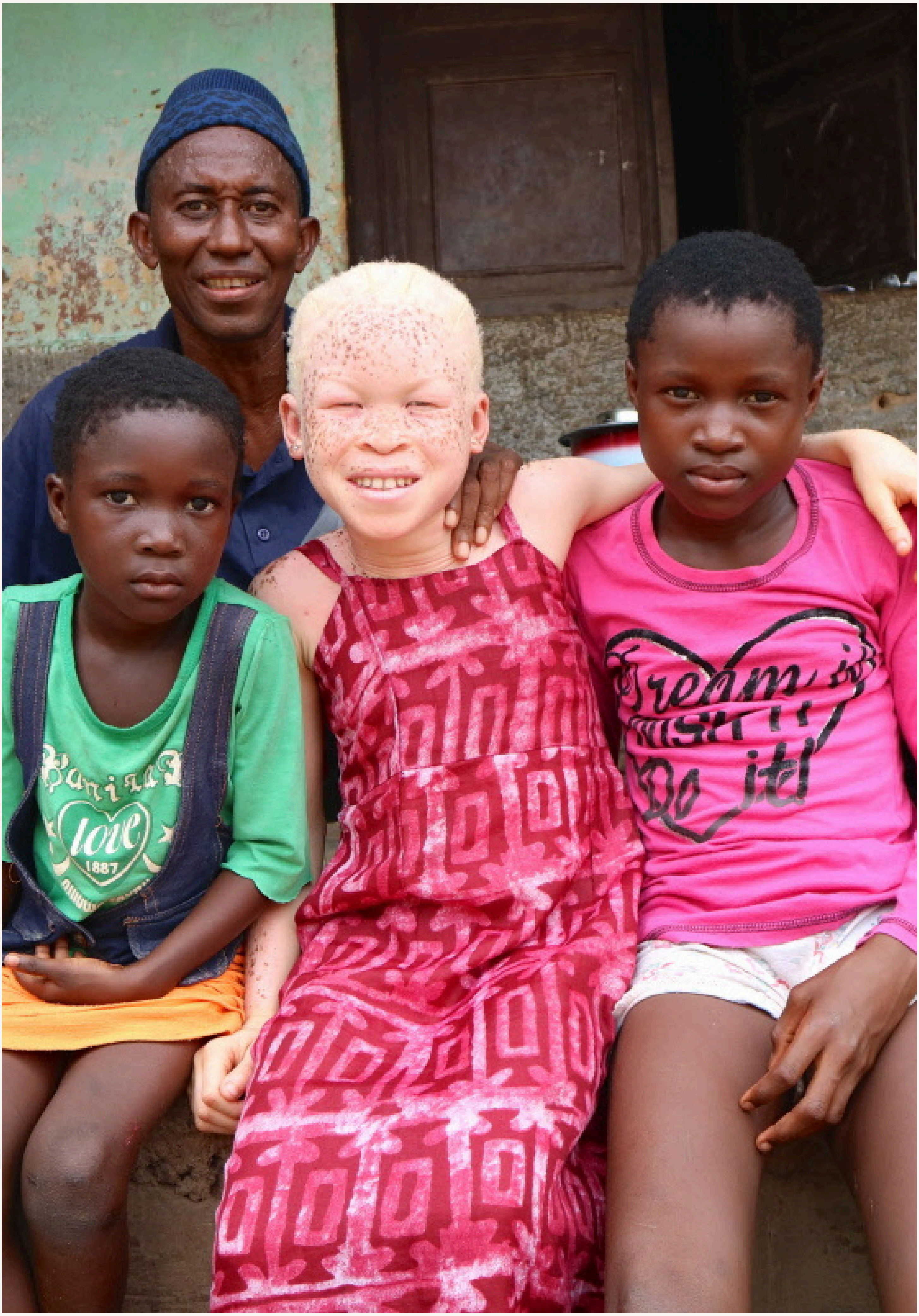
**[32]** World Bank Group (as above).
**[33]** Collen Goko 'Surge in cedi currency eases Ghana's foreign debt burden' https://www.reuters.com/world/africa/surge-cedi-currency-eases-ghanas-foreign-debt-burden-2025-05-28/.
**[34]** International Monetary Fund (IMF) 'Ghana: Third Review Under the Arrangement Under the Extended Credit Facility, Request for Modification of Performance Criteria, and Financing Assurances Review—Debt Sustainability Analysis' (2024) https://www.elibrary.imf.org/view/journals/002/2024/334/article-A002-en.xml.
**[35]** World Bank Group (n 30 above).



Return to Table of Contents

# 4 LEGISLATIVE AND POLICY FRAMEWORK

## A. International and Regional Standards and Normative Framework

International human rights treaties are critical tools for ensuring that states adhere to agreed-upon standards in the treatment of individuals within their jurisdictions. In this regard, Ghana, as a member of the international community, has ratified several key human rights instruments, demonstrating its commitment to protecting and promoting human rights. These ratified human rights treaties are intended to be implemented within the domestic legal system to benefit all Ghanaian citizens, including persons with albinism.

The key human rights treaties Ghana has ratified include the International Covenant on Civil and Political Rights (ICCPR), which it acceded to on September 7, 2000. This treaty commits state parties to respect individuals' civil and political rights, including the right to life, freedom of speech, religion, movement, dignity, non-discrimination, and the right to family life. The Human Rights Committee, which supervises the implementation of the ICCPR, in its 2016 Concluding Observations, raised concerns about 'the stigmatization of and discrimination against persons with albinism'[36] and recommended that the state 'ensure that persons with albinism are protected against discrimination and find lasting solutions that will give them access, without discrimination, to health care, social services, employment, and education.' [37]

Ghana ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) on the same day as the ICCPR, requiring the country to work towards ensuring that economic, social, and cultural rights, including labor rights, the right to health, the right to education, social security, and an adequate standard of living are enjoyed by individuals. Ghana also ratified the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) on February 2, 1986, the Convention on the Rights of the Child (CRC) on January 5, 1990, and the Convention on the Rights of Persons with Disabilities (CRPD), together with its optional protocol on the individual complaints procedure on July 31, 2012. The CRPD requires state parties to respect, protect, fulfil, and promote the full and equal enjoyment of all human rights by persons with disabilities (including persons with albinism) and to ensure that they enjoy full equality under the law.

**[36]** Human Rights Committee 'Concluding observations on the initial report of Ghana', CCPR/C/GHA/CO/1 (2016) para 13.
**[37]** As above, para 14.

Other relevant UN human rights treaties ratified by Ghana include the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment and its Optional Protocol, the United Nations Convention against Transnational Organized Crime and its Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women, and Children.

In addition to United Nations treaties, Ghana has also ratified a number of African Union (AU) human rights instruments, including the African Charter on Human and Peoples' Rights (ACHPR or African Charter) and its protocol on the rights of women in Africa (Maputo Protocol) as well as the African Charter on the Rights and Welfare of the Child (ACRWC). Ghana has also accepted the jurisdiction of the African Court on Human and Peoples' Rights (ACHPR) by ratifying the Court's protocol and depositing the Article 34(6) declaration allowing individuals and civil society organizations to directly submit cases to the Court. Regrettably, as of the writing of this report, Ghana has neither signed nor ratified the protocol to the African Charter on the Rights of Persons with Disabilities[38], which contains essential provisions for the protection of the rights of persons with disabilities, including essential recognition of violations suffered by persons with albinism within the African context. Nevertheless, following its fifteenth ratification on 5th May 2024, this protocol entered into force on 5th June 2024.[39]

African Union institutions have also provided some guidance on the measures that African states need to adopt to ensure that the rights of persons with albinism are respected, protected, and fulfilled. These include the African Union Plan of Action on Albinism (2021-2031) and the Pan African Parliament Guidelines on harmful practices occurring as a result of accusations of witchcraft and ritual attacks (PAP Guidelines), both of which encourage African states to take legislative, administrative, budgetary and other measures to ensure that persons with albinism are free from systemic violations of their rights.

[38] https://au.int/en/treaties/protocol-african-charter-human-and-peoples-rights-rights-persons-disabilities-africa

[39] https://africandisabilityforum.org/press-release-ratifications-of-the-protocol-to-the-african-charter-on-human-and-peoples-rights-on-the-rights-of-persons-with-disabilities-in-africa/

## B. National Legal Framework

Interlocutors observed that there is no explicit recognition of albinism as a disability in national laws and policies, even though the National Council on Persons with Disabilities (NCPD) recognizes persons with albinism as a constituency of persons with disabilities. This may be because most of the legal frameworks preceded Ghana's ratification of the CRPD and prior to any consistent advocacy on the rights of persons with albinism.[40]

That said, the protection of human rights and fundamental freedoms in Ghana is underpinned by the 1992 Constitution, which guarantees civil and political rights as well as some economic, social, and cultural rights for all persons, including the right to life,[41] liberty of the person,[42] dignity,[43] protection from cruel, inhuman and degrading treatment,[44] protection from slavery and forced labor,[45] equality before the law and non-discrimination.[46] Notably, even though the non-discrimination provision under Article 17(2) of the 1992 Constitution does not explicitly indicate disability as one of the protected grounds for non-discrimination, it prohibits discrimination on the basis of color, which holds promise for the protection of persons with albinism from discrimination.

Other rights guaranteed include the right to property,[47] the right to privacy,[48] and the right to a fair trial.[49] The Constitution also guarantees freedom of expression,[50] freedom of thought and conscience,[51] freedom of religion,[52] freedom of assembly and protest,[53] freedom of association, including to form or to join trade unions,[54] the right to information,[55] freedom of movement,[56]

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**[40]** Ghana's Persons with Disabilities Act was enacted in 2006, while the CRPD was ratified in 2012.
**[41]** Art 13.
**[42]** Art 14.
**[43]** Art 15(1).
**[44]** Art 15(2).
**[45]** Art 16.
**[46]** Art 17.
**[47]** Art 18(1) & 20.
**[48]** Art 18(2).
**[49]** Art 19.
**[50]** Art 21(1)(a).
**[51]** Art 21(1)(b).
**[52]** Art 21(1)(c).
**[53]** Art 21(1)(d).
**[54]** Art 21(1)(e).
**[55]** Art 21(1)(f).
**[56]** Art 21(1)(g).

the right to political participation,[57] property rights of spouses,[58] the right to fair administrative procedure,[59] the right to work under a satisfactory, safe and healthy environment including the right to form or join trade unions,[60] the right to education,[61] the right to culture,[62] women's rights,[63] children's rights,[64] and rights of persons with disabilities and the sick.[65]

In particular, Article 29 guarantees the rights of persons with disabilities to live with their families and to participate in social, creative, or recreational activities; the right to non-discrimination; protection against exploitation, abusive or degrading treatment; reasonable accommodation in judicial proceedings; accessibility of public places; incentives to engage in trade or business, while incentivizing businesses to employ persons with disabilities 'in significant numbers.' The Constitution also mandates the state to abolish harmful cultural practices, which, as this study shows, have a significant negative impact on the rights of persons with albinism.[66] Parliament is mandated to enact legislation to implement Article 29 of the Constitution for the benefit of persons with disabilities.[67]

It is also important to highlight that in terms of Article 33(5) of the Constitution, the rights expressly guaranteed are not supposed to be deemed as exhaustive and may include 'others not specifically mentioned which are considered to be inherent in a democracy and intended to secure the freedom and dignity of man.'

The jurisprudence of the Supreme Court has confirmed that the unenumerated rights proclaimed under Article 33(5) of the Constitution may include those guaranteed in 'treaties, conventions, international or regional accords, norms, and usages'[68] including 'provisions of international human rights instruments (and practice under them) or from the national human rights legislation and practice of other states'.[69]

[57] Art 21(3).
[58] Art 22.
[59] Art 23.
[60] Art 24.
[61] Art 25.
[62] Art 26.
[63] Art 27.
[64] Art 28.
[65] Arts 29 & 30 respectively.
[66] Arts 26(2) & 39(2).
[67] Art 29(8).
[68] Adjei-Ampofo v Attorney General [2003-2004] SCGLR 418.
[69] Ghana Lotto Operators Association & Others v National Lottery Authority [2007-2008] SCGLR 1088

Consequently, Article 33(5) provides a permissive framework through which the rights of persons with albinism not specifically protected in the Constitution but guaranteed in international human rights law and best practices from other democracies can be protected and fulfilled.

Following the provisions of the Constitution, several legislations have been enacted to ensure the promotion, respect for, protection of, and fulfilment of the rights of persons with disabilities, including persons with albinism. Key among them is the Persons with Disability Act of 2006 (Act 715), which, despite its limitations (such as its failure to address the equality of persons with disabilities broadly as required by the CRPD),[70] further elaborates on the rights of persons with disabilities (including persons with albinism) to family life, non-discrimination, protection against exploitation and abuse, access to public spaces, right to employment and protections in employment, right to free education, right to ‘free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons with total disability.’ The Act further mandates the Ministry of Health to include ‘the study of disability and disability-related issues in the curricula of training institutions for health professionals to develop appropriate human resources to provide general and specialized rehabilitation services’[71] and ‘education on disability and disability issues in health care programmes’.[72]

The Act provides criminal sanctions for the use of derogatory names against persons with disabilities, the failure of parents or guardians to send their children with disabilities to school, the refusal of the head of an educational institution to admit a learner with disabilities, and failure to provide reasonable accommodation to persons with disabilities in accessing public services. Despite these protective provisions, interlocutors expressed that the absence of legislative instruments or regulations to operationalize many parts of the Act means that it has remained largely unimplemented since its enactment.[73]

**[70]** E Gyamfi ‘Ghana – Country Report’ (2013) http://www.rodra.co.za/index.php/ghana; UN Partnership on the Rights of Persons with Disabilities (UNPRPD ‘Situational analysis of the rights of persons with disabilities in Ghana’ (2022) https://unprpd.org/sites/default/files//library/2022-11/CR_Ghana.pdf. Section 59 of the Persons with Disabilities Act defines a person with disability as ‘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 more of the major life activities of that individual’.

**[71]** Section 32 of Persons with Disabilities Act, 2006 (Act 715).

**[72]** Section 33 of Persons with Disabilities Act, 2006 (Act 715).

**[73]** See also Fordjour (n 18 above) 13.

The Children's Act of 1998 (Act 560) also makes provision for the protection of all children, including children with albinism. Essential guarantees include the right to non-discrimination, including on the basis of disability, the right to parental care, education and well-being, leisure and recreation, and protection from exploitation and inhuman and degrading treatment. Section 10 of the Children's Act specifically prohibits the treatment of a child with disabilities in an undignified manner. It guarantees the rights of children with disabilities to special care, education, and training that enables them to develop their potential and be self-reliant.

For its part, the Education Act 2008 (Act 778) guarantees the right to all children, including children with albinism, to free, compulsory, and universal primary education (FCUBE) and obliges the state to ensure that educational facilities are inclusive and can accommodate the needs of children with disabilities.

