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Access to Healthcare for Persons with Albinism in Ghana A Human Rights Approach

HRDA, The Master's Programme in Human Rights and
Democratisation in Africa

ANDREWS KWAME DAKLO

ACCESS TO HEALTHCARE FOR PERSONS WITH ALBINISM
IN GHANA: A HUMAN RIGHTS APPROACH

FOREWORD

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- Tisi, Alessandra, *Patent rights or patient rights? An Assessment of Intellectual Property and Right to Health within the Covid-19 Pandemic*, Supervisors: Steven L. B. Jensen, Danish Institute for Human Rights and Lars Binderup University of Southern Denmark. European Master's Programme in Human Rights and Democratisation (EMA), coordinated by Global Campus of Human Rights Headquarters.

This publication includes the thesis *Access to Healthcare for Persons with Albinism in Ghana: A Human Rights Approach* written by Andrews Kwame Daklo and supervised by Annette Lansink, University of Venda (South Africa) and Charles Ngwena, University of Pretoria.

BIOGRAPHY

Andrews Kwame Daklo is a person with albinism and a disability rights advocate with a focus on albinism. He is the current Albinism Program Coordinator at Engage Now Africa and the Communications Officer for Africa Albinism Network. Kwame holds a BA Social Studies degree from the University of Education, Winneba and MPhil in Human rights and democratisation in Africa from the University of Pretoria. Kwame has six years of advocacy experience on the rights of persons with albinism in Ghana and beyond. He is a YALI RLC Alumni as well Obama Foundation Leaders Africa program participant.

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ABSTRACT

The realisation of the right to health is crucial to the survival of everyone, including persons with albinism in Ghana. Access to healthcare facilities, goods and services is fundamental to the enjoyment of this right which is closely connected to the enjoyment of the right to life by persons with albinism. Against the backdrop of international human rights law, this study critically examines Ghana's domestic legal frameworks and institutional arrangements for respecting, promoting, protecting and fulfilling the rights to health for persons with albinism. It identifies barriers hindering access to healthcare and enjoyment of the right to health, including legal and policy constraints, lack of health-related information, reasonable accommodation, and harmful practices. The study proposes legal, policy and institutional reforms and intensive public education to address these barriers. It draws on best practices from other African countries to realise the right to health of persons with albinism.

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TABLE OF ABBREVIATIONS

African Charter	African Charter on Human and Peoples' Rights
AU	African Union
BCC	Basal cell carcinoma
CESCR	Committee on Economic, Social and Cultural Rights
CHPS	Community-Based Health Planning Services
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil society organisation
GAPA	Ghana Association of Persons with Albinism
HIV/AIDS	Human Immunodeficiency Virus/Acquire Immune Deficiency Syndrome
HPS	Hermansky-Padlak Syndrome
ICESCR	International Covenant on Economic, Social and Cultural Rights
NASSP	National Albinism Sunscreen Support Program
NCPD	National Council on Persons with Disabilities
NGO	Non-governmental organisation
NHIS	National Health Insurance Scheme
NOAH	National Organization for Albinism and Hypopigmentation
OA	Ocular albinism

OCA	Oculocutaneous albinism
RDTC	Regional Dermatology Training Centre
SCC	Squamous cell carcinoma
SCPP	Skin Cancer Prevention Programme
SPF	Sun protection factor
UN	United Nations
UV	Ultra violet
WHO	World Health Organization

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ANDREWS KWAME DAKLO

DEDICATION

To my daughter (Nusinyo T Daklo), my wife (Mavis A Daklo) and all
women and children with albinism in Africa.

1.

INTRODUCTION

1.1 INTRODUCTION

Albinism is an inherited genetic condition that results in a lack of melanin in any or all of the skin, hair or eyes. Both parents must be carriers of a recessive gene to pass it onto their offspring resulting in little or non-production of pigment.¹ Albinism affects both genders and can be found in all ethnic and racial groups across the globe.² The lack of pigmentation presents various health concerns, such as visual impairment and skin-related challenges, including skin cancer.³ Other challenges associated with the condition include systematic and structural discrimination, stigmatisation, social exclusion and more serious ones such as ritual attacks and killings, maiming, infanticide⁴ and cultural banishment.⁵

Several types of the condition exist, with oculocutaneous albinism (OCA) identified as the most common type in Africa, affecting the eyes, the skin and the hair.⁶ OCA poses significant health risks to individuals with the condition due to the raging tropical sun beating mercilessly on the melanin deficient skin of the affected population. These health risks

¹ Human Rights Council (HRC), 'Persons with albinism. Report of the Office of the United Nations High Commissioner for Human Rights' (2013) A/HRC/24/57 para 10.

² *ibid* para 11.

³ ES Hong, H Zeeb and M Repacholi, 'Albinism in Africa as a public health issue' (2006) 6 BMC Public Health 212 DOI: 10.1186/1471-2458-6-212. 115.

⁴ Human Rights Council (HRC), 'Preliminary study on the situation of human rights of persons with albinism' (2014) A/HRC/AC/13/CRP.1 paras 10-12.

⁵ Ghana Association of Persons with Albinism (GAPA), 'Ritual banishment and stigmatization of persons with albinism in Ghana. A contextual analysis report' (GAPA 2019) 12 <<https://actiononalbinism.org/api/files/1564577071633r4nwvrgc26e.pdf>> accessed 8 July 2021.

⁶ Hong, Zeeb and Repacholi (n 3) 1.

such as skin cancer and visual impairment require consistent, adequate and appropriate healthcare services readily accessible, available, acceptable and of good quality to persons with albinism.⁷ In addition, these services will enable them to manage and live with the condition that requires lifelong management.⁸

Unfortunately, persons with albinism have lacked access to healthcare services appropriate to their health needs because of structural and systemic discrimination, stigma and lack of knowledge on the condition.⁹ These social factors pose a significant violation of their right to an attainable standard of physical and mental health as enshrined in article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR),¹⁰ article 25 of the Convention on the Rights of Persons with Disabilities (CRPD),¹¹ article 16(1) of the African Charter on Human and Peoples' Rights (African Charter)¹² and article 17(1) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.¹³

1.2 BACKGROUND

Persons with albinism face multiple intersecting challenges in accessing education, employment, legal protection and healthcare due to structural discrimination, marginalisation and stigma coupled with

⁷ CESCR, 'General Comment No 14: The right to the highest attainable standard of health' (2000) E/C/12/2000 para 12.

⁸ Hong, Zeeb and Repacholi (n 3) 5-6.

⁹ S Reimer-Kirkham and others, 'Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights: a scoping review' (2019) 34(5) *Disability & Society* 747, 759 DOI: 10.1080/09687599.2019.1566051.

¹⁰ International Covenant on Economic, Social and Cultural Rights (Adopted 16 December 1966, entered into force 3 January 1976) (ICESCR) art 12(1): 'The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.

¹¹ Convention on the Rights of Persons with Disabilities (adopted on 13 December 2006, entered into force on 3 May 2008). (CRPD) art 25: 'states Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'.

¹² African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 (African Charter) art 16(1): 'every individual shall have the right to enjoy the best attainable state of physical and mental health'.

¹³ Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disability 2018 art 17(1): 'every person with a disability has the right to the highest standard of health'.

social exclusion emanating from societal prejudices and stereotypes.¹⁴ In addition, ritual attacks, harvesting of body parts and killings of persons with albinism for ritual purposes result in this population's 'nasty, brutish and short' lives.¹⁵ The United Nations (UN) Human Rights Council described the situations of persons with albinism as follows:¹⁶

if they survive infanticide at birth, they face a constant threat of physical attacks. Should they survive those physical threats, they are unlikely to be educated, owing to the absence of reasonable accommodation for their poor eyesight. A lack of education leads to unemployment or employment outdoors in the sun, vulnerable to developing skin cancer.

The situations described above are not different from what persons with albinism go through in Ghana. It is commonplace to state that discrimination, stigma and societal prejudices against persons with albinism abound. These are manifested in everyday practices and attitudes such as name-calling, ritual banishment from communities, infanticide and abandonment of children.¹⁷ Persons with albinism lack reasonable accommodation in education, eluding them access to jobs that will keep them in the shade.¹⁸ Lack of knowledge on albinism among health workers and persons with albinism contributes to this population's deteriorating health conditions in Ghana and Africa.