The Labour Act 2003 (Act 651) prohibits discrimination in employment based on disability. It mandates the provision of special incentives for organizations that employ persons with disabilities who are also engaged in a trade or business. The Act further makes provisions for the protection of persons with disabilities in employment, including considerations to be made in transferring a person with a disability to a new station and on-the-job training for persons with disabilities but fails to specifically mandate reasonable accommodation or persons with disabilities in employment.

On the other hand, the National Health Insurance Act provides the framework for funding healthcare services, including those utilized by persons with albinism. The Act exempts persons with disabilities, including persons with albinism, from paying premiums as a prerequisite for benefits under the NHIS. Others include the Mental Health Act of 2012, which aims to ensure humane care and promote culturally appropriate, affordable, accessible, and equitably distributed, integrated, and specialized mental health care.

Other legislation that has implications for the protection of persons with albinism include the Human Trafficking Act of 2005 (Act 694), which defines exploitation to include the removal of organs[74] (but is silent on the removal of body parts which are not organs per se) and the Criminal Offences (Amendment) Act of 2012, which criminalizes the unlawful use of human parts, including the removal and possession of human parts.[75] Together, these two legislations protect persons with albinism from mutilations of their organs and body parts, usually for ritual purposes.

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**[74]** Section 1(2) of Human Trafficking Act, 2005 (Act 694).

**[75]** Section 1 of Criminal Offences (Amendment) Act, 2012 (Act 849).

## C. National Policy Framework

Several policies have been enacted by the government to specifically respond to the plight of persons with disabilities, including persons with albinism. Others are of general application but have a significant impact on the rights of persons with albinism. Key among the policies that are relevant to persons with albinism include the Disability Policy of 2000, which aims to ensure that appropriate legislation is enacted and existing ones are made functional to promote the full integration of persons with disabilities into the national economy and to protect their rights as citizens of Ghana to create an enabling environment for them to promote their economic well-being and to enhance their capacity to perform better, to improve their socio-economic status as well as create awareness about the plight of persons with disability and to generate national support (including the use of local resources) to promote their welfare.[76]

Other key policies include the Inclusive Education Policy of 2015, which seeks to ensure that all learners are able to access the same educational facilities irrespective of their disabilities and that teachers and other educational workers are equipped with the skills and knowledge to cater to the diverse needs of learners with disabilities within the ‘regular’ classroom environment.

The 2015 National Social Protection Policy aims to ‘promote access to essential social security transfers and social services; with disability and gender issues mainstreamed into these considerations.’

The National Council on Persons with Disability Guidelines for the Disbursement and Management of the District Assemblies Common Fund for Persons with Disability[77] provides a framework for the management, disbursement, and utilization of the 3% allocation from the District Assemblies Common Fund that is earmarked for the benefit of persons with disabilities. This 3% allocation from the District Assemblies Common Fund (DACF) for the benefit of persons with disabilities is aimed at providing support to PWDs to engage in income-generating activities, provide educational support, build the capacity of organizations for persons with disabilities, and support PWDs with technical aids and other assistive devices.

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**[76]** Initial report submitted by Ghana under Article 35 of the Convention, due in 2014 (2018), CRPD/C/GHA/1, para 24.

**[77]**https://rodra.co.za/images/countries/ghana/policy/Guidelines%20for%20Disbursement%20of%20District%20Assembly%20Common%20Fund.pdf.

Other policy responses include the Livelihood Empowerment Against Poverty (LEAP) programme, a cash transfer programme that supports poor households, including those consisting of orphaned and vulnerable children and infants under 12 months old.[78] It must, however, be highlighted that the LEAP programme is only available to persons with albinism, to the extent that they have a 'severe disability without any productive capacity' or come from a household that is 'extremely poor' [79], which significantly limits access to the programme.

## D. National Institutions

A number of institutions are tasked constitutionally or by legislation to provide services or ensure that the human rights of persons with disabilities, including persons with albinism, are respected, protected, and fulfilled. Politically and administratively, the Ministry of Gender, Children, and Social Protection is mandated to promote gender equality and social justice and safeguard the rights and welfare of women, children, persons with disabilities, and other vulnerable groups.[80] The Ministry is thus responsible for formulating and implementing policies and legislation to promote, protect, and fulfill the rights of persons with albinism.

In the performance of this mandate, the Ministry is supported by several departments and agencies, key among them being the Department of Social Welfare, which is responsible for integrating disadvantaged, vulnerable, and marginalized people, including persons with disabilities, into mainstream society and ensuring their wellbeing. Under Ghana's decentralized local government system, this mandate is mainly implemented by the social welfare departments within local government authorities, even though the National Department of Social Welfare continues to maintain the policy and coordinating role in addition to a limited implementation mandate.

Another key institution is the NCPD, established under the Persons with Disabilities Act of 2006 with the mandate to propose and evolve policies and strategies to ensure that persons with disabilities are able to enter and participate in the mainstream of the national development process.

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**[78]** UNICEF 'Early Childhood development' https://www.unicef.org/ghana/earlychildhood-development(accessed 7 November 2023); MG Nyarko 'Implementation of the African Charter on the Rights and Welfare of the Child in Ghana' in Elvis Fokala, Nkatha Murungi and Mai Aman (eds) The status of the implementation of the African Children's Charter: A ten-country study (2022).

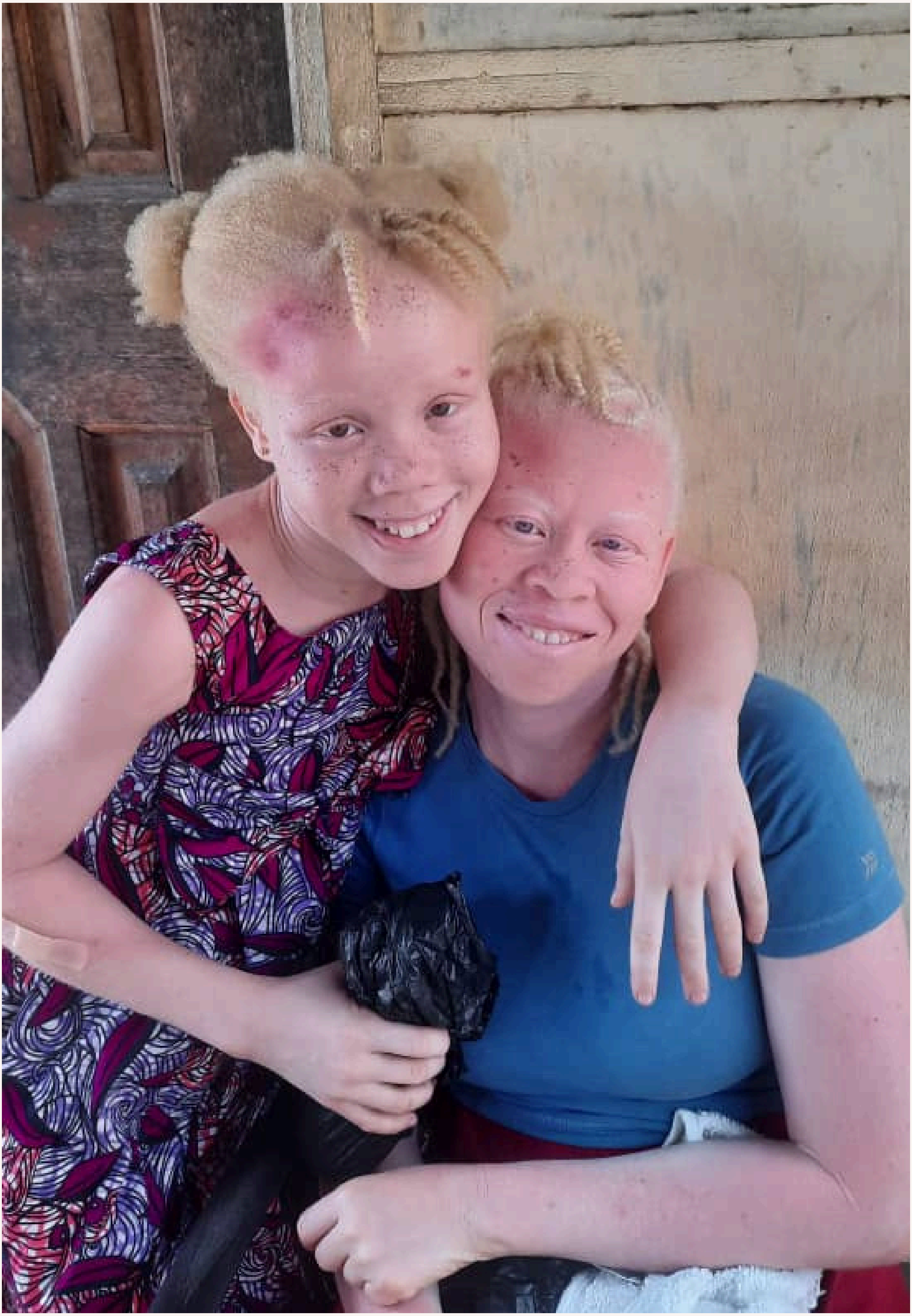
**[79]** https://www.mogcsp.gov.gh/livelyhood-empowerment-against-poverty-leap/.

**[80]** Initial report submitted by Ghana under Article 35 of the Convention, due in 2014 (2018), CRPD/C/GHA/1.

The NCPD, in this regard, is mandated to, among others, monitor and evaluate disability policies and programmes, formulate strategies for broad-based inter-sectoral, interdisciplinary involvement and participation in the implementation of the national disability policy, advise the Ministry on disability issues and submit to the Minister proposals for appropriate legislation on disability. Other mandates include coordinating activities of organizations of persons with disability, international organizations, and non-governmental organizations that deal with disability, promoting studies and research on issues of disability, and providing education and information to the public on issues of disability.

Another state institution that has mandates relevant to the rights of persons with albinism is CHRAJ, which is constitutionally mandated to ensure compliance with the human rights contained in the Constitution and international human rights standards and may receive, investigate, and adjudicate on complaints alleging the violations of the rights of all persons including persons with albinism. Others include the National Commission on Civic Education (NCCE), which is responsible for ensuring that society is sensitized about social, political, and other issues that should be of importance to the public, including educating the public about disability, albinism and engendering attitudinal change in society. On the other hand, the Legal Aid Commission (LAC) is tasked with ensuring equal access to justice and treatment before the law by serving as a public defender for the poor and vulnerable needing legal representation or advice.

Return to Table of Contents



Return to Table of Contents

# 5 THE HUMAN RIGHTS SITUATION OF PERSONS WITH ALBINISM: MAIN FINDINGS

## a. Public awareness about albinism and the rights of persons with albinism

As illustrated in the preceding section, several state institutions are mandated to engage in public awareness about various human rights issues, including the rights of persons with albinism. These national institutions should work with other state institutions, civil society organizations, and other stakeholders that advocate for respecting, protecting, and fulfilling the rights of persons with albinism. However, interlocutors indicated that there is limited public awareness about albinism, in particular, and disability generally. This was confirmed by a representative of the NCPD who indicated that while the Council generally engages in awareness-raising about disability and the rights of persons with disabilities, there has not yet been specific awareness-raising programming on albinism and the rights of persons with albinism. The representative of the Council confirmed that there had been some sensitization with committees at the district assembly level responsible for the disbursement of the portion of the DACF that is allocated to support persons with disabilities to enable the members of the committees to understand the various disabilities, including albinism, that the Council recognizes to benefit from the DACF. The absence of albinism-specific programming and awareness-raising campaigns from these institutions means that beyond occasional public statements that are made during annual celebrations of the International Albinism Awareness Day (IAAD), the general public is deprived of essential knowledge about albinism and the rights of persons with albinism. This has resulted in a situation where ‘even among persons with disabilities there is discrimination because some people in the disability groups do not understand why persons with albinism should be included as among persons with disabilities.'[81]

> **“Most of our parents don’t know much about albinism and, therefore, are not able to protect our rights and help us take care of ourselves.”**

Many persons with albinism themselves are unaware and often have difficulty accepting that they are persons with disability and, therefore, are entitled to certain services from the state and reasonable accommodation in society. Representatives of GFD, for instance, indicated that limited self-awareness among persons with albinism themselves means that many persons with albinism are not aware of the risk factors their environment poses to them to be able to protect themselves.

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**[81]** As expressed by one of the interlocutors.

The government shares the same views expressed by the interlocutors and acknowledges in its Initial Report to the Committee on the Rights of Persons with Disabilities that the situation of persons with disabilities ‘is characterized by ignorance, prejudice, superstition, neglect and fear’ because of the lack of awareness.[82] The government also indicated in its initial report to the Committee that one of the deficiencies of the Persons with Disabilities Act of 2006 is its silence on the need to raise awareness about the rights of persons with disabilities.[83] The government also acknowledged ‘[t]he failure of state institutions to discharge their responsibilities in educating the public on the rights of persons with disability in a coordinated manner’ as one of the challenges facing the implementation of the CRPD in Ghana. The government further acknowledged that state institutions do not have adequate resources needed to raise awareness about disability issues.[84]

Because state actors have failed to raise awareness about the rights of persons with albinism, interlocutors indicated that civil society organizations have had to take on the mantle of awareness raising on albinism and the rights of persons with albinism. However, these efforts are ad hoc and inconsistent because of civil society organizations' limited funding and capacity to advocate for the rights of persons with albinism. The leading civil society organizations engaged in advocacy and awareness raising about albinism and the rights of persons with albinism include Engage Now Africa, the Ghana Association of Persons with Albinism (GAPA), and Rise Africa, among others.

## b. Data and Statistics

Statistics on the population of persons with albinism in Ghana are challenging to come by as these are not readily 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.[85] While these may be conservative figures, they indicate that there are thousands of persons with albinism in Ghana.

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**[82]** Initial report submitted by Ghana under Article 35 of the Convention, due in 2014 (2018), CRPD/C/GHA/1, para 122.

**[83]** Initial report submitted by Ghana under Article 35 of the Convention, due in 2014 (2018), CRPD/C/GHA/1, para 114.

**[84]** Initial report submitted by Ghana under Article 35 of the Convention, due in 2014 (2018), CRPD/C/GHA/1, para 116.

**[85]** Commission on Human Rights and Administrative Justice (CHRAJ) ‘Systemic Investigation Report on Alleged Ritual Banishment and Stigmatization against Persons ith Albinism (PWA) in Ghana’ (2023) on file.

**Return to Table of Contents**

For instance, Under the Same Sun estimated in 2015 that given the prevalence of albinism in Africa is 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.