Lack of education, misguided beliefs, poverty, systemic and structural discrimination and social exclusion makes it difficult for persons with albinism to access adequate healthcare in Ghana. The 1992 Constitution of Ghana, the Persons with Disability Act¹⁹ and the National Health Policy²⁰ are silent on albinism as a disability requiring appropriate healthcare. Furthermore, the National Health Insurance Act²¹ covers no part of persons with albinism's specific healthcare needs. Skin cancer surgeries, radiotherapy and chemotherapy services, and the acquisition of lenses and other optical aids must be paid for, which most persons with albinism cannot afford. As it stands, Ghana can only boast

¹⁴ HRC 'Persons with albinism' (n 1) paras 26-27.

¹⁵ *ibid* para 27.

¹⁶ *ibid* para 27.

¹⁷ GAPA (n 5) 12.

¹⁸ HRC 'Persons with albinism' (n 1) para 27.

¹⁹ The National Disability Act 715 of 2006.

²⁰ National Health Policy Revised Edition (2020).

²¹ National Health Insurance Act 852 of 2012.

of 23 dermatologists serving a population of over 30 million.²² These conditions, coupled with inadequate health facilities, robs persons with albinism of the right to an attainable standard of physical and mental healthcare appropriate to their specific health needs.

This study seeks to assess the constitutional, legislative, policy and institutional framework available to respect, protect, promote and fulfil the rights to health in Ghana and how these frameworks reflect the rights to health of persons with albinism under international human rights law.

1.3 PROBLEM STATEMENT

Melanin deficiency in persons with albinism poses a significant public health concern across Africa.²³ This is because the condition predisposes them to health risks such as visual and skin problems, including skin cancer,²⁴ bowel and lung, diseases and excessive bleeding common in Hermansky-Padlak Syndrome (HPS) – a rare type of albinism. Research indicates that, in Sub-Saharan Africa, 90% of persons with albinism die before the age of 40 due to skin cancer,²⁵ and almost all persons with albinism have varying degrees of visual impairment.²⁶

Ghana is located a few degrees north of the equator, with daily sunshine ranging between six to seven hours. The tropical climate with temperatures ranging from 25 to 35 degrees Celsius poses a significant challenge for Ghanaians with albinism. The sun's ultraviolet (UV) radiations have been identified as the main causative factor for skin cancer among persons with albinism.²⁷ Lack of information on albinism and the need to protect oneself from the sun and lack of access to sunscreen lotions and protective clothing leaves persons with albinism exposed

²² E Smith-Asante, 'Only 23 dermatologists in Ghana; Rabito plans a rescue' (*Graphic Online*, 16 October 2018) <www.graphic.com.gh/news/health/only-23-dermatologists-in-ghana-rabito-plans-a-rescue.html> accessed 24 September 2021.

²³ Hong, Zeeb and Repacholi (n 3) 4.

²⁴ PT Lekalakala and others, 'Oculocutaneous Albinism and Squamous Cell Carcinoma of the Skin of the Head and Neck in Sub-Saharan Africa' [2015] *Journal of Skin Cancer*. 2015; 2015:167847. Epub 2015 Aug 12. PMID: 26347819; PMCID: PMC4549604.

²⁵ HRC, 'Preliminary study' (n 4) para 22.

²⁶ *ibid* para 5.

²⁷ SK Kiprono, MC Baraka and H Beltraminelli, 'Histological review of skin cancers in African Albinos: a 10-year retrospective review' (2014) 14 *BMC Cancer* 157, 1.

to ultra violet (UV) radiation, increasing their risks and vulnerability to developing skin cancer.²⁸ In addition, poverty, lack of education resulting in unemployment or employment outdoors, discrimination and lack of adequate, affordable and accessible healthcare services are responsible for the high incidence rate of skin cancer among persons with albinism.²⁹ In Ghana, skin cancer cases get to the health facilities at an advanced stage due to a lack of knowledge or finance.³⁰

Observations indicate that many skin cancer patients reach out to primary health facilities with recurrent skin problems. However, they are wrongly diagnosed. In most cases, patients complained of being administered antibiotics and creams. However, they are not taken through further procedures to establish the cause of the problem, leaving these skin lesions to develop and spread to other organs. Studies indicate that skin cancer among persons with albinism is 1,000 times greater than in the general population, with the head and neck being the most affected areas.³¹

Since the eyes of persons with albinism lack natural protection, penetration of sunlight and other sources of light cause impaired vision, Nystagmus,³² strabismus³³ and continuous deterioration of vision of persons with albinism by age are standard features among this population. Surgeries and corrective lenses are required to enable them to function with little or no support. Right sunglasses and wide-brimmed hats help to shade off direct lights from reaching the eyes. However, access to these services lacks accessibility, availability, affordability and quality.

Aside from these health conditions, discrimination, stigma, harmful cultural practices and beliefs impede persons with albinism from accessing the required healthcare services. Furthermore, structural and systemic discrimination results in a lack of data and policies covering issues relating to albinism. Consequently, this results in a

²⁸ Human Rights Council (HRC), 'Report of the Independent Expert on the enjoyment of human rights by persons with albinism: A preliminary survey on the root causes of attacks and discrimination against persons with albinism' (2016) A/71/255 para 69.

²⁹ *ibid.*

³⁰ W Thompson-Hernández, 'The Albino Community in Ghana: "I'm Motivated to Believe That I Can Survive"' (*The New York Times*, 9 June 2018) <www.nytimes.com/2018/06/09/world/africa/living-with-albinism-in-ghana.html> accessed 24 July 2021.

³¹ CR Marcon and M Maia, 'Albinism: epidemiology, genetics, cutaneous characterization, psychosocial factors' (2019) 94(5) *Anais Brasileiros de Dermatologia* 503.

³² Continuous involuntary eye movement causing impaired vision.

³³ Also known as 'crossed eyes', this is the condition in which both eyes do not line up with each other.

lack of awareness of the condition, further strengthening stigma, social exclusion and marginalisation. Additionally, the lack of legal and institutional frameworks on the rights to health of persons with albinism coupled with other social factors makes it difficult for these individuals to enjoy the highest attainable standard of physical and mental health, thus violating their rights to health enshrined in international human rights law.

1.4 RESEARCH OBJECTIVES

This study aims to examine:

- I. The healthcare needs of persons with albinism in Ghana;
- II. The legal and institutional framework on the rights to access to health by persons with albinism in Ghana and their conformity to international human rights law;
- III. The measures to be taken to protect, promote and fulfil the rights to health by persons with albinism under international human rights law and best practices.

1.5 SIGNIFICANCE OF THE STUDY

There is a dearth of literature on the rights to health of persons with albinism in Ghana; thus, this study will contribute to filling this gap. Furthermore, this study will be of great significance to the Ministry of Health, Ghana Health Service and the Government of Ghana in drawing their attention to the health needs of persons with albinism, thus shaping policy formulation, implementation and service provision on the rights to health of persons with albinism. It will also be an advocacy tool for civil society organisations (CSOs) and non-governmental organisations (NGOs) working on albinism related issues to help advocate for the rights of persons with albinism in the country. Subsequently, it will provide persons with albinism the needed understanding of their rights to health and Ghana's international and constitutional obligations to respect, protect, promote and fulfil their health rights, thus enabling them to advocate and demand their rights.

1.6 RESEARCH QUESTIONS

The overall research question is whether Ghana's constitutional, legislative, policy and institutional framework of the right to health for persons with albinism complies with its international human rights obligations. To answer this question, the following sub-questions will be addressed:

- I. What are the healthcare needs of persons with albinism in Ghana?
- II. How do the constitutional, legislative, policy and institutional frameworks on the right to health in Ghana reflect international human rights standards on the right to health for persons with albinism?
- III. How can deficiencies in healthcare provision for persons with albinism in Ghana be brought in line with Ghana's international obligations and best practices?

1.7 METHODOLOGY

This study adopts a qualitative research method that involves desk research of primary sources of data, including national laws, policy documents, relevant international human rights instruments and other normative frameworks related to the study. In addition, other secondary sources such as academic articles, journal publications and mainstream media and news publications relevant to the study were consulted.

1.8 SCOPE AND LIMITATIONS

This study focuses on the rights to health of persons with albinism in Ghana. It is limited in scope to Ghana, its international human rights obligations and how these are reflected in its national legal and institutional framework. The research method adopted for the study does not involve interviews with persons with albinism or organisations of or working for persons with albinism due to limited time available to the research and the processes involved in getting approval for conducting empirical research. The study is limited to documents available and

related to the study at the research time. It is worthy to note that the researcher is a person with albinism and an advocate for the rights of persons with albinism; thus, his personal views and lived experiences on issues relating to the study may surface in some instances. Finally, this dissertation is submitted for MPhil and not an LLM degree.