Recent statistics from Malawi, however, suggest that the prevalence of albinism in Africa may be much higher than previously estimated. For instance, the 2018 population census of Malawi estimated the population of persons with albinism to be 134,636 out of a total national population of 17,563,749, indicating an albinism prevalence ratio of 1 to 130.[86] While the prevalence may vary across the continent, the example of Malawi speaks to the need to have accurate and up-to-date data on the populations of persons with albinism in Africa. Kenya's 2019 Population and Housing Census, documented 9,729 persons with albinism out of a total population of 47,564,296, indicating a prevalence of 1 in 4,889[87]. While in Tanzania, the 2022 Census estimates the population of persons with albinism at approximately 74,273[88], out of total national population of 61,741,120, indicating a prevalence of 1 in 831.

With the 2021 population and housing census estimating the population of Ghana to be around 31 million,[89] it is reasonable to assume that the population of persons with albinism has also increased over this period.

Regrettably, while the Ghana Statistical Service (GSS) collected data on persons with a disability during the 2021 population and housing census, this data is only disaggregated based on functionality (i.e., sight, hearing, physical, intellectual, self-care, and speech), without any specific data collected on the numbers of persons with albinism.

**[86]** Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond: Visit to Madagascar, A/HRC/52/36/Add.1 (2023) para 18.
**[87]** Kenya National Human Rights Commission 'Press statement: Commemoration of the 2023 International Albinism Awareness Day' (13 June 2023). https://www.knbs.or.ke/wp-content/uploads/2023/09/2019-Kenya-population-and-Housing-Census-Volume-4-Distribution-of-Population-by-Socio-Economic-Characteristics.pdf
**[88]** Tanzania Basic Demographic and Social-Economic Profile – Key Findings (April 2024) https://sensa.nbs.go.tz/publication/08.%20Key_Findings_Basic_Demographic_and_Socio-economic_%20Eng_%2012.06.2024%20Final.pdf
**[89]** Ghana Statistical Service 'Ghana population and housing census: General report volume 3A' https://statsghana.gov.gh/gssmain/fileUpload/pressrelease/2021%20PHC%20General%20Report%20Vol%203A_Population%20of%20Regions%20and%20Districts_181121.pdf (accessed 2 November 2023).

This is irrespective of the fact that both GFD and GAPA indicated that they made representations to the GSS to collect data on albinism before the census, which was unsuccessful because the GSS approach to disability is mainly on functionality rather than specific category or designation of the disability.

Consequently, comprehensive national statistics on persons with albinism as a distinct group have yet to be available. There is also no indication that various government agencies and service providers collect accurate administrative data on persons with albinism. The absence of data on persons with albinism is concerning as it makes it challenging for the state to plan and budget for the rights and needs of persons with albinism. That said, the Ghana Statistical Service indicated that the 2021 Population and Housing Census revealed that 8% of the population of 30.8 million Ghanaians documented reported having some form of disability.[90]

### c. Myths and harmful beliefs about albinism and persons with albinism

Several myths and harmful beliefs underpin the ill-treatment, discrimination, and accompanying human rights violations that persons with albinism suffer in Ghanaian society, often because of the limited awareness about albinism. The various myths and harmful beliefs about albinism and persons with albinism that interlocutors shared with the researchers are briefly highlighted, including beliefs that persons with albinism do not excrete on Fridays and that their feet may turn into fire at night. Among the Anlo people, persons with albinism are referred to as Gesoshi (which translates to ‘fallen from the sky’)[91] to reference their perceived supernatural means of being incomplete. In contrast, Akan-speaking communities refer to persons with albinism as ofri or ofridjato, a derogatory term denoting a ‘scorched or marked person.’[92] Other derogatory terms used to describe persons with albinism in Ghana include Gele so si in Ewe and Gbangu in Dagati, which both mean supernatural.[93] These derogatory terms often suggest the inferior status of persons with albinism, which further exposes them to other forms of dehumanization.[94]

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**[90]** Fordjuor (n 18 above) 11.

**[91]** AK Daklo & OS Obadire ‘Exploring the experiences of persons with albinism in Ghana’ (2024) 11 Cogent Education 1 5.

**[92]** FEK Benyah ‘Are Albinos People like Us? Albinism and Social Exclusion in Ghana’ in AA Alemanji, CM Meijer, M Kwazema, F Benyah (eds) Contemporary Discourses in Social Exclusion (2022) 143 151.

**[93]** F Benyah ‘Equally able, differently looking: Discrimination and physical violence against persons with albinism in Ghana’ (2017) 30 Journal for the Study of Religion 161 168.

**[94]** Benyah (n 77 above) 152.

**As one interlocutor recounted:**

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

**Another interlocutor recounted:**

Other myths and harmful beliefs include perceptions that anyone who marries a person with albinism will become poor and that persons with albinism cannot see during the day but can only see at night and therefore cannot cook during the day; that persons with albinism are ghosts, cursed or are a product of adultery of the mother and thus a source of ‘bad luck’ for the family; that pregnant women should not be exposed to persons with albinism because albinism will be spiritually transferred to the unborn child; that children are born with albinism if the mother comes into contact with a mythical dwarf [95] while pregnant.

> **“People perceive albinism based on what they see in the media. People perceive persons with albinism as a tool to be used for sacrificial purposes. Others think persons with albinism do not do certain things on some days, the most popular being that persons with albinism do not excrete or use the toilet on Fridays. People also think that persons with albinism do not die but simply disappear, while others jovially remark that they will send persons with albinism to Tanzania in reference to the reported ritual killings of persons with albinism in Tanzania.”**

The myths and harmful beliefs do not only affect persons with albinism, but often, their parents, family members, and other people who are close to them are equally targeted because of their association with persons with albinism.

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**[95]** Dwarf is not used here to refer to human beings who are short in stature but rather to the mythical or folklore species or short human-like creatures who are often said to have supernatural powers.

Interlocutors also expressed that because learners with albinism have visual impairment, they are sometimes believed to have spiritual powers to change the scripts of other learners if they perform well in school. Interlocutors in the northern belt expressed that there is a belief that women with albinism can only get married to a chief or traditional healer (mallam or 'fetish priest') because any other man will be victim to an early death if they get married to a woman with albinism. A number of female interlocutors confirmed being propositioned for marriage by mallams or traditional healers who expressed that they would become rich when they got married to a woman with albinism.

**As one interlocutor recounted:**

> **"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 the same to my mother and family members".**

Interlocutors in the northern belt indicated that in some communities, persons with albinism are accused of witchcraft and blamed for the death of loved ones. Women with albinism have also become targets for rituals because there are beliefs that having sexual intercourse with a woman with albinism can enhance opportunities for wealth or may cure diseases such as HIV/AIDS. Interlocutors also expressed that there is a general societal belief that persons with albinism are bad omen/luck, and therefore, encountering a person with albinism early in the morning is a sign that they will have bad luck in the course of the day. As a result, some community members would even refuse to sell things to persons with albinism in the morning until a person without albinism has purchased some of their merchandise.

The myths and harmful beliefs associated with persons with albinism dehumanize and portray them as people who are 'beyond general boundaries of fair and moral treatment,' resulting in discrimination, denial of their dignity, and social exclusion and further increasing their vulnerability to other harmful practices and human rights violations.

Return to Table of Contents

## d. Stigma and Discrimination

Stigma and discrimination are the most common violations suffered by persons with albinism in Ghana. Often, 'people with albinism are constantly ridiculed in public with derogatory names and social tags that serve as a form of stigmatization that shows they are different.'[96] The stigma is often underpinned by harmful myths and misconceptions held in society, as illustrated above. One interlocutor indicated that societal perceptions that persons with albinism smell or have foul body odor lead to stigmatization, which results in people not wanting to associate with persons with albinism. Poverty was identified as being responsible for this type of stigmatization as the perception is fueled by the fact that most persons with albinism generally live in poverty and do not have access to livelihood support opportunities, which makes it likely that they are unable to take good care of themselves. Stigma and discrimination permeate every aspect of the lives of persons with albinism, including in religious settings.

**As one interlocutor recounted:**

> **"Even in terms of religion, we are discriminated against because even though the church would take your tithes and offerings, we are not usually allowed in leadership roles, and if the church leadership doesn't let us lead, the general membership will also not stop the stigma".**

Stigma and discrimination against persons with albinism often correlate with their socioeconomic status in society, as interlocutors indicated that the discrimination reduces as persons with albinism become more economically empowered.

Some interlocutors indicated that because it is generally difficult for persons with albinism to perform activities in the sun, as a result of the sensitivity of their skin to sunlight, they are perceived to be lazy and not willing to pull their weight, which makes some members of society doubt their competence, resulting in further discrimination.

This, in turn, leads to a situation where many persons with albinism often shy away from public engagements and opportunities because of the fear of being embarrassed, further leading to the marginalization and impoverishment of persons with albinism.

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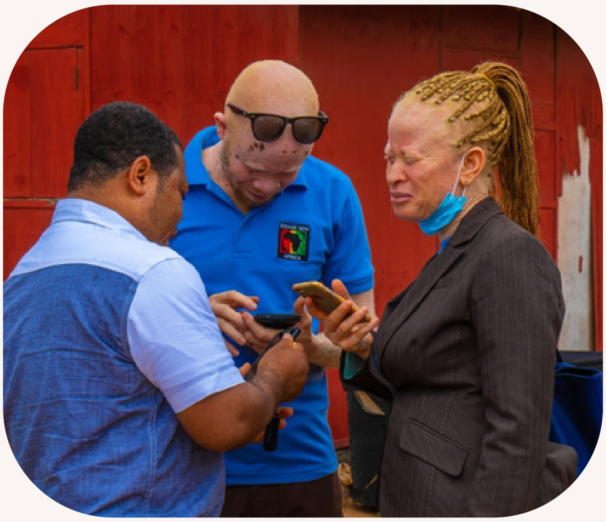
**[96]** Benyah (n 77 above) 151.

Verbal abuse and other forms of teasing, ridiculing, and bullying of persons with albinism are widespread in communities across Ghana. This is confirmed by an investigative study conducted by CHRAJ, which indicates that 'Persons with albinism in all the communities visited were subjected to derogatory name-calling and labelling' and 'were stigmatized at social gatherings such as at church, weddings, parties, etc.'[97] This also affects the family members of persons with albinism who are often stigmatized including the refusal of community members to patronize their business.[98]

Interlocutors also expressed that in classrooms, some learners refuse to touch the same books that a learner with albinism has touched because of the myth that they may also become persons with albinism or have bad luck, which makes it difficult for children with albinism to access education. Because of the stigma and discrimination, persons with albinism are sometimes hidden from the public, which makes persons with albinism shy and lack the confidence to speak in public.

**As one interlocutor recounted:**

> **"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".[99]**



Thus, stigmatization and discrimination often result in social exclusion either by the broader community refusing to interact with or shunning away from persons with albinism and or, in many instances, persons with albinism themselves shying away from public or social interactions for fear of being ridiculed, name-called, bullied or made fun of, which has a significant impact on their mental health and wellbeing.[100]

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**[97]** Commission on Human Rights and Administrative Justice (CHRAJ) 'Systemic Investigation Report on Alleged Ritual Banishment and Stigmatisation against Persons with Albinism (PWA) in Ghana' (2023) Draft report on file.
**[98]** CHRAJ (as above).
**[99]** As expressed by one of the interlocutors.
**[100]** AA Afframi, E Teye-Kwadjo & AA Gyasi-Gyamerah 'Influence of social stigma on subjective wellbeing of persons with albinism in Ghana' (2019) 29 Journal of Community and Applied Social Psychology 323.

Besides interpersonal discrimination, persons with albinism experience structural and systemic discrimination in almost all aspects of their lives. As discussed in more detail in subsequent sections, persons with albinism experience discrimination in accessing education, healthcare, justice, and social protection, among others, as many of these essential services are not generally structured in a manner that accommodates their needs to adequately and appropriately support them.

## e. Harmful Practices, Physical Safety, and the Right to Life

Interlocutors indicated that attacks against persons with albinism for ritual or other purposes are not rampant or often reported in the media. However, they have heard stories that confirm that the hair, nails, and body parts of persons with albinism are used for rituals in some parts of the country. The most recent report of an attack resulting in the death of a person with albinism occurred on 17 February 2015, when the deceased body of Kofi Yeboah, a person with albinism, was found in Amanase-Boketey near Suhum in the Eastern Region, suspected of having been killed by a local pastor.[101] Local police were initially passive 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 of the case. Even then, the police indicated that they didn’t have enough evidence to charge the accused, and the family of the deceased was not keen on pursuing other redress mechanisms, such as a complaint to CHRAJ.

More recently, an attempted abduction of a 16-year-old boy with albinism was reported in the town of Garu in the Upper East Region on January 1, 2023. When the perpetrator approached him on a motorbike, the boy and his teammates were playing football to celebrate the new year. The perpetrator pleaded with the boy to go with him to get his bicycle from a nearby neighborhood and bring it back to where they were playing football since he couldn't ride two bikes at once. The boy agreed, but when they reached the said neighborhood, the perpetrator did not stop. When the boy protested, the perpetrator insisted he stop at the next neighborhood. Upon reaching the next neighborhood, the perpetrator still refused to stop despite the victim's protests, prompting the boy to jump off the bike. In his attempt to flee, the boy met a lady and narrated the story. Little did he know, she was the mastermind behind the attempted abduction and had a syndicate following them on a motorcycle.

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**[101]** Under the Same Sun contribution to CCPA List of Issues Prior to Reporting: Ghana – October 12, 2015 [https://ccprcentre.org/files/documents/Ghanians_with_Albinism.pdf](https://ccprcentre.org/files/documents/Ghanians_with_Albinism.pdf) (accessed 10 November 2023).

This became obvious as concerned members of the public who were observing the interactions when the boy jumped off the motor bike interrogated the man on the motor bike who subsequently confessed to the conspiracy and named the lady as the one who had contracted them to abduct the boy with albinism.

Through GAPA's advocacy intervention, the two culprits were apprehended and charged with the crime of attempted abduction. The accused have appeared twice in court, but the case has stalled as GAPA has struggled to get updates from the relevant authorities.

**“I have a personal experience of being targeted for ritual sacrifice. I was informed that there were people in the community from the chief’s palace who wanted to capture me and take me to a fetish priest. Fortunately, I was notified by one of the people who was at the chief’s palace when this decision was made. This made me so scared I had to quickly leave town for fear of my safety.”**

**One interlocutor recounted his experience as follows.**

While there has been little information regarding physical attacks against persons with albinism, the cases below indicate that cases do happen, albeit on a potentially small scale. Furthermore, endemic poverty, and the ambition of some people to get rich quickly, coupled with the widespread prevalence of harmful myths relating to the use of the body parts of persons with albinism for ritual money, makes the possibility of ritual attacks highly likely.

Additionally, the existence of elaborate myths, such as the myth held across the country that persons with albinism do not die but simply vanish, may confirm the suspicion that persons with albinism have for a very long time been victims of ritual murders, even if these are infrequent in the recent past. This myth seems to have been created to conceal the disappearance of persons with albinism for ritual purposes so that community members do not bother to look for persons with albinism who go missing. The clandestine nature of the practice of ritual murder makes it challenging to have concrete data on the practice, but this continues to threaten the right to life of persons with albinism. Interlocutors expressed that while harmful practices such as infanticide are rare, these used to happen in the past, and there is no reason to believe that they no longer occur, even if in very limited instances.

Return to Table of Contents

**Another interlocutor recounted as follows:**

> **"My grandfather married three wives. Somebody told me that when I was born, one of his wives advised that I should be killed at birth because I would have no use in life. My grandfather resisted this and took very good care of me. He advised me and took me to school, but it was not easy in school because I faced a lot of teasing and discrimination. Once, when I was sick in the house and could not go to school and wanted medication for my headache, my grandmother, the same wife who had advised that I be killed at birth, commented that she was right that I would not amount to anything in life as I was not willing to go to school. That comment so touched me that I put on my uniform, went to school, and promised her that I would make something out of my life."**

Interlocutors also indicated that because of the myths in some communities that someone can use persons with albinism for money rituals, there is sometimes general fear among persons with albinism, which sometimes makes it difficult for persons with albinism to move around freely. Similarly, because there is still the belief that persons with albinism are sometimes used for rituals by traditional authorities, parents do not allow their children with albinism to go to public gatherings, especially during cultural celebrations and festivals.

> **"When I was born, my father rejected me, and 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."**

Again, because of beliefs that the hair and nails of persons with albinism can be used for money or other rituals, persons with albinism are sometimes forced not to use public salons. Some persons with albinism are therefore forced to cut their hair at home, and when they venture to take the risk of using public salons, they would often pick their hair and nails, rather than have it disposed of by the salon staff, out of fear that these may be sold or used for ritual purposes. Sometimes, people steal the clothes of persons with albinism to use for rituals, which causes financial hardships to persons with albinism who are usually already poor.

## f. Right to Health

Persons with albinism face significant challenges with healthcare. Notably, the absence or reduction of melanin exposes persons with albinism to the risk of skin cancer, which is one the most common causes of death among persons with albinism.[102] 'Persons with albinism are highly vulnerable to skin cancer and often have disabilities, mainly as a result of vision impairment and skin impairment.'[103] Persons with albinism also experience significant challenges with eyesight, which may worsen as they age**.**[104]

The most common challenges with eyesight include photophobia (sensitivity to bright light) caused by the absence of melanin, which results in blurred vision or sudden and momentary blackouts upon exposure to bright lights.[105] Persons with albinism may also suffer from nystagmus, which 'results in involuntary and uncontrolled eye movement either horizontally, vertically or in a circle' and consequently causes blurred or reduced vision.[106]

**[102]** Report of the Independent Expert on the enjoyment of human rights by persons with albinism (2016), A/HRC/31/63, Para 37.

**[103]** Report of the Independent Expert on the enjoyment of all rights by persons with albinism, Albinism Worldwide, A/74/190, 18 July 2019, para 5; see also ES Hong, H Zeeb and M Repacholi, 'Albinism in Africa as a public health issue' (2006) 6 BMC Public Health 212 DOI: 10.1186/1471-2458-6-212. 115; AK Daklo 'Access to healthcare for persons with albinism in Ghana: A human rights approach (2020).

**[104]** Human Rights Council, 'Social development challenges faced by persons with albinism. Report of the Secretary-General' (2017) A/72/169 para 28.

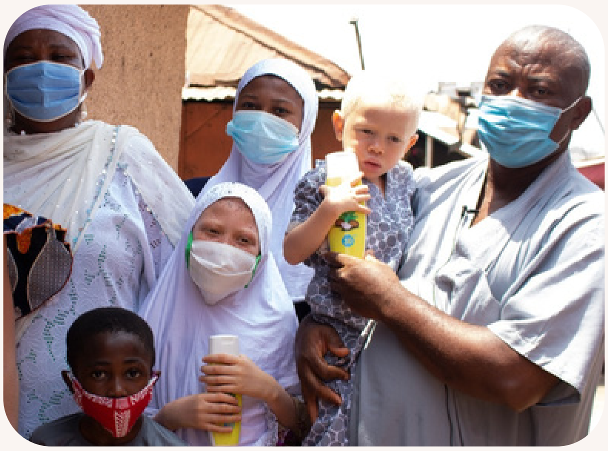
**[105]** Daklo (n 88 above) 19.

**[106]** Daklo (as above).

Return to Table of Contents

These health risks, such as skin cancer and visual impairment, require consistent, adequate, and appropriate healthcare services that are readily accessible, available, acceptable, and of good quality to persons with albinism' to 'enable them to manage and live with the condition that requires lifelong management.'[107] However, despite the heightened need of skin care for persons with albinism, the number of licensed dermatologist in Ghana is estimated to be between 25[108] and 40[109] serving a population of more than 30 million people with most of the physician dermatologist stationed in teaching hospitals in Accra and Kumasi, resulting in extreme deprivation of dermatological services to populations in rural and deprived communities across the country.[110] Similarly, even though a reported 5% of the population has visual impairment, with about 1% being blind, there were an estimated number of only 91 ophthalmologists in Ghana in 2017, with 80% of this number based in Greater Accra and Ashanti regions, leaving the rest of the country underserved.[111] Further, as at the year 2020 Ghana had only 4 clinical oncologists, '12 radiation oncologists, and ten resident radiation oncologists in training'[112] posing significant challenges to cancer care, with a reported 24,009 new cases of cancer in 2020.[113]

In the face of these health challenges, interlocutors expressed that most persons with albinism, especially those in rural areas and their parents/families, have limited knowledge about the impact that exposure to the sun can have on the skin of persons with albinism, including the fact that consistent exposure to the sun over a significant period could lead to the development of skin cancer.



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**[107]** Daklo (as above) 1-2.

**[108]** S Simister, N Flint, J Webb, O Nyarko, A Secrest, B Lewis & T Dickerson 'Exploring the knowledge, attitude, and practices of over-the-counter medical sellers in Ghana' (2023) 14 Journal of Public Health in Africa 2122, doi: 10.4081/jphia.2023.2122.

**[109]** S Wiafe 'Tropical dermatology; the most neglected area in medical practice', 15 May 2022 https://www.modernghana.com/news/1158021/tropical-dermatology-the-most-neglected-area-in.html.

**[110]** Wiafe (as above).

**[111]** EKA Morny, SB Boadi-Kusi, S Ocansey, S Kyei, K Yeboah & MA Mmaduagwu 'Assessing the progress towards achieving "Vision 2020: The right to sight" initiative in Ghana' (2019) Journal of Environment and Public Health doi: 10.1155/2019/3813298.

**[112]** AS Erem, A Appiah-Kubi, TO Konney, K Amo-Antwi, SG Bell, TRB Johnson, C Johnston, AT Odoi & ER Lawrence 'Gynecologic Oncology Sub-Specialty Training in Ghana: A Model for Sustainable Impact on Gynecologic Cancer Care in Sub-Saharan Africa' (2020) Frontiers in Public Health, doi: 10.3389/fpubh.2020.603391.

**[113]** LR Roberts , BM Rivers , CC Yates , LA Newman , BD Sarkodie , MB Davis , Y Asare-Aboagye , AA Adjei , AE Harris & B Awuah 'Unmet Needs in Oncology Clinical Research and Treatment in Africa: Focus on Ghana' (2020) 27 The Oncologist 760-767, https://doi.org/10.1093/oncolo/oyac109.

Return to Table of Contents

This means that many persons with albinism are not able to protect themselves through the use of sunscreen and/or wearing clothing and other apparel that protects their skin from being overly exposed to sunlight. In the absence of awareness raising by government agencies such as the Ghana Health Service, many persons with albinism are exposed to the risk of developing skin cancer.

Interlocutors also indicated that there is limited awareness among health professionals, which manifests itself through nurses and doctors sometimes making derogatory comments about persons with albinism who access healthcare facilities. One interlocutor recounted that:

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

The limited knowledge among healthcare professionals about albinism and the high risk of skin cancer faced by persons with albinism means that they do not often receive adequate diagnosis early enough when they present symptoms such as lesions on their skin, which are usually symptomatic of the early onset of skin cancer.

Consequently, by the time persons with albinism are correctly diagnosed, often the disease would have been quite advanced, requiring surgeries, radiotherapy, or chemotherapy services, which are not covered by the NHIS and are often entirely unaffordable for most persons with albinism. [114]

Even in instances where persons with albinism can afford treatment, the fact that ‘cancer in Ghana is treated at major referral centres in the largest cities, Accra, Kumasi, and more recently Tamale and Cape Coast’ and ‘most expertise in diagnosing cancer care resides at more extensive facilities such as regional and referral hospitals’ means that ‘community and district level services may not have sufficient expertise to recognize and refer suspected cancer patients’.[115] This places skin cancer diagnoses and treatment outside the reach of a significant number of persons with albinism, especially those who live in rural and resource-poor communities.

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**[114]** See also Daklo (as above) 3.

**[115]** CZ Tuck, R Cooper, R Aryeetey, LA Gray & R Akparibo ‘A critical review and analysis of the context, current burden, and application of policy to improve cancer equity in Ghana’ (2023) 22 International Journal for Equity in Health, Article number: 254.

Many interlocutors expressed dissatisfaction with the services they receive from healthcare centres, including for their eye care. Apart from derogatory comments and the neglect they often experience from healthcare professionals or their lack of urgency proportional to the care persons with albinism require, many persons with albinism indicated that the optometrists and ophthalmologists they have interacted with, who are supposed to be eye care specialists, had no idea that persons with albinism often suffer from nystagmus, which sometimes causes uncontrollable rapid eye movements. The lack of knowledge among healthcare professionals exposes persons with albinism to the risk of misdiagnoses by the same healthcare professionals who are supposed to be providing care and attention to their healthcare needs. As another interlocutor recounted, 'physicians often do not understand the skin of persons with albinism and misdiagnose skin cancer as ulcers.'

Interlocutors also expressed dissatisfaction and often frustration with the prescriptions given to them by healthcare professionals, which are often not accessible.

Interlocutors further expressed that there are limited government policies and programmes aimed at ensuring that persons with albinism have access to the necessary healthcare products, such as sunscreen, that they require to protect their skin against sunburn, which is the leading cause of skin cancer among persons with albinism. For instance, although access to sunscreen and skin cancer treatment is essential to the survival of persons with albinism, and eye care and assistive devices are often necessary to ensure their full participation in society, these essential healthcare products and services are not covered by the NHIS, leaving most persons with albinism with unfulfilled healthcare needs.

**One interlocutor recounted that:**

> **"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 leaflets in medications are usually in very small font, which is inaccessible to most people with albinism who have low vision."**

Consequently, persons with albinism have had to sometimes rely on the benevolence of civil society organizations and occasionally the allocation from the portion of the DACF designated for persons with disabilities to be able to access emergency treatment for skin cancer.

Access to such emergency assistance from the DACF is often contingent on whether the patient is influential or has access to an influential individual or organization that can intercede with the relevant decision-makers on their behalf. Access to sunscreen and other assistive devices has thus generally been provided by civil society organizations such as GAPA and Engage Now Africa rather than the state, which is the primary duty bearer responsible for ensuring that the right to health of persons with albinism is protected and fulfilled.

In addition to skin cancer and visual impairment, persons with albinism experience mental health challenges because of the often-consistent stigma, discrimination, bullying, marginalization, and social exclusion that they face in society.[116] These, coupled with the fact that persons with albinism are sometimes exposed to extreme danger for their lives and well-being because of the threat of attacks or myths surrounding ritual killings, put a lot of psychological pressure on them, which, therefore, exposes them to mental health challenges.

### g. Sexual and Reproductive Rights of Women

Women with albinism expressed that they have often faced challenges while accessing sexual and reproductive health services as many healthcare professionals, especially nurses and midwives in rural areas, generally believe the myths and misconceptions about albinism. One interlocutor shared a harrowing story of how she had two stillbirths because of the refusal by nurses to attend to her when she was in labor. Other interlocutors expressed how nurses and midwives ridiculed them while they were in labor, often suggesting that they should be asexual or refrain from having children because of their albinism. The challenges faced by women with disabilities in accessing reproductive healthcare, including the insensitivity and negative attitudes of healthcare providers as well as their lack of flexibility and specific information on addressing the special maternity care needs of women with disabilities, are well documented in the literature.[117] The general feeling among women with albinism who are also mothers is that nurses and midwives are often overly aggressive during the process of seeking reproductive healthcare, especially while they are in labor.

> **“I faced challenges on my visit to the clinic while pregnant because a nurse made a comment when the doctor asked me to do a stool test, and the nurse was wondering if I would be able to bring a stool for testing or if I would go and collect someone else’s stool because she had learned that persons with albinism could not pass stool on Fridays.”**

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**[116]** Daklo (n 88 above) 22; AA Affram, E Teye-Kwadjo & AA Gyasi-Gyamerah (n 85 above).

**[117]** See for example JK Ganle, E Otupiri, B Obeng, AK Edusie, A Ankomah & R Adanu ‘Challenges women with disability face in accessing and using maternal healthcare services in Ghana: A qualitative study’ (2016) 11(6):e0158361 PLoS One, doi: 10.1371/journal.pone.0158361.

## h. Right to Education

Information on the enrollment of persons with albinism at various levels of education is not generally available, as there is no indication that the relevant educational authorities collect disaggregated data of this nature. If the relevant authorities collect such information in the educational sector, such information is not publicly available and cannot be procured with diligent search. However, anecdotal evidence from our interactions with interlocutors during this study suggests that most persons with albinism enroll in mainstream schools except in instances of severe visual impairment, wherein persons with albinism may be enrolled in special schools for visually impaired students.

> **“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.”**

> **“I was supposed to write an examination from class 6 for promotion to Junior High School, but because I couldn’t see the board and I wasn’t placed in front of the class, I failed the exams as I couldn’t read from the board and attempts to get the authorities to allow me to resit the exams was not accepted by the teachers.”**

That said, because persons with albinism have varying degrees of low vision, they usually require reasonable accommodation and or assistive devices to be able to fully benefit from education on equal terms with others. However, despite the promise of an inclusive legislative and policy framework for the right to education, which persons with albinism should enjoy, interlocutors throughout the country expressed that persons with albinism face significant challenges in accessing education, especially at the primary and secondary levels.

The challenges run through the whole process of accessing education, from enrolment to examination. Interlocutors indicated that while enrolment forms at the tertiary level of education usually provide the space for learners to indicate if they have any disabilities that require accommodation, this is not generally available at the primary and secondary school levels, which means that the needs of learners are not individually assessed for reasonable accommodation. This is often also influenced by the fact that learners with albinism do not often understand their condition as a disability, which teachers and school administrators should be aware of for individualized assessment so that they can be supported.

Interlocutors indicated that registration for the Basic Education Certificate Examination (B.E.C.E) administered by the West African Examination Council only asks learners to indicate if they are blind to provide exam questions in braille, but this is not inclusive enough to cover some of the other challenges that persons with albinism face, such as being short-sighted or having low vision, which may require having larger fonts rather than braille.