1.9 LITERATURE REVIEW

1.9.1 *Types of albinism*

There are two significant albinism types: oculocutaneous albinism (OCA) and ocular albinism (OA).³⁴ According to Hong, Zeeb and Repacholi, OCA is a heterogeneous group of genetic conditions characterised by hypopigmentation of the skin, hair and eyes resulting from inadequate or no melanin production.³⁵ OCA affects the skin, hair and eyes and is categorised into seven sub-types – OCA1 to OCA7.³⁶ According to the National Organization for Albinism and Hyperpigmentation (NOAH), OCA1 results from a defect in the enzyme tyrosinase, which helps the body transform the amino acid tyrosine into pigment. There are two subtypes of OCA1, and individuals affected by OCA1a produce no melanin leaving them with white hair and very light skin. Those having OCA1b produce a small amount of melanin leading to blond or light brown hair with slightly pigmented skin.³⁷

OCA2, also known as the P gene, is common among Africans. People with OCA2 produce some melanin and can have hair colours ranging from light blond to brown.³⁸ People with OCA3 produce a substantial amount of melanin, while those with OCA4 have a similar level of melanin production as OCA2. OCA5, 6 and 7 are recently discovered and considered very rare.³⁹ Lekalakala and others summarise the OCA as follows:

³⁴ HRC 'Persons with albinism' (n 1) para 12.

³⁵ Hong, Zeeb and Repacholi (n 3) 1.

³⁶ *ibid.*

³⁷ National Organization for Albinism and Hyperpigmentation (NOAH), 'What is Albinism?' <www.albinism.org/information-bulletin-what-is-albinism/> accessed 14 July 2021.

³⁸ *ibid.*

³⁹ *ibid.*

At birth, persons with the different phenotypic forms of OCA have white hair and very pale and pink-white skin. Those with OCA1a, OCA2, OCA3, or OCA4 will acquire some pigmentation during life, but those with OCA1a will remain completely unpigmented. The degree of pigmentation associated with the OCA 5-7 phenotype is not clear.⁴⁰

OCA is the most visible type of albinism seen across Africa. Individuals with OCA are strikingly different in complexion from the general African population, while people with OA, which affects only the eyes, are predominantly common among males.⁴¹ People with OA have pigmented skin as the general population, aside from their non-pigmented eyes, which affects their vision.⁴² OA is caused by a mutation in the X chromosome; since males have only one X chromosome, any alteration in it causes OA. Like OCA, people with OA suffer from eye conditions such as nystagmus, photophobia and strabismus due to a lack of melanin in the eyes. Other rare types of the condition include HPS, which comes with multiple health complications such as lung and bowel diseases, bruising and bleeding, Chediak-Higashi Syndrome⁴³ and Griscelli Syndrome.⁴⁴

1.9.2 Prevalence of albinism

Albinism is a global phenomenon occurring in all ethnic and racial groups in all countries worldwide.⁴⁵ However, the prevalence rate of the condition varies from region to region, and variation also exists in different ethnic groups.⁴⁶ While some present a very high prevalence rate, others are low in occurrence. Close consanguinity has been identified as a contributory factor to the high prevalence rate among some ethnic groups worldwide.⁴⁷ In the United States of America, the prevalence rate is estimated to be approximately one in 18,000 to

⁴⁰ Lekalakala (n 24) 2.

⁴¹ NOAH (n 37).

⁴² *ibid.*

⁴³ Chediak-Higashi Syndrome (CHS) is a rare inherited immune disorder characterised by reduced pigment in skin and eyes, immune deficiency and easy susceptibility to infections, bruising and bleeding. Griscelli Syndrome also affects the immune system and patient die in childhood.

⁴⁴ NOAH (n 37).

⁴⁵ Human Rights Council, 'Visit to South Africa, Report of the Independent Expert on the enjoyment of human rights by persons with albinism' (2020) A/HRC/43/42/add.1 para 10.

⁴⁶ *ibid.*

⁴⁷ Marcon (n 31) 507.

one in 20,000 people.⁴⁸ In contrast, estimates in North America and Europe ranges from one in 17,000 to one in 20,000, according to the UN Independent Expert on the enjoyment of human rights by persons with albinism (the Independent Expert).⁴⁹ Among the Guna tribe in Panama, the prevalence rate is as high as one in 160 people.⁵⁰

In Africa, the frequency of albinism ranges from one in 5,000 to one in 15,000. The prevalence rate goes as high as one in 832 to one in 1,000 people in some selected populations in the Southern Africa region.⁵¹ In Tanzania, the frequency of albinism is estimated to be one in 2,652 people, according to the country's 2012 national population census.⁵² A study conducted among school children in Zimbabwe projected the prevalence rate of albinism to one in 4,182 for the country.⁵³ In Nigeria's East Central region, albinism is estimated to be one in 15,000 people.⁵⁴ While data is scarce on the frequency of albinism in Ghana, an unpublished academic study conducted in Abura, Asebu, Kwamankese district of the central region of Ghana projected the prevalence rate of albinism to one in 1,067 people in the district.⁵⁵ The data on the prevalence rate of albinism in Africa are primarily from academic research projections and may not represent persons with albinism across the region.

1.9.3 *Myths, beliefs and misconceptions about albinism*

Albinism has been deeply misunderstood, resulting in myths and misconceptions about the condition, especially in some African

⁴⁸ NOAH (n 37).

⁴⁹ United Nations, 'International Albinism Awareness Day 13 June' <www.un.org/en/observances/albinism-day> accessed 15 July 2021.

⁵⁰ I Ero and others, 'People with albinism worldwide. A human rights perspective' (United Nations 2021) 12 <www.ohchr.org/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf> accessed 24 July 2021.

⁵¹ HRC, 'Visit to South Africa, Report of the Independent Expert' (n 45) para 12.

⁵² Resource Center Applied Research and Disability, 'Albinism in east and southern Africa. Knowledge based upon a descriptive literature review of research' (2017) <www.firah.org/upload/1-appel-a-projets/projets-laureats/2018/albinisme/rl-en-albinisme.pdf> accessed 14 July 2021.

⁵³ *ibid.*

⁵⁴ Hong, Zeeb and Repacholi (n 3) 3.

⁵⁵ A Mwandida, 'Prevalence rate of albinism in Abura, Asebu Kwamankese district in Central region' (Master's thesis, African Institute for Mathematical Sciences, University of Ghana 2018).

communities.⁵⁶ Childbirth always follows with joy and celebration; however, these jubilations can suddenly turn into a situation of misery for the family and, in most cases, the mother when the child is born too white (with albinism). In addition, women (mothers of children with albinism) are often blamed for a child born with albinism due to the belief in infidelity or associations with a person with albinism during pregnancy. As critical work in the field demonstrates, while these beliefs are both shared and vary between contexts, their impact on the lives of persons with albinism is profound.

A study conducted by Baker and others in Zimbabwe and South Africa revealed the belief that pregnant women who encounter a person with albinism end up giving birth to one.⁵⁷ For example, among the Venda of Northern South Africa, Baker and others noted that a traditional belief in snakes as spirits monitoring pregnancies could cause a child to be born with albinism. They explained that the snake turns away from such a pregnancy or the pregnant woman's association with a person with albinism makes the snake turn the child into albinism.⁵⁸

Giving birth to a child with albinism is believed to be a curse or a form of punishment from the gods for wrongdoing.⁵⁹ This act may lead to killing such a child,⁶⁰ mother and child facing rejection by the husband and his family⁶¹ and, in some cases, banishment from the community.⁶² Persons with albinism are believed to be supernatural beings and therefore do not die but instead vanish. The widespread belief that the condition is contagious leads to people spitting on themselves upon meeting a person with albinism in their attempt to cleanse themselves.⁶³ Others avoid close contact with those with the condition to prevent them from contracting it.⁶⁴ According to Baker and others, people refuse handshakes with albinism and avoid sitting close

⁵⁶ HRC, 'Preliminary study' (n 4) para 13.

⁵⁷ C Baker and others, 'The myths surrounding people with albinism in South Africa and Zimbabwe' (2010) 22(2) *Journal of African Cultural Studies* 169, 172-174.

⁵⁸ *ibid.*

⁵⁹ F Benyah, 'Equally Able, Differently Looking: Discrimination and Physical Violence against Persons with Albinism in Ghana' (2017) 30(1) *Journal for the Study of Religion* 161. DOI: <<http://dx.doi.org/10.17159/2413-3027/2017/v30n1a7>> accessed 14 September 2021

⁶⁰ *ibid.*

⁶¹ Baker and others (n 57) 172-174.

⁶² GAPA (n 5) 12.

⁶³ Baker and others (n 57) 177.