> **“When I went to school, my family commented that it would be useless to educate me as I had no useful purpose in life. I also faced a lot of teasing, which led me to quit school.”**

Some of the experiences interlocutors shared with the researchers are summarized below to illustrate the challenges faced by persons with albinism in accessing education.

Interlocutors indicated that registration for the Basic Education Certificate Examination (B.E.C.E) administered by the West African Examination Council only asks learners to indicate if they are blind to provide exam questions in braille, but this is not inclusive enough to cover some of the other challenges that persons with albinism face, such as being short-sighted or having low vision, which may require having larger fonts rather than braille.

As a result, learners with albinism are not often considered by educational institutions as persons with disabilities who require reasonable accommodation and assistive devices to be able to fully participate in the process on equal terms with their peers.

Thus, because learners with albinism are not often provided with the opportunity to declare their challenges during the enrolment process, especially at the primary and secondary levels of education, they often do not receive reasonable accommodation such as being placed close to the board so that they can read text written by teachers, being provided with larger font textbooks, additional time during exams or assistive devices that would enable them to participate fully in class.

**"When I finished Junior High School, I had the opportunity to go to Senior High School, but on my first day at school, I almost quit. I was given to the girl's prefect to accompany me to the dormitory, and before we got to the dormitory, I heard loud screams and people running; some even almost fell 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."**

**"In terms of access to education, persons with albinism struggle a lot because of our shortsightedness. We cannot see the board, so most of us become school dropouts. This then affects our ability to get employment. Because of my condition, my father had to introduce the printing of exam questions in my school so that I could study in school."**

Interlocutors indicated that teachers do not seem to have much knowledge about albinism and that learners with albinism may be shortsighted or have low vision and, therefore, may not be able to read from the board from a distance.

**"During my time in the early 1960s, I was made to redo classes 1, 2, and 3 because I usually sat at the back, and because I could not read from afar, I was generally last in class. One of the teachers realized my difficulty and moved me to the front of the class, and that term, I was 5th in class. Since then, even if the teacher did not put me in front, I would put myself in front to see the board; that is the only way I could complete teacher training school."**

**"While in school, I could not usually see from the board, so I had to rely on what classmates wrote and copy from them, and therefore, if they made mistakes, I would also make a mistake."**

Consequently, learners with albinism who request to be moved to the front of the class are often deemed to be ill-disciplined or disruptive and not often accommodated. This places learners with albinism at a significant disadvantage. Interlocutors expressed that even where teachers know the challenges of the learner with albinism, there is generally little enthusiasm among teachers to accommodate the needs of learners with albinism and learners with disabilities in general.

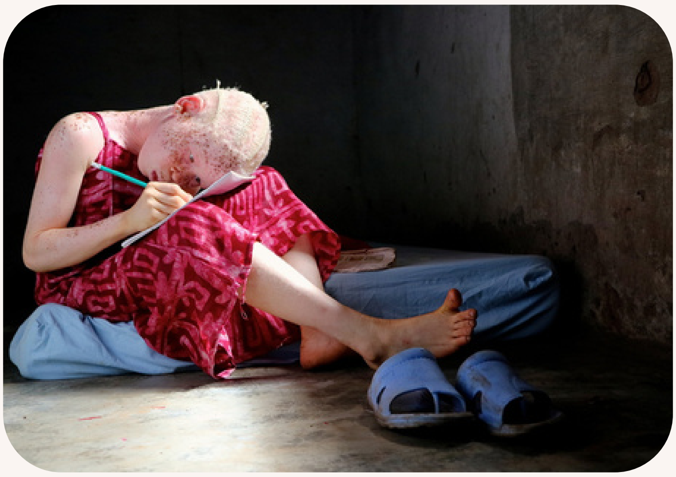
Interlocutors indicated that these discriminatory practices place significant impediments in the ability of persons with albinism to equitably access education, often resulting in learners with albinism struggling to pass their modules and, subsequently, many dropping out of school.

Mothers of children with albinism indicated that they have sometimes been discouraged by teachers in public schools from enrolling their children in public schools and sent them to private schools because of the lack of accommodation in public schools. Learners with albinism also indicated that they are often stigmatized, ridiculed, bullied, and often socially excluded by other learners because of myths and stigma.

**"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."**

However, when these learners with albinism report their abuse, this is not taken seriously by teachers, which sometimes results in learners with albinism fighting back to defend themselves against verbal abuse and bullying. Teachers and school authorities often punish learners with albinism who resort to such measures without addressing the abuse that they often face from other learners.

**"My teacher would make mocking comments about me, which made me uncomfortable, and I started missing classes."**



The stigmatization and bullying faced by children with albinism in school makes them lose self-confidence and become reclusive, resulting in them avoiding interacting with other learners and sometimes dropping out before they complete High School, further perpetuating the cycle of poverty and lack of economic and livelihood support opportunities among persons with albinism.

This lack of self-confidence limits the ability of learners with albinism to put themselves out there and compete for leadership positions in school, such as being class prefects or head students. Some interlocutors who are currently students indicated that they had been discouraged by teachers not to contest for leadership positions in school.

> **“My economics teacher used to throw a marker at me every day because I had difficulty seeing the board. Every time I strained my eyes 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.”**

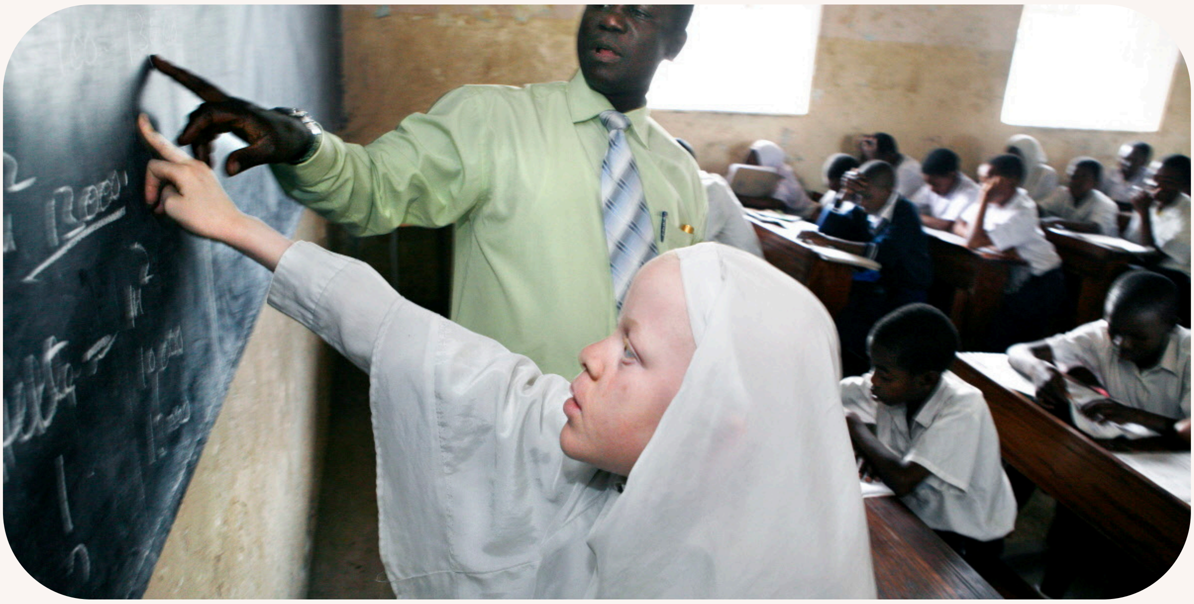
> **“When I registered for the teacher training college, the admission forms asked candidates to tick if they had any disabilities, which we did, but I wasn’t provided with reasonable accommodation.”**

In addition to all these, learners with albinism often have to be aware of their physical safety due to the fear of ritual attacks. They may also face ritual banishment, limiting their educational opportunities and options within some communities.

One learner with albinism shared a story of how she was the victim of an attempted kidnapping, which made it difficult for her to go out at night to study on her school campus. Another learner with albinism shared that even though he had gained admission to a High School, he was not able to enroll because community members expressed that persons with albinism are not allowed to reside in that community. He, therefore, had to enroll in another high school.

Other learners shared the stigma and discrimination they faced in school, including the refusal of other learners to share school boarding houses with them on account of harmful myths and beliefs about persons with albinism.

“In the classroom, it is difficult to see if you are not sitting closer to the board and cannot read from it and follow lessons. This will affect your academic performance and create the appearance that you are not intelligent enough to do well in school. I was fortunate to have a teacher who would usually speak while teaching mathematics so that I could hear and follow the lesson because he realized I could not see the board.”



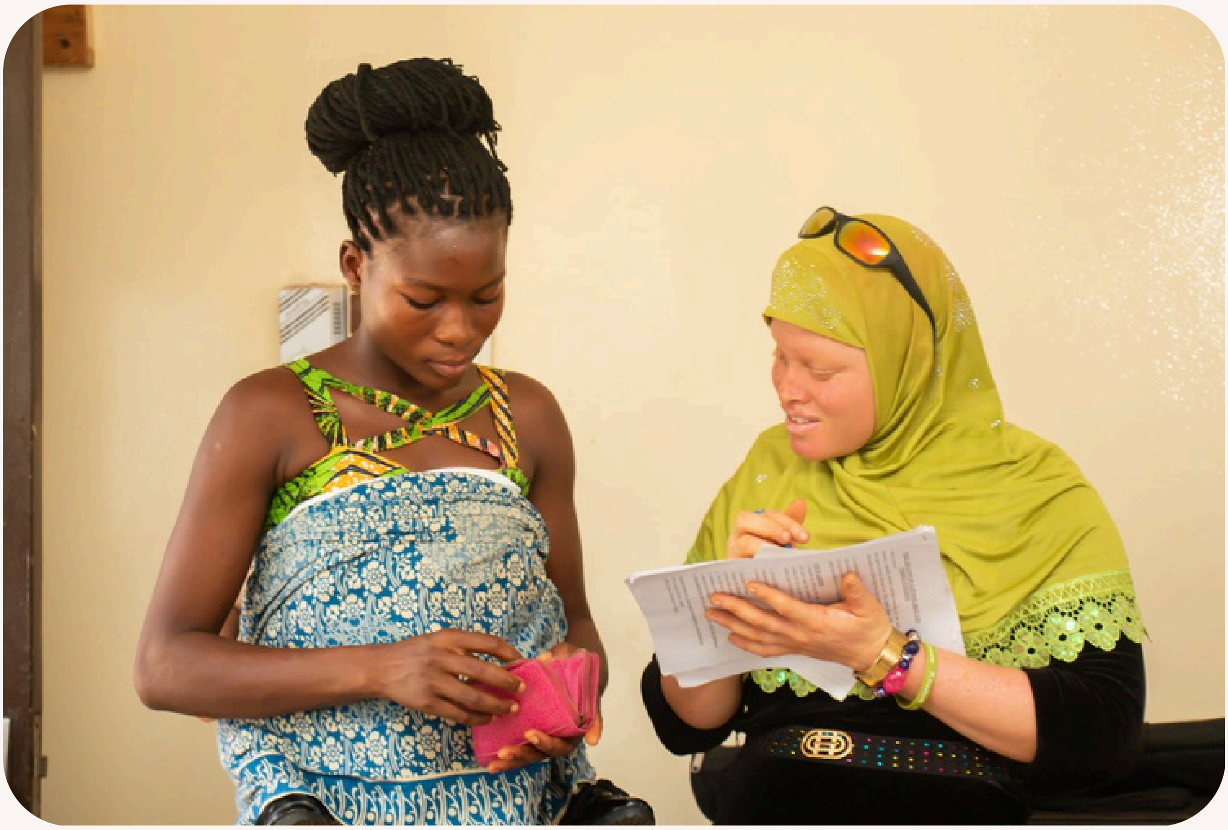
“When I was seven years old, I was herding cattle, but I went to my mother and told her that I wanted to go to school. She did not object to this and enrolled me, but I was sacked from school, and I persistently returned to school until I was accepted and officially registered in school. Unfortunately, none of the learners wanted to sit close to me. Though I could not see well in school, I was very smart and performed creditably. However, when I moved to another school, I was made to sit at the back, and I really struggled in class and therefore failed my tests.”

**"My economics teacher used to throw a marker at me every day because I had difficulty seeing the board. Every time I strained my eyes 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."**

**"Even though there are elements of special needs in the curriculum of teaching training schools, these are not detailed enough, and teachers are not orientating on special needs. Even the special education supervisors do not usually know about albinism, and therefore, they often do not show much interest in the progress of learners with albinism in schools."**

### i. Employment and Livelihood Opportunities

The intersection of discrimination and stigmatization, together with the general low socioeconomic status of persons with albinism, means that many of them have limited access to employment and other livelihood support opportunities. From the literature and interaction with persons with albinism across the country, interlocutors indicated that the challenges faced by persons with albinism to access education mean that many end up dropping out of school and, therefore, do not have the educational qualifications and skills to be able to secure gainful employment in an economy that is already reeling with high levels of unemployment among young people. For instance, the International Labour Organization reports that in Ghana, at least 29.6% of young people (between 15-29 years) with disabilities are not in employment, education, or training as compared to 22.3% of young people without disabilities.[118] The disparity is much glaring when gender is considered, with at least 32% of young males with disabilities not in education, employment, or training as compared to 19.2% of young males without disabilities. The rates are much less stark among females, with 27% of young females with disabilities not in education, employment, or training as compared to 25.3% of young females without disabilities.



Even in situations where persons with albinism can overcome the challenges faced in accessing education and completing their education, they are often discriminated against in employment because of the general stigma in society.

Thus, even well-qualified persons with albinism often face challenges in access to employment because of the general stigma and discrimination in society, which results in them being denied employment opportunities even within state institutions.

Interlocutors indicated that they have often been directly discriminated against by potential employers who doubted their competence. Other potential employers did not want to be associated with persons with albinism because of the perception that their customers or other people they provide services to would feel uncomfortable interacting with staff who have albinism.

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**[118]** International Labour Organization ‘ILO youth country briefs: Ghana’ (2023) 8, available at https://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_886402.pdf.

Return to Table of Contents

Persons with albinism who canaccess employment are often discriminated against by their colleagues who pass vile comments about them or refuse to interact with them at the workplace and sometimes face challenges getting promoted or being placed in positions of authority.

Interlocutors indicated how they have often been discouraged from seeking formal employment because they are not deemed capable of doing the job. Some interlocutors indicated that they often received negative commentary about their competence or sometimes even questioned about their ‘audacity’ to dare to think that they, too, were entitled to employment.

**One interlocutor recounted his experience as follows:**

**“In 2004, I wanted to become a poling agent for elections, and when I went for the screening, one of the recruitment officers commented and asked if I could be a poling agent. This can discourage people with albinism who are looking for employment.”**

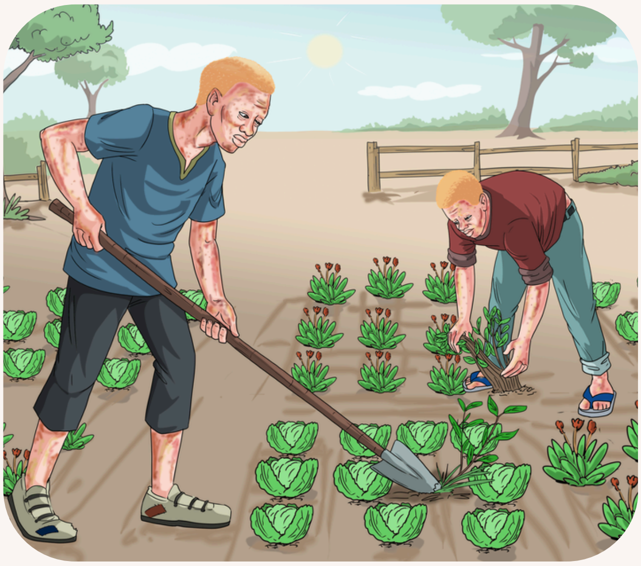
**One interlocutor recounted his experience as follows:**

**“Even now that I am working, I have faced a lot of discrimination in my workplace, and all my colleagues were promoted except me. Even though I qualify for a promotion, I have not been promoted because they do not want to see me in a position of authority.”**

Some interlocutors recounted how they were ignored during job interviews once they arrived, and the potential employer became aware of their albinism. In the limited instances where they were interviewed for job positions, interlocutors indicated that they often never received a call back for employment. Others indicated that employers have been honest about their inability to employ them because of the stigma in society, which could affect their businesses.

Interlocutors also expressed their frustration with systemic discrimination regarding recruitment into the state's security and other law enforcement agencies, where they are often excluded by blanket requirements relating to 'physical fitness'. Persons with disabilities are thus generally excluded from recruitment into the security services because of this requirement. While physical fitness including concerns with vision or ability to endure long periods outdoors may be a legitimate requirement for frontline roles in security and law enforcement agencies, there are arguably many administrative roles that can be performed without the 'physical fitness' that is often required by the security agencies and which can be performed by persons with disabilities, including those with albinism and their blanket exclusion is therefore not warranted.

Persons with albinism who graduate from technical and vocational training schools do not often have the capital to start businesses or trades. It is also often a challenge to get placement for internships that are sometimes essential requirements for their education and career, simply based on their albinism. Those who are farmers usually have challenges because they cannot work in the sun for extended periods.



Even persons with albinism who are self-employed also face challenges with their ability to gain and retain customers for their businesses or trade. Women with albinism are particularly impacted by the stigma and discrimination in employment and livelihood support activities because of the already existing patriarchal and gender biases in society and, therefore, are often forced to start their businesses.

Even persons with albinism who are self-employed also face challenges with their ability to gain and retain customers for their bus However, there is limited patronage for their businesses, especially when they are engaged in services such as vending cooked food because there is the belief that their albinism can be transmitted through eating the food they cooked.

Because of the limited employment opportunities and support to start and retain their businesses and other livelihood activities, some persons with albinism turn to begging to support themselves. Even that is a challenge sometimes because members of their communities would often not give them money for fear of being bewitched, which forces some of them to travel far distances to beg to support their livelihoods, usually putting their physical safety at risk. Others are forced to take up jobs such as farming and other forms of work that involve manual labor in the sun, further exposing them to the risk of skin cancer.

Besides the social exclusion and systemic barriers that impact the ability of persons with albinism to fully access employment, the failure of the Labour Act to expressly mandate reasonable accommodation in employment for persons with disabilities, including persons with albinism, reduces the legal avenues for redress in employment related discrimination.

**An interlocutor recounted her experience when she decided to learn the trade of hairdressing as follows:**

> **“When I dropped out of school, I decided to learn a trade as a hairdresser. I was treated badly in this apprenticeship business because I was never allowed to touch anyone’s hair. For about three years, I was not taught anything by my madam, who had agreed to train me. Later, I was told that my madam said that she would not train me even if I spent 20 years in the establishment because I am a child from the gods, and she is scared of me.”**

## j. Home and Family Life

Even though all persons with albinism of marriageable age have the right to marry and found a family just like any other adult resident in Ghana, interlocutors expressed that there are significant challenges with the family lives of persons with albinism due to stigmatization and harmful myths that members of society hold. Women with albinism are particularly affected by discriminatory practices, which affect their ability to start and sustain a family life. Persons with albinism are often rejected by family members of their partners or spouses because of the myth that albinism is bad luck and, therefore, would bring bad luck to the family or the fear that the children of the union will also be persons with albinism. Because of this stigma, men who get into romantic relationships or marry women with albinism are sometimes teased or ridiculed until they abandon the relationship. In other instances, men are only willing to get into relationships with women with albinism as long as the relationship is kept secret and not known to the public.

Women with albinism have become targets for rituals because there are rumors that sleeping with a woman with albinism can enhance opportunities, wealth, or good luck. The myths surrounding albinism also mean that women with albinism are sometimes targeted and lured into predatory relationships with men who are only interested in having sexual intercourse with them because they believe they may gain some luck spiritually or that the sensation derived from having sex with a woman with albinism may be different from others. This exposes a lot of young women and girls to predatory sexual targeting, resulting in pregnancies that are then subsequently denied by the men and or their families.

**As one interlocutor recounted:**

> **"When it comes to marriage, there are many issues because partners who do not have albinism sometimes think that they are doing the spouse with albinism a favour. I have also heard some men say that if you have HIV and you sleep with a woman with albinism, you will be cured, and I asked if that would rather not lead to the spread of the disease… I have also been approached by men who say that because of my skin colour, they want to taste us sexually to see if there is a difference. A lot of women with albinism are exposed to sexual harassment because of these beliefs."**

**Another interlocutor recounted her experience as follows:**

> **"I was once in conversation with a man who indicated that he had learned he would become rich if he married a woman with albinism, and for that reason, he married a woman with albinism, but he regretted it because he didn't become rich."**

Because women with albinism often face the challenge of being left by their male partners once they become pregnant, this has resulted in a situation where a lot of women with albinism have children with different men but usually have the sole responsibility for the nurturing and maintenance of the children.

Given that women with albinism generally face low access to employment and other livelihood support activities, this compounds their economic burden. Again, because this phenomena of sexual predation and abandonment by male partners as a result of stigma and family rejection leads to many women with albinism having multiple children with multiple men, they are sometimes perceived to be sexually promiscuous and therefore presumed unworthy or incapable of maintaining a stable family life with one partner.

In the northern parts of the country, interlocutors expressed that many women with albinism have challenges finding male suitors because of the myth that women with albinism can only get married to mallams, fetish priests, or chiefs and that any other man who marries a woman with albinism will either die early or become poor.

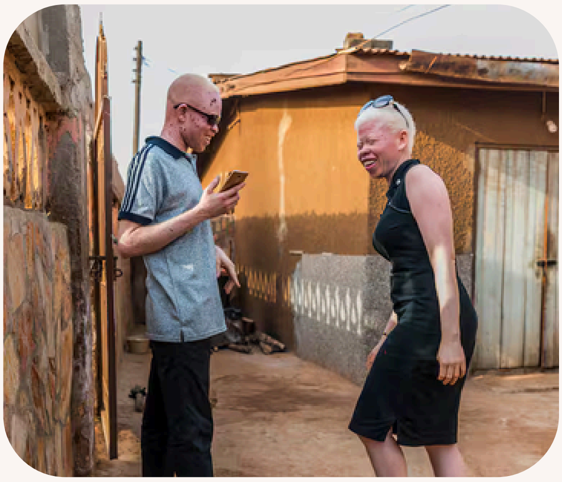
**One of the interlocutors recounted her experience as follows:**

> **"My mom told me that when I was born, the community was mocking her because they believed that she had cheated on my father and I was the result of adultery, and that is why I had albinism. But my mother had two more children with albinism, and after that, the family became convinced that they were wrong and that my mother had not cheated."**

The challenge to family life also affects women who do not have albinism but give birth to children with albinism, as this is often thought of as a curse or resulting from the woman engaging in extramarital affairs. Consequently, women who give birth to children with albinism are often rejected by their partners or spouses and the families of their spouses and left to fend for the children themselves. **One of the interlocutors shared his experience as follows:**

> **"I was born in Tema, and my father rejected paternity on suspicion that my mother had committed adultery. This resulted in the breakdown of the marriage between my parents, and I was raised singlehandedly by my mother. When my mother remarried another man, her new husband subjected me to a lot of ill-treatment. There was also discrimination in the community. When I completed Junior High School and wanted to further my education to Senior high school, my mother sent me to my father, who agreed to assist me in furthering my education. Still, he did not allow me to go out with him as he would with the other children that he had with his new wife. My father would always question me, and even when I was just sitting outside or playing with my friends, he would always ask me to go back into the house. I was also teased in school, including comments that if I was in Congo, I would have been used for money rituals."**

While men with albinism do not face challenges to their family life to the extent faced by women with albinism, there are some instances where men with albinism reported that their marriage proposals were rejected by the family of their partners who did not have albinism. One interlocutor expressed that his first romantic partner, who did not have albinism, once terminated a pregnancy because she thought that their child would be born with albinism.



Men with albinism also expressed that women with albinism do not often accept marriage or relationship proposals from them because of the perception that they have limited economic opportunities and, therefore, cannot provide for themselves or support a family. 'Some men with albinism also face sexual harassment because women want to 'taste' how it feels to have sex with a person with albinism.'[119]

## k. Right to Social Protection

Access to social protection is a general problem in Ghanaian society broadly, which places a significant burden on persons with albinism who are often poor, marginalized, and lack access to employment and other livelihood support opportunities and, therefore, should ordinarily be beneficiaries of social protection. There are three main social protection policies that the government has put in place for the benefit of persons with disabilities. While persons with albinism are not explicitly mentioned in these policies, they are beneficiaries in practice. These are the 3% share of the District Assemblies Common Fund (DACF) that is allocated for the benefit of persons with disabilities, the NHIS, and the LEAP.[120] The District Assemblies Common Fund aims to support the livelihoods of persons with disabilities. At the same time, the NHIS exempts persons with disabilities from paying premiums, ensuring they have access to some healthcare services without a charge. The LEAP, on the other hand, supports indigent persons, including persons with 'severe disabilities' through direct cash transfers.[121]

While most interlocutors indicated they could access the DACF when they needed assistance to start a trade, engage in business, or attend to educational or urgent healthcare needs that the NHIS does not cover, other interlocutors were unsuccessful. Similar views were expressed regarding the NHIS, where most interlocutors indicated that they could register or renew their membership without paying premiums if the registration was done through the district social welfare department. However, a significant minority were refused assistance, especially in districts where officials were not aware that persons with albinism qualified for these interventions.

**[119]** As recounted by one of the male interlocutors in Accra.
**[120]** UN Partnership on the Rights of Persons with Disabilities (UNPRPD 'Situational analysis of the rights of persons with disabilities in Ghana' (2022) 38.
**[121]** https://www.mogcsp.gov.gh/livelyhood-empowerment-against-poverty-leap/.

According to interlocutors, this disparity in access to these social protection policies results from the fact that even though the NCPD and other national agencies recognize albinism as a disability, this doesn't seem to have been formally communicated to officials at all levels of government. As a result, there is no general understanding among all government officials that persons with albinism are persons with disabilities.

Consequently, officials in some districts who still do not understand that albinism is a disability and, therefore, persons with albinism are entitled to these social protection initiatives often refuse to allow persons with albinism to benefit from these programmes. Some interlocutors also expressed that because persons with albinism themselves do not understand that they are persons with disabilities or, even if they have this understanding, do not want to be associated with a disability because of the general stigma in society, they often do not avail themselves to benefit from these social protection initiatives.

**An interlocutor from the Department of Social Welfare in one of the districts in the Northern Region recounted that:**

> **"Persons with albinism are regarded as persons with disabilities and, therefore, are considered for assistance under the District Assemblies Common Fund, but this is not largely patronized by persons with albinism. Persons with albinism have no awareness of the services that are available through social welfare and other state departments. Sometimes persons with albinism do not consider themselves to be persons with disabilities, and this creates a challenge sometimes."**

Even those who were able to access the NHIS indicated that they have often not benefited much from it because the medical health services that they require the most, such as sunscreen for their skin to prevent skin cancer and dermatological screening and treatment, are not covered by the NHIS. Neither does it cover specialist eyecare nor assistive devices, which they require the most.

With regards to LEAP, persons with albinism can only benefit from it if they have a 'severe disability without any productive capacity'. Consequently, most persons with albinism do not qualify to benefit from the LEAP programme.

## I. Freedom of movement and residence

Throughout the study, persons with albinism reported some impediments to their freedom of movement owing to a combination of factors. First, ritual banishment in some communities means that persons with albinism are expressly prohibited from residing in or even visiting some communities. Stories were relayed of how some interlocutors had gone to a community in the Eastern Region for an advocacy visit but were prevented from getting out of the vehicle they had travelled in with other colleagues. Community members told them they were not allowed to step on the soil of that community because the community's deities do not accept the presence of persons with albinism in the community.

**As some interlocutors recounted:**

> **"In Akwamufie, we were not even allowed to get out of the vehicle we had been driven to the town when we had gone there for an advocacy mission to engage the chiefs and traditional authorities. We were told they would not allow us to enter the town because it was taboo. At Kwahu Bukuruwa, we were told that persons with albinism were not allowed to enter the chief's palace, but since the chief's caretaker is a former police officer, he allowed us to enter. A community member subsequently informed us that when we left, they had to pour libation to appease the gods."**

Thus, persons with albinism continue to face challenges with cultural banishment on account of superstition and traditional beliefs.[122] Interlocutors reported cultural banishment in many Ashanti, Bono East, Oti, Western, and Eastern communities. Cultural banishment also means that parents (usually mothers) of children with albinism have to move out of some communities for fear of being attacked by community members.

In other communities, while persons with albinism are not generally prohibited from residing in the community, they are prohibited from accessing the chief's place and other traditional sites such as shrines, often depriving them of the right to enjoy their cultural heritage on equal terms with other members of the community.

**One interlocutor recounted 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."**

**Another interlocutor recounted his experience as follows:**

> **"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."**

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**[122]** UN Partnership on the Rights of Persons with Disabilities (UNPRPD 'Situational analysis of the rights of persons with disabilities in Ghana' (2022) 24 https://unprpd.org/sites/default/files//library/2022-11/CR_Ghana.pdf

Even in places where there is no cultural banishment, interlocutors indicated that their freedom of movement is significantly impacted because they are usually scared for their safety due to the harmful myths that they hear in society and the daily reminder that they receive from people that they are ‘walking money’ and could be used for rituals. Consequently, persons with albinism often do not travel at night and avoid generally going out in places they are unfamiliar with because of the fear of being harmed by persons who believe they can use their body parts for money rituals.