⁶⁴ *ibid.* 174.

to them on public transport.⁶⁵ In some instances, albinism is believed to cure HIV/AIDS subjecting women and girls with albinism to rape and subsequent death from the virus.⁶⁶

Moreover, several other myths surrounding albinism documented in a report by Under The Same Sun (UTSS) include:⁶⁷

- ‘persons with albinism do not visit the toilet on Fridays,
- that the mother of a child with albinism slept with a white man,
- that a child born with albinism is conceived when a woman has intercourse while she is menstruating,
- persons with albinism cannot see during the day but see well at night,
- that body parts of persons with albinism make potent charms that can make people wealthy and successful,
- that drinking the blood of a person with albinism gives extra magical powers’.

Over the years, these myths, beliefs, and misconceptions about albinism have created room for serious human rights violations and put the lives and security of persons with albinism at constant risk.⁶⁸ These beliefs have led to harvesting body parts and killing persons with albinism in Africa for ritual purposes.⁶⁹ The belief that weaving the hair of a person with albinism into a fishing net or burying body parts of a person with albinism in mining sites increases catch or the prospect of getting gold has led to attacks, maiming and killing of persons with albinism in Africa.⁷⁰ These myths and harmful practices against persons with albinism are discrimination, marginalisation, stigma and social exclusion. These acts violate the core human rights to life, security of persons, non-discrimination, education, health, employment and prohibition of torture and inhuman treatment as enshrined in international human rights law.⁷¹

⁶⁵ Baker and others (n 57) 174.

⁶⁶ *ibid* 176.

⁶⁷ Under the Same Sun, ‘The truth about people with albinism’ <<https://underthesamesun.com/sites/default/files/Myth%20Busting%20Brochure%20-%20English.pdf>> accessed 15 July 2021.

⁶⁸ HRC ‘Persons with albinism’ (n 1) para 15.

⁶⁹ HRC ‘Preliminary study’ (n 4) para 10.

⁷⁰ HRC ‘Persons with albinism’ (n 1) para 17.

⁷¹ *ibid* para 30.

Meanwhile, these myths and beliefs are incorrect with no scientific proof. Instead, they are primarily embedded in archaic cultural and traditional practices and attitudes that are centuries old.⁷² For instance, the practice of not allowing persons with albinism to stay overnight in Bukuruwa, a small farming community in the Eastern region of Ghana, was believed to have emanated from a river goddess.⁷³ Though the traditional leaders could not explain the reason behind this practice, they still followed it since it was part of their tradition.⁷⁴

1.9.4 Rights to health for persons with albinism under international human rights law

According to the World Health Organization (WHO), ‘health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’.⁷⁵ The WHO further emphasised that ‘the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition’.⁷⁶

The right to health is a fundamental human right of everyone, including persons with albinism. As a result, numerous human rights instruments at the international and regional levels gave legal recognition to this right and further imposed obligations on states to respect, protect and fulfil health rights and ensure their progressive realisation.⁷⁷ Thus, for example, the Universal Declaration of Human Rights accords everyone ‘rights to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services’.⁷⁸

The ICESCR in article 12(1) calls on state parties to recognise ‘the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ and further outlines steps to be taken to

⁷² HRC ‘Preliminary study’ (n 4) para 13.

⁷³ GAPA (n 5) 13.

⁷⁴ *ibid.*

⁷⁵ The Constitution of the WHO (adopted by the International Health Conference, New York, 19-22 June 1945) 14 UNTS 185 para 2.

⁷⁶ *ibid* para 3.

⁷⁷ CESCR ‘General Comment No 14’ (n 7) para 33.

⁷⁸ Universal Declaration of Human Rights (adopted 10 December 1948 UNGA Res 217 A(III) (UDHR) art 25.

ensure their full realisation.⁷⁹ According to the Committee on Economic, Social and Cultural Rights (CESCR), the right to health mandates state parties to respect, protect, and fulfil a minimum core obligation of equality and non-discrimination on prohibited grounds of race, colour, or disability.⁸⁰ Furthermore, the health right extends beyond the right to be healthy to include freedoms and entitlements – freedoms include the right to control one’s health and body, and the right to be free from interference and entitlement entails the right to a health protection system.⁸¹ This right also includes enjoying various health facilities, goods and services appropriate to healthcare needs.⁸² However, primary healthcare services are inadequate as they do not address specific and specialised healthcare needs such as sunscreen, skin cancer treatment, psychosocial support and eye care services for persons with albinism.⁸³

According to the Independent Expert, persons with albinism need access to appropriate gender-sensitive healthcare services tailored to the condition of albinism and close to their communities.⁸⁴ These services are essential to women and girls with albinism because of their vulnerability to intersecting forms of gender-based discrimination. The Independent Expert further notes that persons with albinism require health professionals to provide appropriate healthcare services equal to the quality provided to others, noting that these services be devoid of discrimination based on colour or disability.⁸⁵ For persons with albinism to enjoy the highest attainable standard of physical and mental health, information on the condition must be provided by state parties to promote understanding and provide adequate healthcare services commensurate to their needs.⁸⁶ Information on skin cancer prevention, sunscreens, protective clothing, psychosocial support and eye care services should be readily available, accessible and good quality.⁸⁷

The right to health is essential for persons with albinism, given the health complications associated with the condition. Access to essential

⁷⁹ International Covenant on Economic, Social and Cultural Rights Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 entry into force 3 January 1976 (ICESCR) art 12.1.

⁸⁰ CESCR ‘General Comment No 14’ (n 7) para 33.

⁸¹ *ibid* para 8.

⁸² *ibid* para 9.

⁸³ Human Rights Council, ‘Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism’ (2017) A/72/131 para 53.

⁸⁴ *ibid* para 52.

⁸⁵ *ibid*.

⁸⁶ *ibid* para 53.

⁸⁷ *ibid*.

medicine, health-related education and information are critical to enjoying their health rights.⁸⁸ Without adequate access to these vital services and resources, people with albinism will be deprived of their lives, education and work rights.⁸⁹ For instance, lack of access to sunscreen and protective clothing means persons with albinism cannot accept employment involving outdoor sun-exposed activities.⁹⁰ Similarly, the lack of assistive devices and reasonable accommodation in the classroom reduces the quality of education for this population, further limiting their chances of securing employment indoors.⁹¹ Thus, the violation of their rights to education implicitly violates their rights to work and an adequate standard of living, further challenging their health rights.⁹²

Aside from the ICESCR, other international treaties provide the recognition of health rights. These include article 25 of the CRPD,⁹³ article 5(iv) of the International Convention on the Elimination of All Forms of Racial Discrimination,⁹⁴ articles 11(1)(f) and 12 of the Convention on the Elimination of All Forms of Discrimination against Women⁹⁵ and article 24 of the Convention on the Rights of the Child.⁹⁶

Health rights gained popularity in several human rights instruments at the regional level. For example, article 16(1) of the African Charter on Human and Peoples' Rights guarantee the rights of everyone to 'enjoy the best attainable state of physical and mental health'.⁹⁷ In addition, the rights to health have been echoed in other human rights documents such as article 14 of the African Charter on the Rights and Welfare of the Child⁹⁸ and Article 14 of the Protocol to the African Charter on

⁸⁸ Ero and others (n 50) 75.

⁸⁹ *ibid.*

⁹⁰ *ibid.*

⁹¹ *ibid.*

⁹² *ibid.*

⁹³ Convention on the Rights of Persons with Disabilities (adopted on 13 December 2006, entered into force on 3 May 2008). (CRPD), art 25

⁹⁴ International Convention on the Elimination of All Forms of Racial Discrimination (adopted 1965 and entered into force 1969), art 5(iv)

⁹⁵ Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (adopted 1979 and entered into force 1981), art 11(1)(f) and 12.

⁹⁶ Convention on the Rights of the Child (CRC) (adopted 1989 and entered into force 1990), art 24.

⁹⁷ African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 (African Charter)' Rights, art 16.1.

⁹⁸ African Charter on the Rights and Welfare of the Child (ACRWC) (adopted July 01 1990, entered into force 29 Nov, 1999), art 14: 'Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health'.

Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol).⁹⁹ The most recent adoptions of the Africa Union recognising the rights to health includes article 17 of the protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities¹⁰⁰ and article 15 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa.¹⁰¹

Despite numerous laws protecting the right to health, persons with albinism face barriers to enjoying this right. According to Durojaye and Nabaneh, persons with albinism encounter discrimination in a society fuelled by cultural practices and misconceptions.¹⁰² They maintain that these multiple forms of discrimination and violation of rights extend into the healthcare settings where healthcare workers exhibit such acts against these individuals, especially women with albinism.¹⁰³ In the views of Ero and others, persons with albinism face multiple and intersecting forms of discrimination because of colour, disability and gender, which further limit their enjoyment of the right to health.¹⁰⁴ They further attributed governments' lack of commitment to the health needs of persons with albinism, inaccessible healthcare facilities and lack of knowledge on albinism among healthcare professionals as factors affecting access to healthcare for persons with albinism across the globe.¹⁰⁵ Similarly, stigma against persons with disabilities, including albinism, deter them from seeking medical attention.¹⁰⁶ Other factors inhibiting access to healthcare for persons with albinism include poverty, prohibitive cost, lack of information and social exclusion.¹⁰⁷

⁹⁹ Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (adopted 01 July 2003, entered into force 25 Nov 2005), art 14(1): 'States Parties shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted'.

¹⁰⁰ African Disability Rights Protocol (n 13).

¹⁰¹ Protocol to the African Charter on human and peoples' rights on the rights of older persons in Africa (adopted 31 January 2016) art 15(1) mandates state parties to 'guarantee the rights of older persons to access health services that meets their specific needs'.

¹⁰² E Durojaye and S Nabaneh, 'Human rights and access to healthcare for persons with albinism in Africa' (2019) 7 African Disability Rights Yearbook 35, 50-51.

¹⁰³ *ibid.*

¹⁰⁴ Ero and others (n 50) 76.

¹⁰⁵ *ibid.*

¹⁰⁶ H Abuaku Howard and A Baisiwa Rhule, 'Socioeconomic Factors Hindering Access to Healthcare by Persons with Disabilities in the Ahanta West Municipality, Ghana' (2021) 32(2) Disability CBR & Inclusive Development 69 DOI: 10.47985/dcidj.419.

¹⁰⁷ Ero and others (n 50) 77.

1.10 STRUCTURE

This study will consist of five chapters, with the first chapter giving background and general insights into the study. It states the research problem, objectives to be achieved and highlights the significance of the study. Research questions, methodology, scope and limitations, literature review and structure of the study are included in this chapter. Chapter two will delve into the healthcare needs of persons with albinism in general and in Ghana in particular. Chapter three reviews Ghana's international obligations concerning the rights to health of persons with albinism and how the country's constitutional, legislative and institutional frameworks on health rights reflect international human rights standards on the rights to health of persons with albinism. Chapter four of this study draws lessons from African countries on best practices on the rights to health of persons with albinism. Finally, chapter five summarises the research findings and recommendations to help align with international standards for providing healthcare for persons with albinism in Ghana.

2.

HEALTH CARE NEEDS OF PERSONS WITH ALBINISM

2.1 INTRODUCTION

Melanin deficiency proved to be a significant health risk factor for persons with albinism, especially in Africa and Ghana in particular. The reduction or absence of melanin in this population increased their susceptibility to harmful effects of UV radiation. The UV radiations make them vulnerable to skin damage and visual problems. Ghana is located a few degrees north of the equator, with daily sunshine ranging between six to seven hours. The tropical climate with temperatures ranging between 25 to 35 degrees Celsius poses a significant challenge for Ghanaians with albinism. This climatic condition dramatically influences their health. This chapter explores the health realities associated with albinism and its effects on individuals with the condition.

2.2 VISION PROBLEMS ASSOCIATED WITH ALBINISM

Visual impairment is a significant feature in all types of albinism due to the reduced or absence of melanin in the irises of persons with albinism. This results in the irises looking translucent, preventing them from blocking light from entering the eye. This condition leads to impaired vision among persons with albinism. According to the Independent Expert, almost all persons with albinism have varying degrees of low vision, and this can deteriorate with age.¹⁰⁸ The lack of melanin in this

¹⁰⁸ Human Rights Council, 'Social development challenges faced by persons with albinism. Report of the Secretary-General' (2017) A/72/169 para 28.

vital organ causes several visual problems, including reduced visual acuity, refractive errors, nystagmus, strabismus, photophobia and astigmatism.¹⁰⁹

Light sensitivity or photophobia is common among persons with albinism. The condition is caused by a lack of melanin, resulting in light entering the eyes. This situation leads to blurred vision or total temporal blackout in sudden exposure to bright lights and glares. Photophobia causes discomfort leading to squinting, closing of eyes and can easily impede the performance of everyday tasks. Tinted sunglasses and wide-brimmed hats are recommended to shade off the excess lights.

Like photophobia, nystagmus is common among persons with albinism. This condition results in involuntary and uncontrolled eye movement either horizontally, vertically or in a circle. This movement reduces how persons with albinism can see and, in most cases, cause blurred vision, especially when tired or stressed. Nystagmus in this population increases with age. A study conducted among 38 persons with albinism in Nigeria indicated that 33 participants had nystagmus with a slight presence in three other persons.¹¹⁰ Persons with albinism may be seen tilting their heads to one side to reduce eye movement and improve vision. As this is not correctable or curable, glasses or contact lenses may help enhance vision and minimise eye movement. In rare cases, surgeries may be conducted to reposition the nerves that cause the movement of the eyes.¹¹¹

Low vision among persons with albinism has negative repercussions on daily tasks, especially in schools.¹¹² Lack of reasonable accommodation in developing countries like Ghana affects the academic performance of persons with albinism, further reducing their chances of accessing employment opportunities indoors.¹¹³ The availability and use of low vision aids such as glasses, contact lenses, handheld telescopes, magnifiers and screen magnifiers help improve the vision of persons

¹⁰⁹ CR Marcon and M Maia, 'Albinism: epidemiology, genetics, cutaneous characterization, psychosocial factors' (2019) 94(5) *Anais Brasileiros de Dermatologia* 504.

¹¹⁰ NN Udeh and others, 'Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population' (2014) 39(3) *Journal of Community Health* 512.

¹¹¹ American Academy of Ophthalmology, 'What is nystagmus?' <www.aaopt.org/eye-health/diseases/what-is-nystagmus> accessed 9 August 2021.

¹¹² EE Anshelevich and others, 'Factors Affecting Quality of Life for People Living with Albinism in Botswana' (2021) 39(1) *Dermatologic Clinic* 129 Doi: 10.1016/j.det.2020.08.012.

¹¹³ *ibid.*

with albinism.¹¹⁴ In addition, sunglasses and tinted glasses with UV protection helps to filter the excess lights and protect the eyes from UV damage. A study conducted in Nigeria indicates that persons with albinism have a compelling need for low vision aids as these assistive devices significantly improve their vision.¹¹⁵

2.3 SKIN PROBLEMS ASSOCIATED WITH ALBINISM

Skin pigment plays a vital role in protecting the skin from UV radiation. Lack of pigment in persons with albinism makes their skin sensitive to UV radiation, increasing their vulnerability to skin problems, including sunburns, rashes, wrinkling, premature skin ageing, and skin cancer.¹¹⁶

Skin cancer – abnormal development of cells in the most sun-exposed body area – is a significant health concern and the cause of morbidity and death among persons with albinism,¹¹⁷ with an increasing incidence rate for those living on or near the equator.¹¹⁸ For example, a recent study conducted among persons with albinism in Togo indicated 95.2% of the participants presented with various skin lesions in sun-exposed areas such as head and neck regions.¹¹⁹ In Tanzania, it is reported that 90% of persons with albinism die before age 40 due to skin cancer.¹²⁰

Skin damages due to sun exposure are noticeable in children as early as one year old.¹²¹ The level of vulnerability to further skin damage and disfigurement increases with age and cumulative sun exposure without proper sun protection measures. In Tanzania, a study conducted among 164 persons with albinism indicates a 25% incidence rate of skin

¹¹⁴ HRC, 'Social development challenges' (n 108) paras 28-29.

¹¹⁵ Udeh (n 110) 512.

¹¹⁶ PM Lund and JS Taylor, 'Lack of adequate sun protection for children with oculocutaneous albinism in South Africa' (2008) 8 *BMC Public Health* 225, 226 doi:10.1186/1471-2458-8-2252.

¹¹⁷ SE Emadi and others, 'Common malignant cutaneous conditions among albinos in Kenya' (2017) 31(1) *Med J Islam Repub Iran* 7 <<https://doi.org/10.18869/mjiri.31.3>>.

¹¹⁸ TL Diepgen and V Mahler, 'The epidemiology of skin cancer' (2002) 146(61) *British Journal of Dermatology* 1, 2.