Interlocutors also shared experiences of persons with albinism being denied access to rental housing on account of harmful myths.

**One interlocutor recounted as follows:**

> **“There are times when landlords refuse to rent their houses to us because they believe persons with albinism are bad luck. My landlady personally asked me, and she indicated that she would not be successful if she did not evict me from the house. Even though I resisted at first, I moved out because I started feeling unsafe.”**

Cultural banishments and ritual attacks are rare in the country's northern belt. However, stigma and discrimination based on myths means that the family sometimes hides away many persons with albinism during family gatherings or other public events. This has a potential impact on the self-confidence and dignity of persons with albinism. Stigma and discrimination also mean that a lot of persons with albinism have grown to become shy and unable to actively participate in public discussions, even those concerning their rights and lived realities.

While a report from CHRAJ indicates that most of the persons with albinism in the communities they visited indicated that they feel safe, it acknowledges that persons with albinism at Adaprase, a community near Abease, lived in fear of being killed for rituals at Abease’.[123]

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**[123]** Commission on Human Rights and Administrative Justice (CHRAJ) ‘Systemic investigation report on alleged ritual banishment and stigmatization against persons with albinism (PWAs) in Ghana’ (2023, hereafter CHRAJ Report).

Return to Table of Contents

Additionally, while the CHRAJ report indicates that there is no general practice of ritual banishment in the communities they visited, it acknowledges that persons with albinism are prohibited from entering or taking residence in Bukuruwa, one of the target communities.'[124] The CHRAJ Report also 'establishes that there are or have been instances of non-admittance of persons with albinism in some communities as well as in some sectors of the community such as the chief's palace,'[125] confirming the insights that persons with albinism shared in the course of this study.

## M. Access to Justice

Even though several institutions exist to support persons with albinism in seeking access to justice, interlocutors in most parts of the country expressed that there is limited awareness among persons with albinism about the mandates of these institutions and how their services may be accessed to vindicate the rights of persons with albinism. This is underpinned by the generally low levels of education and access to economic opportunities among persons with albinism, which often means that they are not aware of their rights. Some interlocutors also expressed that even though they are aware of some of the mechanisms that could be utilized to access justice, they have not been keen to approach them because complaints by persons with albinism are not generally taken seriously by law enforcement authorities and other state institutions that are mandated to assist them in accessing justice.

**As one interlocutor recounted:**

> **"Many people do not know about the institutions available to protect and defend their rights and, therefore, have limited access to justice. Even for those who know about how to access justice, persons with albinism most of the time feel that their complaints are not taken seriously by the relevant authorities. Persons with albinism also do not have the financial resources to access justice sometimes, and many of the institutions that have to respond to them require the payment of some fees that they cannot afford."**

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**[124]** CHRAJ Report (on file).
**[125]** CHRAJ Report (on file).

Overall, persons with albinism in the Southern and middle belts of the country appear to have a greater awareness of access to justice institutions than their counterparts in the northern belt of the country. This has a direct correlation with the higher levels of education and access to economic and livelihood opportunities in the southern and middle belts of the country relative to the northern belt, as well as the predominantly rural nature of the Northern belt of the country, which means that the institutions are often not within proximity and/or well resourced.

**Another interlocutor expressed that:**

> **“Many persons with albinism have been so stigmatized and discriminated against. They have sometimes been stuck at home for so long they cannot communicate confidently about their issues and seek assistance.”**

Violations against persons with albinism, especially those in rural settings, are only taken seriously by law enforcement and other state agencies when disability rights activists, other civil society organizations, or the media get involved. Otherwise, persons with albinism are generally advised to disregard abuse without the relevant authorities taking complaints seriously and seeking accountability. Consequently, ‘[n]ormalized marginalization, as well as stigma, discrimination, and negative attitudes on the part of others, may be disempowering, and prevent them from pursuing complaints or initiating cases when their rights are violated.’[126]

The challenges with access to justice are impacted by the limited resources that are generally available to institutions such as CHRAJ and the Legal Aid Commission to provide avenues for redress for the violations of the rights of persons with albinism. Some interlocutors recounted that they do not seek the assistance of the Legal Aid Commission because sometimes applicants are requested to pay for fuel and other incidental costs, which they cannot afford, depriving them of access to justice.

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**[126]** DA Anyorigya ‘Daniel Anyorigya writes: Born Different; Fair skin, Golden hair and Pink lips in Ghana’ (2021) https://citinewsroom.com/2021/02/daniel-anyorigya-writes-born-different-fair-skin-golden-hair-and-pink-lips-in-ghana/#:~:text=On%20February%2017%2C%202015%2C%20the,to%20respond%20to%20such%20crimes (accessed 11 November 2023.)

Interactions with representatives of some of these institutions showed that they have a general awareness about the rights of persons with albinism and the mandate of these institutions to provide them with services to enable them to access justice, even though limited resources often hamper the ability and willingness to assist.

Even for those who are aware of the mechanisms to access justice, pursuing claims in court can be challenging because of the cost implications involved in the filing of cases, payment of bailiffs, and other process servers, which most persons with albinism cannot afford because of their generally limited access to economic resources. An interlocutor from the Judicial Service indicated that the Legal Aid Commission Act had done away with filing fees for cases filed in court through the Legal Aid Commission on behalf of indigent clients. However, this has not necessarily increased access to justice for persons with albinism because even Legal Aid Commission clients still have to bear the associated cost of litigation, including the costs of bailiffs and other process servers.

Again, access to legal aid is based on the assessment of the indigence of the applicant, which takes time. Interlocutors also expressed concern with the length of time it takes for cases to be adjudicated in court. These are coupled with the fact that persons with albinism who approach the Legal Aid Commission may also be required to bear the cost of transportation of the staff of the Legal Aid Commission to court. These costs place significant impediments in accessing justice for persons with albinism and discourage them from seeking justice through the formal justice system.

Some interlocutors also expressed that apart from the magistrate courts that provide psychosocial support to persons appearing before the courts, especially in family law issues, through the Department of Social Welfare, the judicial service does not generally offer psychosocial support, which in some instances is necessary for some persons with albinism who are shy, lack the social skills to articulate their violations or may be facing specific mental health issues.

## N. Representation and Participation

There has generally been very low participation of persons with disabilities in Ghanaian politics, often impacted by harmful cultural practices and perceptions.[127] One of the more prominent illustrations of this challenge relates to the nomination of Dr Henry Seidu Danaa, a blind lawyer, as the Minister for Chieftaincy and Traditional Affairs in January 2013. This was met with loud resistance from some chiefs, one of whom described the nomination as an ‘abomination’, on account that the customs and traditions of communities did not allow persons with disability to hold such high positions of authority.[128] This was even though the nominee was the first lawyer with blindness in the country and had worked in the same ministry as director of research for more than a decade.[129] While the objections were countered by GFD and other civil society organizations, culminating in the eventual approval of his nomination by parliament, this is illustrative of the general stigma that persons with disabilities face in accessing public office.[130] Sackey further illustrates that less than 20 persons with disabilities were elected or appointed to the district assemblies in 2013 out of a vacancy of approximately 9720.[131] This further demonstrates the very limited participation of persons with disabilities in public office in the absence of any legislative requirements for the appointment or election of persons with disabilities into designated seats. There is no indication that the situation has significantly improved over the last decade as no legislation has been passed by the parliament nor policy adopted by the executive to make provision for such ‘special’ seats for persons with albinism to encourage their participation in public political life.

That said, interlocutors indicated that persons with albinism generally have limited representation in public life and are invisible in elected or appointed political office because of stigma and discrimination. This is coupled with aggressive campaigns from political opponents, even within the same political party, who usually challenge the capabilities of persons with albinism, like other persons with disabilities, to perform in public office.

**[127]** E Sackey ‘Disability and political participation in Ghana: An alternative perspective’ (2015) 14 Scandinavian Journal of Disability Research 366 367.

**[128]** Sackey (as above).

**[129]** As above.

**[130]** As above.

**[131]** As above.

The fear of public ridicule and the general lack of confidence among persons with albinism as a result of persistent stigmatization, discrimination, and social exclusion means that most persons with albinism are unprepared to put themselves up for elected office.

**One interlocutor shared his experience as follows:**

> **"Sometimes taking leadership positions becomes difficult because even when you have the potential, those doing the screening may ignore you… Even in organisations and schools, I was always ignored whenever I put myself up for inclusion in leadership positions."**

Interlocutors also shared the story of Martin Obeng, a person with a physical disability who was nominated in 2017 to occupy the position of Chief Executive of the Sunyani West Municipal Assembly but faced fierce opposition from members of his own political party and community members who questioned the suitability of a person with a disability to lead them. The intervention of the GFD was used to resist the pressure on the president from the community and the party to prevent the withdrawal of his nomination.

**Another interlocutor recounted his experience as follows:**

> **"Recently, I have been in the leadership of an organisation, and a meeting was called so that we put a budget together, but no one attended the meeting because of me. I was forced to do the meeting alone with the team leader. People then individually sent their budgets to the team leader."**

Additionally, because political campaigns are usually costly and most persons with albinism belong to the lower socioeconomic classes of society, it is usually impossible for them to have the funding needed to compete and sustain political campaigns for elected office. Interlocutors reported being aware of a few instances where persons with albinism have contested public office at the local government level but none at the national level.

Return to Table of Contents

The challenges with accessing public office by persons with albinism also often affect their ability to occupy leadership positions in communities as chiefs and other traditional leaders because the custom in many Ghanaian communities prohibits persons with disability from accessing traditional leadership positions.

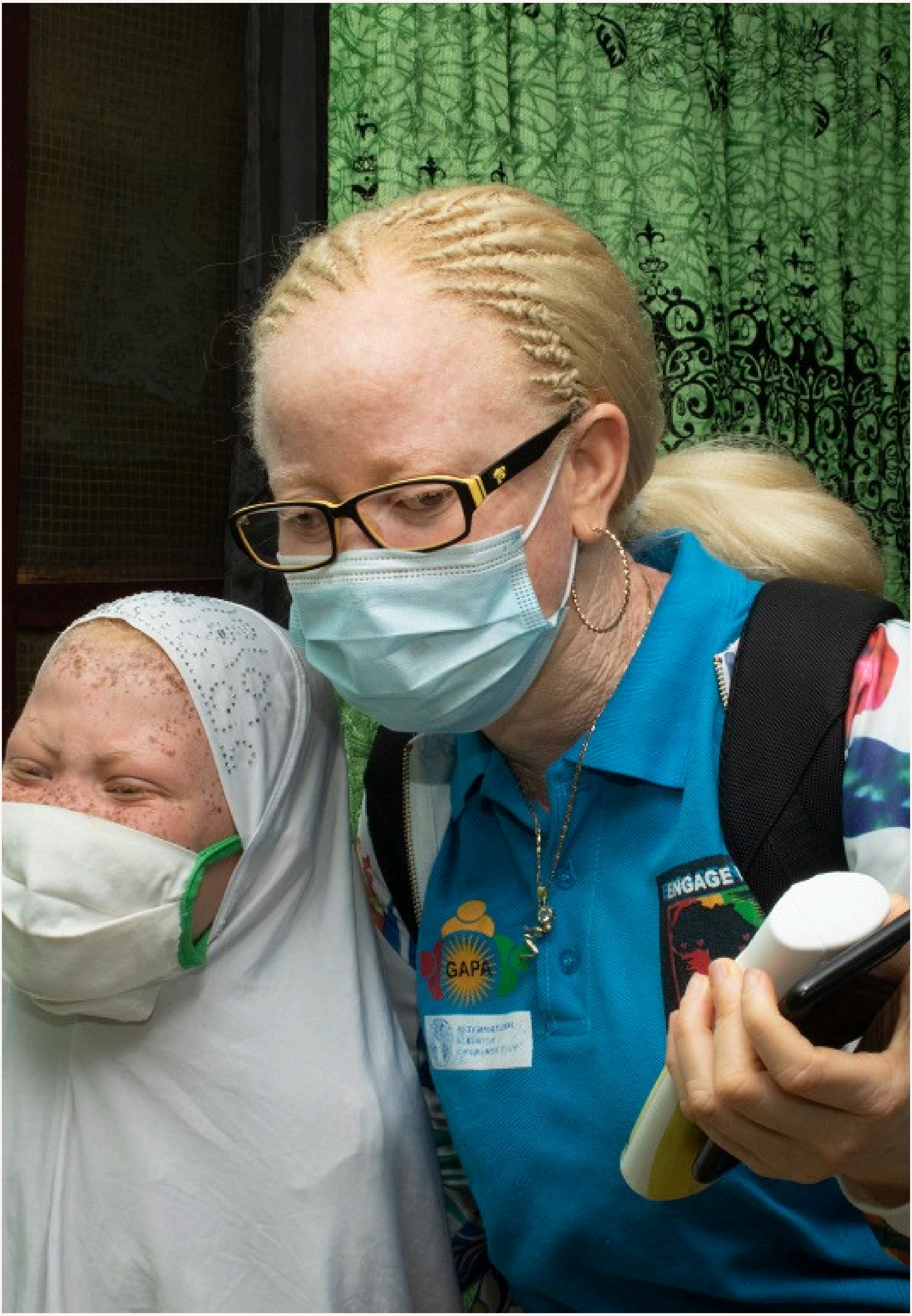
## O. Organizations representing the interests of persons with albinism

The challenges with representation and participation also affect organizations that represent the interests of persons with albinism. Interlocutors, while appreciative of the existence of the GAPA and its efforts to secure the rights of persons with albinism, expressed concern about the lack of capacity in terms of human resources and funding. Consequently, GAPA is constrained in its ability to engage in policy advocacy and awareness raising on the rights of persons with albinism. Interlocutors indicated that GAPA organizers work on a volunteer basis and the secretariat does not have permanent staff, which means that the organization cannot even distribute sunscreen that benevolent organizations have donated.

While this lack of capacity has not entirely deprived persons with albinism from being consulted in enacting laws, policies, and programming that affect their rights, such representation is often achieved through GFD, representing the interest of all the disability organizations in Ghana. Interlocutors also voiced the need to strengthen the capacity of GAPA to play a more influential role in advocacy for law and policy reform, awareness-raising campaigns, and generally representing the interest of persons with albinism, which is essential.

Interlocutors also expressed that GAPA needs to be resourced and streamline its communication structures and processes to ensure members are aware of the organization's activities.

Return to Table of Contents



Return to Table of Contents

# 6 CONCLUSION

Protecting the rights of persons with albinism in Ghana is a multi-layered issue requiring concerted efforts from various sectors and stakeholders. Strengthening the legal framework, coupled with effective implementation and awareness-raising aimed at societal attitudinal change, is essential for ensuring the well-being and rights of persons with albinism in Ghana.