¹¹⁹ B Saka and others, 'Skin cancers in people with albinism in Togo in 2019: results of two rounds of national mobile skin care clinics' (2021) 21 *BMC Cancer* 26 <<https://doi.org/10.1186/s12885-020-07747-8>>.

¹²⁰ Human Rights Council (HRC), 'Persons with albinism. Report of the Office of the United Nations High Commissioner for Human Rights' (2013) A/HRC/24/57 para 27.

¹²¹ Lund and Taylor (n 116) 3.

cancer.¹²² Similar studies in South Africa and Nigeria showed 23% and 20.98%, respectively.¹²³ However, a recent survey in Togo reported a lower figure of 11.8% skin cancer incidence rate among persons with albinism.¹²⁴ The recorded low incidence rate of skin cancer in Togo can be explained by the fact that the research participants are urban dwellers and have access to more information through the media on sun protection measures and easy access to health facilities than their counterparts in remote areas.

There are two main types of skin cancer – melanoma and non-melanoma skin cancers. Melanoma skin cancer is the least common type of cancer among persons with albinism. Melanoma develops from the melanocytes – cells responsible for giving colour to the skin. Studies indicate a low rate of 0.75% in Tanzania¹²⁵ and 9.1% in Nigeria.¹²⁶ On the contrary, non-melanoma skin cancer, including basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), are the most prevalent among persons with albinism. Unlike melanoma which develops at any part of the body and has no clear-cut relations with sun exposure, BCC and SCC are caused mainly by continuous or cumulative sun exposure owing to its appearance on sun-exposed parts of the body. Studies conducted on persons with albinism in Tanzania and Nigeria put the incidence rate of SCC ahead of BCC, with Tanzania recording 53.7%¹²⁷ and a high rate of 68.2% in Nigeria, with BCC being 45.5% and 22.7%, respectively.¹²⁸ Contrary to these figures, similar studies in Togo indicate a high BCC rate of 57.4%, with SCC recording 38.9%.¹²⁹

Environmental and personal factors account for the high incidence rate of skin cancer among individuals with albinism. Average daily sunshine of six hours with temperatures ranging from 25 to 35 degrees Celsius in Ghana presents challenging skin cancer causative factors for Ghanaians with albinism. Outdoor activities such as farming, street

¹²² Lund and Taylor (n 116) 3.

¹²³ *ibid.*

¹²⁴ Saka and others (n 119) 3.

¹²⁵ SK Kiprono, MC Baraka and H Beltraminelli, 'Histological review of skin cancers in African Albinos: a 10-year retrospective review' (2014) 14 *BMC Cancer* 157, 3.

¹²⁶ OO Awe and TA Azeke, 'Cutaneous cancers in Nigerian albinos: A review of 22 cases' (2018) 24 *Niger J Surg* 34, 35.

¹²⁷ Kiprono (n 125) 3.

¹²⁸ Awe and Azeke (n 126) 35.

¹²⁹ Saka and others (n119) 3.

hawking, among others, increase sun exposure.¹³⁰ Lack of protective clothing such as wide-brimmed hats, long sleeve shirts, long skirts and trousers, and high temperatures contributes largely to skin damage. Inadequate public health policies, expensive and inaccessible sunscreen lotions, inadequate and inaccessible dermatological services, and lack of information and awareness on the condition are barriers to adequate skin health among persons with albinism in developing countries like Ghana. In addition, the low socioeconomic status of families of persons with albinism coupled with social factors such as stigma, discrimination and marginalisation create barriers to persons with albinism accessing adequate health care proportionate to their health needs with those in rural areas at most significant risks.¹³¹

Practising adequate sun protection is key to reducing the incidences of skin cancer in this population. The use of sunscreen, wearing protective clothing and sun avoidance are primary means of preventing skin damage that may develop into skin cancer. Effective public health policies, available and accessible dermatological services, public awareness and sunscreens availability play a vital role in preventing skin cancer. In addition, early detection and treatment of skin lesions, availability and accessibility of skin cancer treatment facilities, including radiotherapy facilities, surgery theatres and health professionals, are vital to curative and palliative skin cancer treatment.

2.4 MENTAL HEALTH OF PERSONS WITH ALBINISM

Aside from the physical health discussed above, persons with albinism experience serious mental health challenges emanating from daily exposure to discrimination, marginalisation, social exclusion and stigma. Mental health is crucial to the general well-being of every individual, and it is considered an essential component of health.¹³² According to the WHO, mental health spans beyond just the absence of mental disability. It includes an individual's ability to think, cope

¹³⁰ Awe and Azeke (n 126) 35.

¹³¹ HRC 'Persons with albinism' (n 120) para 33.

¹³² World Health Organization (WHO), 'Mental health: strengthening our response' (WHO, 17 June 2022) <www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response> accessed 24 August 2021.

with everyday life issues, be productive, show emotions, contribute effectively to his community through interaction with others, earn a living and live a happy life.¹³³ It is important to note that just as anyone else without albinism may experience mental health issues, persons with albinism experience the same and even more due to discrimination and social exclusion based on their disability, colour, gender and age.

Discrimination and stigmatisation begin early in a person with albinism, perpetrated mainly by parents and teachers.¹³⁴ For instance, children with albinism are excluded from playing with others either on teachers' instructions in schools or from parents.¹³⁵ For example, a class teacher maltreated a five-year-old boy with albinism because of the belief that getting close to the boy would cause her to give birth to a child with albinism.¹³⁶

Bullying, name-calling and social exclusion have a severe negative impact on the mental health of persons with albinism. In Ghana, persons with albinism are called *ofri*, meaning 'borrowed' among the 'Akans' and *gelesoshi*, meaning 'fallen from heaven' in 'Ewe'¹³⁷ and in some cases, they are referred to as pigs or cats because of their skin and eye colour.¹³⁸ In Malawi, derogatory names such as 'ghosts', *mzungu osauka* (poor white person) and *Nzungudala* (fake white person) are common names for persons with albinism.¹³⁹ These attitudes against persons with albinism lead to depression and sometimes alcoholism due to their persistent nature.¹⁴⁰ Many persons with albinism develop low self-confidence and lose their self-worth and esteem due to discrimination, stigma and social exclusion.¹⁴¹ To avoid the taunts and jeers they receive from the public, persons with albinism tend to keep to themselves.¹⁴² This situation increases depression and loneliness,

¹³³ WHO (n 132).

¹³⁴ Human Rights Council, 'Albinism worldwide. Report of the Independent Expert on the enjoyment of human rights by persons with albinism' (2019) A/74/190 para 24.

¹³⁵ *ibid.*

¹³⁶ Adonai StudiosGH, 'My Colour' (Albinism documentary, Thisability Episode 10, 2020) <www.youtube.com/watch?v=alu2g30CQKs&t=12s> accessed 24 August 2021.

¹³⁷ F Benyah, 'Equally Able, Differently Looking: Discrimination and Physical Violence against Persons with Albinism in Ghana' (2017) 30(1) *Journal for the Study of Religion* 161. DOI: <<http://dx.doi.org/10.17159/2413-3027/2017/v30n1a7>> accessed 14 September 2021.

¹³⁸ Adonai StudiosGH (n 136).

¹³⁹ Amnesty International, "'We are not animals to be hunted or sold" violence and discrimination against people with albinism in Malawi' (Amnesty International 2016).

¹⁴⁰ HRC 'Albinism worldwide' (n 134) para 24.

¹⁴¹ Amnesty International (n 139) 17.

¹⁴² *ibid.*

leading to suicidal thoughts and tendencies.¹⁴³ Persons with albinism who attempt to engage in business activities face stiffer challenges of not getting potential customers because of stigma and the prejudices they suffer due to their condition. As a result, many people would not like to patronise items sold by this vulnerable group.¹⁴⁴

Lack of self-confidence and self-esteem have profound negative implications on the outlook of persons with albinism, increasing their vulnerability and reducing their chances of demanding their rights, diminishing self-defence and coping mechanisms. A study conducted among 105 persons with albinism in Ghana indicates that these individuals are at high risk of developing mental health problems due to discrimination and social exclusion.¹⁴⁵ The study shows that Ghanaians with albinism experience high levels of social stigma, contributing adversely to their subjective well-being.¹⁴⁶ In Sierra Leone, a public survey shows 78.87% of the participants indicating that persons with albinism experience discrimination and stigma in their communities.¹⁴⁷

Lack of information and awareness leads to myths and superstitions about the condition. For instance, the belief that using body parts of persons with albinism in ritual brings good luck and wealth while others think persons with albinism are cursed and deserve to be killed raises security concerns.¹⁴⁸ Worse of it is when price tags are put on these individuals, reflected in the names they are called publicly.¹⁴⁹ For example, in Malawi, persons with albinism are referred to as ‘money’ or ‘millions’.¹⁵⁰ In Sierra Leone, 80.18% of persons with albinism surveyed in a study said they had been called names due to their condition.¹⁵¹ Parents of children with albinism similarly face mental health issues due to discrimination they experience because of their child’s appearance.

¹⁴³ Amnesty International (n 139) 17.

¹⁴⁴ Engage Now Africa, ‘Albinism in Ghana’ (8 December 2020) <www.youtube.com/watch?v=oNWGPbdmPlk&t=14s> accessed 26 August 2021.

¹⁴⁵ AA Afram, E Teye-Kwadjo and AA Gyasi-Gyamerah, ‘Influence of social stigma on subjective well-being of persons with albinism in Ghana’ (2019) 29(4) *Journal of Community and Applied Social Psychology* 323, 332 <<https://doi.org/10.1002/casp.2403>>. accessed 26 August 2021.

¹⁴⁶ *ibid.*

¹⁴⁷ FM Conteh and L Braima, ‘Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone’ (Lady Ellen Women’s Aid Foundation/Open Society Institute for West Africa (OSIWA) 2018).

¹⁴⁸ Amnesty International (n 139) 18.

¹⁴⁹ *ibid.*

¹⁵⁰ *ibid.*

¹⁵¹ Conteh and Braima (n 147).

For example, nurses mocked a baby born with albinism at the Tema General Hospital in Ghana, leading to the mother's dejection of the baby. Her husband subsequently abandoned her because of the colour of the boy.¹⁵²

The outbreak of coronavirus (COVID 19) and its subsequent declaration as a global pandemic have created an added wave of stigma for persons with albinism across Africa. Due to the colour of their skin, some people even harbour the belief that persons with albinism are carrying and spreading the disease.¹⁵³ As a result, persons with albinism have been tagged 'Corona virus', increasing their vulnerability to attack, discrimination and stigma.¹⁵⁴ Furthermore, lack of community support, inadequate information and awareness on the condition, and myths and superstitions strengthen discrimination and social exclusion of persons with albinism. In addition, the lack of psychosocial support in the health institutions and lack of information on mental health conditions and means of accessing help complicate the woes of persons with albinism. Due to these challenges, persons with albinism develop coping mechanisms such as withdrawing from society and alcoholism, which in the long run worsen their health conditions both physically and psychologically.

2.5 CONCLUSION

Melanin deficiency in people with albinism is not the primary concern, but this affects visual acuity and thus has severe implications on daily task performance. However, this can be averted, and the vision of persons with albinism improved with the right technology and assistive devices. In a similar vein, the weather conditions in Africa has been the primary cause of alarm for this population. High UV radiation, high temperatures and scorching African sun have high destructive effects

¹⁵² Adonai StudiosGH (n 136).

¹⁵³ J Kossoff, 'People with albinism are being blamed for the spread of the coronavirus in Africa because of their "whiteness"' (*Business Insider*, 13 June 2020) <www.businessinsider.com/coronavirus-africans-with-albinism-are-blamed-because-of-whiteness-2020-6?IR=T> accessed 26 August 2021.

¹⁵⁴ GhanaWeb, 'We are not carriers of coronavirus, stop tagging us – Person with Albinism' (*GhanaWeb*, 14 June 2020) <www.ghanaweb.com/GhanaHomePage/NewsArchive/We-are-not-carriers-of-coronavirus-stop-tagging-us-Person-with-Albinism-979582> accessed 26 August 2021.

on the skin of persons with albinism, especially those living on or near the equator. People with albinism who develop skin problems early in life have a shorter lifespan due to skin cancer.

Furthermore, the visual problems and skin disfigurement caused by UV radiation have led to discrimination, marginalisation and stigma against persons with albinism. These social factors, including lack of information, low level of education and lack of adequate healthcare, negatively impact persons with albinism. In addition, lack of community support creates loneliness, leading to depression, low self-esteem and confidence, and mental health problems among this vulnerable group.

3.

LEGAL AND INSTITUTIONAL FRAMEWORK ON THE RIGHT TO HEALTH FOR PERSONS WITH ALBINISM IN GHANA

3.1 INTRODUCTION

In recent years, there has been greater awareness of the issues surrounding albinism following the adoption of Human Rights Council resolution 23/13 on attacks and discrimination against persons with albinism¹⁵⁵ and the subsequent creation of the mandate of the Independent Expert in 2015.¹⁵⁶ These developments were triggered by a series of attacks on persons with albinism in Africa, especially in Eastern and Southern Africa, leading to killings and the mutilation of their body parts.¹⁵⁷ In response to these attacks and to protect persons with albinism, various measures were adopted, including regional action plans on albinism in Africa,¹⁵⁸ succeeded by the African Union (AU) plan of action on albinism.¹⁵⁹

Though there were few reported physical attacks on persons with albinism in Ghana, discrimination, marginalisation, social exclusion and stigma persist due to their disability, colour, gender and age. These acts of discrimination result in the violation of their rights, including quality education, an adequate standard of living, employment and

¹⁵⁵ Human Rights Council, '23/13. Attacks and discrimination against persons with albinism' (2013) A/HRC/RES/23/13.

¹⁵⁶ Human Rights Council, '28/6. Independent Expert on the enjoyment of human rights by persons with albinism' (2015) A/HRC/RES/28/6.

¹⁵⁷ Human Rights Council, 'Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism' (2015) A/HRC/28/75.

¹⁵⁸ Human Rights Council, 'Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Regional Action Plan on Albinism in Africa (2017–2021)' (2017) A/HRC/37/57/Add.3.

¹⁵⁹ African Union, 'Implementation matrix of the plan of action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031)' (2021).

health. This chapter reviews Ghana's international and domestic legal obligations and the institutional framework for respecting, protecting and promoting the rights to health of Ghanaians with albinism.

3.2 GHANA'S INTERNATIONAL OBLIGATIONS ON THE RIGHT TO HEALTH FOR PERSONS WITH ALBINISM (INTERNATIONAL AND REGIONAL OBLIGATIONS)

Since independence in 1957, Ghana has signed and ratified numerous international and regional treaties, including human rights instruments that guaranteed the rights of everyone, including persons with albinism. Prominent among these human rights instruments are the ICESCR of 1966, the CRPD of 2006 and the African Charter of 1981. Ghana signed and ratified the ICESCR in 2000, CRPD in 2012 and the African Charter in March 1989. These human rights instruments have the right to health enshrined to safeguard, protect and promote physical and mental health. However, the crucial part of these instruments is the obligations imposed on states parties to ensure these rights are realised without discrimination on several prohibited grounds, including disability within which albinism falls.

Article 12 of the ICESCR provides 'the right of everyone to enjoy the highest attainable standard of physical and mental health' and further outlines steps to be adopted by member states to achieve the rights enshrined therein.¹⁶⁰ Similarly, article 16 of the African Charter provides for the enjoyment of the right to health and enjoins states parties to ensure the provision and protection of these rights without discrimination on the ground of colour, disability or other social status.¹⁶¹ Furthermore, the CRPD in article 25 provides 'that persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination based on disability'.¹⁶² The Convention further obliges state parties to ensure such health services are specific to their disabilities, including early detection and prevention of further disabilities.¹⁶³ Ghana is obligated to ensure such rights are respected, protected and fulfilled with the maximum available resources as a state party to these instruments.

¹⁶⁰ International Covenant on Economic, Social and Cultural Rights (Adopted 16 December 1966, entered into force 3 January 1976) (ICESCR) art 12.

¹⁶¹ African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 (African Charter) art 16.

¹⁶² Convention on the Rights of Persons with Disabilities (CRPD) (2006) art 25.

¹⁶³ *ibid.*

The obligation to respect requires Ghana to refrain from direct or indirect interference with enjoying economic, social and cultural (ESC) rights, including health rights.¹⁶⁴ Access to preventive, curative and palliative health services should not be limited or denied by state and or non-state actors and access to health-related information and essential medicine.¹⁶⁵ In this regard, Ghana is obliged to ensure that the rights to health of persons with albinism are not violated by state agencies or private individuals and ensures measures are taken to safeguard these rights.

Like other ESC rights, health rights must be protected from being violated by international corporations, local companies and other private individuals.¹⁶⁶ As a measure of protection, activities of non-state actors that affect access to health must be regulated and continuously monitored.¹⁶⁷ In addition, Ghana must ensure that harmful social and traditional practices that impart these individuals' physical and mental health are prohibited. In the view of the CESCR, the obligation to promote the rights to health includes:¹⁶⁸

- (i) fostering recognition of factors favouring positive health results, e.g. research and provision of information; (ii) ensuring that health services are culturally appropriate and that healthcare staff are trained to recognise and respond to the specific needs of vulnerable or marginalised groups; (iii) ensuring that the State meets its obligations in the dissemination of appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices and the availability of services; (iv) supporting people in making informed choices about their health.