Even though the government of Ghana has made some efforts towards the protection of the rights of persons with albinism, there seems to be a general lack of recognition of the challenges faced by persons with albinism, resulting in limited action towards ensuring that persons with albinism can enjoy their human rights on the same terms as other persons in society. Consequently, the governing legislative and policy framework on disability is relatively silent on the need to make specific provisions to safeguard the rights of persons with albinism. Whether out of lack of interest or the absence of advocacy by persons with albinism and their representative organizations, all the evidence leads to the conclusion that not enough has been done by the state and relevant institutions to provide for and safeguard the rights of persons with albinism. Thus, for instance, even though there is widespread knowledge in society of the discrimination and stigmatization that persons with albinism face, there has been little to no effort on the part of the government and relevant institutions to consistently raise awareness about the challenges faced by persons with albinism and the need to sensitize society about albinism and to dissuade people from perpetuating harmful myths and discriminatory practices. Civil society organizations have made some effort to fill the gap left by state neglect and inaction, even though they are also challenged by resource limitations, which places challenges on the activities they can engage in towards the protection of the rights of persons with albinism. Consequently, institutions such as CHRAJ and NCCE need to include albinism-specific programming in their mandates and raise consistent awareness in communities about albinism and the rights of persons with albinism.

Despite recent efforts such as the recognition of persons with albinism as persons with disabilities by the NCPD and therefore entitled to benefit from disability initiatives under the DACF, interlocutors expressed that there is significant ignorance among local government officials concerning the entitlement of persons with albinism to disability-related social interventions such as being able to register for free under the NHIS and livelihood support programmes under the District Assemblies Common Fund.

From the denial of primary healthcare services resulting from insufficient awareness among healthcare professionals to non-coverage of essential healthcare services and medication and other products required by persons with albinism through the NHIS, severe challenges experienced in accessing education emanating from the non-availability of assistive devices, adaptive educational materials and reasonable accommodation from teachers and educational authorities; to the threat of physical violence and the perpetuation of harmful myths; and the absence of comprehensive social protection programmes, it is clear that persons with albinism in Ghana navigate a precarious existence, marginalized and often excluded from the very fabric of society that should offer protection and support.

The findings underscore the imperative for Ghana to adopt and implement a National Action Plan that aligns with the African Union's Plan of Action on Ending Attacks and Discrimination against People with Albinism and relevant international and regional as well as constitutional and legislative human rights commitments. The National Action Plan should aim to fulfill Ghana's international and regional human rights obligations and create a more inclusive society where people with albinism can enjoy their rights fully and equally. The policy recommendations provided herein serve as a roadmap for achieving these objectives, emphasizing the need for legislative reform, capacity development among stakeholders, and robust public awareness campaigns to shift societal perceptions and behaviors.

More specifically, the study has revealed significant deficiencies in the availability and accessibility of essential services for persons with albinism, including healthcare, education, social protection, and employment opportunities. These services have to be inclusive, accessible, and sensitive to the needs of persons with albinism to ensure their full participation in societal life. This calls for an integrated approach involving government agencies, civil society organizations, and the regional and international community to ensure that the rights of persons with albinism are recognized, protected, and fulfilled.

The findings of this study call for an urgent and concerted response from all sectors of Ghanaian society. The government, civil society, the private sector, and the international community must come together to address the deep-rooted prejudices and systemic barriers that lie at the heart of the challenges faced by persons with albinism. This includes legislative and policy reforms and a shift in societal attitudes and beliefs about albinism.

Effective programming for the rights of persons with albinism will require a holistic, coordinated, multi-sectoral, and inclusive approach that recognizes the dignity and worth of every individual, regardless of their physical appearance, to ensure the rights and well-being of persons with albinism are protected and promoted. By taking decisive action to implement the recommendations outlined in this report, Ghana can make significant strides toward ensuring that persons with albinism are protected, respected, and empowered to lead fulfilling lives. The journey ahead is undoubtedly challenging, but with commitment, collaboration, and compassion, it is possible to create a more just and equitable society for persons with albinism in Ghana. Consequently, the following recommendations are made to improve the lives and livelihoods of persons with albinism in Ghana.

**Return to Table of Contents**

# 7 RECOMMENDATIONS

### 1. National Action Plan on Albinism

The government of Ghana must adopt a National Action Plan (NAP) on persons with albinism in line with the Africa Union Plan of Action of Albinism (2021-2031), outlining the critical measures that need to be put in place, inclusive of the legislative, policy, institutional framework, and programmes that will be marshaled towards the respect for, protection of, and fulfillment of the rights of persons with albinism in Ghana, including the necessary implementation plan and required budget. The NAP should emphasize a multi-sectoral and coordinated approach to ensure the efficiency and coherence of responses from the relevant implementing institutions.

The adoption of the NAP by the Ghanaian government will demonstrate its commitment to protecting the human rights of persons with albinism as the duty bearer. It will also ensure that persons with albinism, who are often further marginalized within the disability community, have specific measures in place to prevent them from being left behind, in line with the UN CRPD and the Africa Disability Protocol. The Ministry of Gender, Children and Social Protection, through its Department of Social Welfare and its agency, NCPD, which is responsible for proposing and updating policies on disability, should collaborate with organizations of persons with disabilities (including those with albinism), other government Ministries (particularly the Ministry of Health and Education), development partners, and other stakeholders, to develop a NAP that raises awareness in the medium to long term, and safeguards the rights of persons with albinism, who have long been marginalized.

### 2. Legislative and Policy Reform

The study has shown that significant gaps exist between the existing legislative framework and Ghana's international, regional, and constitutional human rights commitments, necessitating comprehensive reforms. This should include the complete overhaul of the Persons with Disabilities Act to comply with the Convention on the Rights of Persons with Disabilities (CRPD) and the Protocol to the African Charter on the Rights of Persons with Disabilities in Africa. The revised Act should explicitly recognize albinism as a category of disability and a supporting National Action Plan should provide specific measures for them, including specific programming, dedicated budgeting and reasonable accommodation measures as has been done in Malawi, Kenya, Uganda, to name a few. In essence, the new Act should adopt a CRPD-aligned, human rights-based approach, defining disability in relation to impairments, barriers, and the state's duty to remove these barriers.

The reenacted Persons with Disability Act should be accompanied by regulations to operationalize its provisions to avoid the fate that has befallen the current Persons with Disabilities Act, which has remained largely unimplemented because of the absence of implementing regulations.

### 3. Data Collection

The absence of comprehensive data on the population of persons with albinism, their educational, healthcare, social protection, access to justice, and other needs deprives the state of essential information required for planning and implementing needed interventions. The state and its agencies particularly the Ghana Statistical Services (GSS) should intentionally collect and store comprehensive disaggregated data on persons with albinism and their needs to adequately plan and budget.

### 4. Awareness-Raising

There is a pressing need to enhance public awareness and understanding of albinism through education and sensitization campaigns using media and other community and social platforms, including religious institutions, to provide accurate information about albinism to dispel harmful myths and beliefs. These campaigns should aim to dismantle the myths and superstitions surrounding albinism and promote a more inclusive and accepting society. The media, educational institutions, the health sector, and cultural, religious, and community leaders play a crucial role in shaping societal attitudes and must be partners in this effort. Other responsible agencies include the Information Services Department (ISD) and the National Commission for Civic Education (NCCE).

Awareness-raising should be mainstreamed, including ensuring that the educational curriculum contains lessons on human diversity and inclusion, which will provide essential knowledge to learners from the primary school to the secondary school level on various issues of human diversity, including albinism, to ensure that the sensitization begins from childhood. This will, over time, provide essential information to a significant part of the population that goes through the formal educational system and help curtail the perpetuation of myths and harmful beliefs, which has a significant impact on the rights of persons with albinism. Awareness-raising campaigns should also target parents of children with albinism, who should be empowered to be advocates for the rights of their children with albinism. Finally, awareness-raising campaigns should also touch on the accessibility needs of persons with albinism, including issues relating to staircases (rather than rumps), slippery tiled floors, and poor lighting, which impedes accessibility to the physical environment.

### 5. Harmful beliefs and practices

The state needs to tackle harmful beliefs and practices, especially those that put the lives and bodily integrity of persons with albinism at risk, as well as those that deprive them of the ability to live in the communities they choose, such as cultural banishment. Traditional leadership such as national and regional houses of chiefs are important in addressing the challenges affecting the rights of persons with albinism. As leaders of society, they must ensure that the rights of persons with albinism are protected and respected in their communities and that community norms are inclusive. Additionally, as custodians of the traditions and customs of communities, they need to be sensitized and, where possible, recruited as allies to reform traditional beliefs and practices that have harmful impacts on the lives and livelihoods of persons with albinism.

### 6. Capacity Development

Effective implementation of programmes for the benefit of persons with albinism will only be sustained if all the relevant stakeholders have a common understanding of the issues. It is therefore important to build the capacity of relevant institutions, including those involved in providing support services to persons with albinism, such as CHRAJ, Legal Aid Commission, Ghana Health Service, Ghana Education Service, the Department of Social Welfare, and law enforcement agencies. Such capacity development should comprehensively cover the issues that affect persons with albinism and the relevant legislative, policy, programmatic, and administrative responses that are to be deployed to address those challenges.

### 7. Healthcare

In terms of healthcare, the report underscores the necessity of making healthcare services accessible and sensitive to the needs of persons with albinism. This includes training for healthcare professionals on the specific health risks faced by persons with albinism, provision of affordable sunscreen and skin cancer screening and treatment and ensuring that persons with albinism have access to visual aids and other assistive devices, which the NHIS should ideally cover. Frequent and regular access to dermatologists for skin cancer prevention, ophthalmologists for low vision consultations, and oncologists for skin cancer management should be ensured in health facilities across Ghana.

Healthcare professionals should also be sensitized to write dosage instructions legibly and in large fonts for persons with albinism, who often have visual impairments. Illegible prescriptions and dosage instructions can result in treatment errors, overdosing or underdosing, which can further deteriorate the health conditions of individuals with albinism. Relevant government agencies responsible to ensure these measures include the Ministry of Health, Ghana Health Services, Korle-Bu Teaching Hospital, Okonfo Anokye Teaching Hospital, and Tamale Teaching Hospital.

### 8. Education

The education system also requires significant reform to accommodate the needs of persons with albinism. This entails the provision of inclusive education from enrollment to examination. This would require that school administrators and teachers be capacitated to enquire from learners at all levels of education if they have any form of disability and the support they will need to fully benefit from education. This must also include reasonable accommodation for persons with albinism, such as adaptive learning materials (including larger fonts), access to assistive technologies, and a curriculum that promotes understanding and acceptance of diversity. The effectiveness of such efforts will only be possible if teachers and educational authorities fully understand the needs of learners with disabilities to create an inclusive environment that allows them to attain the best educational outcomes. Teachers must, for instance, understand that some learners with albinism may not be able to read from a chalkboard or white marker board even if they sit close to the board and, therefore, the need to devise other means of making their lessons accessible to learners with albinism. Continuous in-service training for educators is essential to ensure they can continue supporting learners with albinism.

The discrimination and bullying of children with albinism in school should also be prioritized and addressed to ensure that learners with albinism can benefit from education. Finally, monitoring and evaluation of the implementation of the Inclusive Education Policy should be prioritized to ensure deficiencies are promptly identified and addressed. Responsible government entities include the Ministry of Education and Ghana Education Services.

### 9. Employment and Livelihoods

The employment sector must be more inclusive, offering equal opportunities for persons with albinism. Legislative reform is required to ensure that the Labor Act explicitly mandates reasonable accommodation for employees with disabilities and to provide penalties for employers that engage in discriminatory practices against persons with disabilities in employment. Employers should also be encouraged to adopt non-discriminatory hiring practices and create a supportive work environment for persons with albinism. This includes training for staff on diversity, equity, and inclusion, as well as providing reasonable accommodation to enable persons with albinism to perform their jobs effectively. The State should also consider providing incentives to organizations and institutions that employ persons with disabilities, including persons with albinism. Within the public sector, the state should consider introducing disability quotas to ensure the employment of suitably qualified persons with disabilities, including those with albinism, into the public sector.

Additionally, livelihood opportunities can be provided for persons with albinism through grants to support those who want to engage in learning a trade or engaging in business. Finally, the state needs to address systemic discrimination against persons with disabilities, including those with albinism, in the security services, where they are often excluded on the grounds of ‘physical fitness’ on account of low vision or inability to work outdoors for extended periods. While physical fitness may be essential for many frontline roles in security services, many administrative roles do not require ‘physical fitness’. They thus can be easily performed by persons with disabilities, including those with albinism.

### 10. Social Protection

The government’s social protection policies, such as LEAP, should be expanded to ensure that support is provided to persons with disabilities, including those with albinism who have no employment or other livelihood support opportunities. As the study shows, there are at least 25% of young people with disabilities in Ghana not in employment, education, or training, which means that the only way they can sustain their livelihoods is through dependence on families, community members, or other benevolent organizations.

This coupled with the continued stigma and discrimination that deprives persons with albinism of employment and livelihood support opportunities, has a significant impact on their lives and dignity and should be recognized and addressed through social grants such as those provided under LEAP. The government, particularly the Department of Social Welfare under the Ministry of Gender, Children and Social Protection, should, therefore, consider expanding LEAP to cover all persons with disabilities who have no dignified source of income or support, rather than the very restrictive framing at the moment where only persons with disabilities who have severe disabilities without any productive capacities are provided social grants.

### 11. Access to Justice

With regard to access to justice, sensitization should be targeted at both the demand and supply sides of the issue. On the demand side, this will involve sensitizing persons with albinism to understand their rights and the institutional arrangements established to facilitate their ability to access justice. On the supply side, the justice institutions actors should be trained on issues relating to albinism and the rights of persons with albinism, their peculiar justice needs, and how to assist them in a manner that is humane, dignifying, and prioritizes their well-being. Institutions should also be supported with the human resources and necessary budgets to effectively execute their mandates, including providing psychosocial support to persons with albinism who come into contact with the justice system.

### 12. Political Participation and Representation

On the issue of political participation, affirmative action policies need to be put in place to ensure that quotas are provided to persons with disabilities, including those with albinism, in elections and appointments into the public sector. Kenya for instance reserves 5% of the seats in the Senate, National Assembly and County Assemblies for persons with disabilities, which Ghana can learn from. While consideration should be given to the enactment of legislation to ensure legislative quotas for persons with disabilities, including persons with albinism, as part of affirmative action, the lowest-hanging fruit that can be immediately realized is the appointment of persons with albinism to the district assemblies to enhance visibility in public/political spaces to encourage higher participation of persons with albinism. This will be bolstered if representative organizations such as GAPA are capacitated to advocate for the rights of persons with albinism and ensure their participation in all private and public life spheres. Government, non-governmental and development partners could play a crucial role in this regard.

Return to Table of Contents

**Thank you for taking the time to read this report.**

Africa Albinism Network

GAPA