The obligation to fulfil requires the state to ensure the rights to health of persons with albinism are realised. Therefore, the state is to ensure that access to health facilities, goods and services are provided for the enjoyment of everyone on an equal basis. At the same time, priority is placed on marginalised groups such as persons with albinism.¹⁶⁹ For

¹⁶⁴ African Commission on Human and Peoples' Rights, 'Principles and guidelines on the implementation of economic, social and cultural rights in the African Charter on human and peoples' rights' para 7. accessed 28 August 2021.

¹⁶⁵ CESCR, 'General Comment No 14: The right to the highest attainable standard of health' (2000) E/C/12/2000 para 34.

¹⁶⁶ African Commission (n 164) para 7.

¹⁶⁷ *ibid.*

¹⁶⁸ CESCR 'General Comment No 14' (n 165) para 37.

¹⁶⁹ African Commission (n 164) paras 10–12.

instance, sunscreen should be easily accessible, affordable, acceptable and of good quality, just as other skin products and health facilities should be as close as possible to the communities of these individuals.¹⁷⁰ Thus, the state ensures a conducive environment is created to ensure that persons with albinism enjoy their health rights equally.

Notably, the right to health is subject to progressive realisation. This obligation requires states parties to continuously improve on the provision of health facilities, goods and services and work towards fully realising the health right.¹⁷¹ The minimum core obligation requires prioritising the health needs of the poor, vulnerable and marginalised in society regardless of the availability of resources.¹⁷² For instance, the right to access health facilities, goods and services such as sunscreen, dermatological services and health-related information for persons with albinism is essential to the enjoyment of their right to health.¹⁷³ To progressively realise the health right, the state has to continuously 'develop healthcare infrastructure, train health professionals or implement healthcare legal reforms' toward transforming the health sector.¹⁷⁴

Article 2(1) of ICESCR requires states to:

... take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Covenant by all appropriate means, including particularly the adoption of legislative measures, to ensure the rights recognised in the Covenant are realised.¹⁷⁵

The steps towards the full realisation of health rights must be taken within a reasonable period after ratification and entry into force of

¹⁷⁰ I Ero and others, 'People with albinism worldwide. A human rights perspective' (United Nations 2021) 75-85 <www.ohchr.org/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf> accessed 24 July 2021.

¹⁷¹ FXB Center for Health and Human Rights and Open Society Foundations, 'Disability, community living, health and human rights' in 'Health and human rights resource guide' (5th edn, 2013) ch 9, 9.4.

¹⁷² African Commission (n 164) para 67.

¹⁷³ Ero and others (n 170) 75-85.

¹⁷⁴ FXB Center for Health and Human Rights and Open Society Foundations (n 171) 9.4.

¹⁷⁵ ICESCR art 2(1).

the ICESCR.¹⁷⁶ These steps must be deliberate, concrete and targeted towards realising the health rights of the most vulnerable in society, including persons with albinism.¹⁷⁷ These steps include healthcare legal reforms and allocation of adequate resources to provide healthcare facilities, goods and services as a state or through international assistance and cooperation.¹⁷⁸

As an obligation, article 2 of the African Charter provides a non-exhaustive list of grounds for non-discrimination, including colour, race and social status.¹⁷⁹ Accordingly, the enjoyment of health rights must cut across all strata of society. In contrast, priority is given to the vulnerable and disadvantaged to equally enjoy the right to health. For instance, failure to provide sunscreen for persons with albinism will amount to discrimination and unequal treatment, violating the equality and non-discrimination provisions encoded in international human rights law. Additionally, healthcare facilities, goods and services must be available, accessible, acceptable and of good quality to persons with albinism.

For the above provisions to be enforceable within Ghana, these international human rights treaties must be domesticated through an act of parliament after ratification or accession. Ghana is a common law nation and, as such, follows the dualist approach to treaty implementation. The dualist approach sees international and domestic law as separate and independent of each other, and ‘the validity of international law in a dualist domestic system is determined by a rule of domestic law authorizing the application of that international norm’.¹⁸⁰ In the case of Ghana, like other common law states, legislative or executive action is required to incorporate ratified international treaties into local or domestic law to make them applicable within

¹⁷⁶ Committee on Economic Social and Cultural Rights, ‘General Comment No. 3: The Nature of States Parties’ Obligations (Art. 2, Para. 1, of the Covenant)’ (1990) E/1991/23 para 2.

¹⁷⁷ *ibid* para 3.

¹⁷⁸ *ibid* para 13.

¹⁷⁹ African Charter art 2 states: ‘Every individual shall be entitled to the enjoyment of the rights and freedoms recognised and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status’.

¹⁸⁰ M Chiam, ‘Monism and Dualism in International Law’ (*Oxford Bibliographies*, 24 February 2021) DOI: 10.1093/OBO/9780199796953-0168 <www.oxfordbibliographies.com/view/document/obo-9780199796953/obo-9780199796953-0168.xml> accessed 14 October 2021.

the local jurisdiction.¹⁸¹ The President is empowered by article 75(1) of the Constitution of Ghana to ‘execute or cause to be executed treaties, agreements and conventions in the name of Ghana’.¹⁸² However, article 75(2) provides that treaties, agreements and conventions executed by the President are ‘subject to ratification by an act of parliament or parliamentary resolution supported by more than one-half of all the members of parliament’.¹⁸³

Notwithstanding, domestication of ratified international treaties remains a challenge in Ghana,¹⁸⁴ noting that few treaties are currently incorporated into the domestic legal system, despite the ratification of numerous international treaties, including international human rights instruments.¹⁸⁵ It is worthy to note that Ghana’s Constitution reflects provisions of international treaties ratified before adopting the Constitution, while some local statutes have been amended to reflect provisions of international law.¹⁸⁶ For instance, chapter five of the Constitution contains some provisions of ICCPR, ICESCR and the African Charter.¹⁸⁷ In addition, non-domestication of international treaties does not necessarily mean national courts should disregard them.¹⁸⁸ Another way the Constitution relate to international law is through provisions in article 40. Article 40(c) encourages the government to ‘promote respect for international law, treaty obligations and the settlement of international disputes by peaceful means’ and to adhere to principles contained in international treaties adopted by all international organisations that Ghana is a member of.¹⁸⁹ By ratifying these international human rights treaties that protect the right to an attainable standard of health for everyone, Ghana is therefore under obligation to take steps (legislative, administrative), including the domestication of treaties to respect, protect and promote the rights to health of persons with albinism.

¹⁸¹ K Appiagyei-Atua, *Ghana: Justice Sector and the Rule of Law, A review by AfriMAP and The Open Society Initiative for West Africa and The Institute for Democratic Governance* (The Open Society Initiative for West Africa 2007) 21. accessed 13 October 2021.

¹⁸² Constitution of the Republic of Ghana art 75(1).

¹⁸³ Constitution of Ghana art 75(2).

¹⁸⁴ F Viljoen, *International Human Rights Law in Africa* (2nd edn, OUP 2012) 530-31. See also MG Nyarko, ‘The impact of the African Charter and Maputo Protocol in Ghana’ in VO Ayeni (ed), *The impact of the African Charter and Women’s Protocol in selected African states* (2nd edn, Pretoria University Law Press (PULP) 2016).

¹⁸⁵ Appiagyei-Atua (n 181) 22.

¹⁸⁶ *ibid.*

¹⁸⁷ Constitution of Ghana ch 5 arts 13–33.

¹⁸⁸ Nyarko (n 184) 99.

¹⁸⁹ Appiagyei-Atua (n 181) 22. See also art 40 (c & d) of the Constitution of Ghana 1992.

3.3 LEGAL FRAMEWORK ON THE RIGHT TO HEALTH FOR PERSONS WITH ALBINISM IN GHANA

3.3.1 *The 1992 Constitution of Ghana*

The 1992 Constitution of the Republic of Ghana guarantees the fundamental human rights and freedoms of all Ghanaians, including persons with albinism. Chapter five of the constitution is dedicated to the fundamental human rights and freedoms of the citizens of Ghana. Article 12(2) states:¹⁹⁰

(E)very person in Ghana, whatever his race, place of origin, political opinion, colour, religion, creed, or gender, shall be entitled to the fundamental human rights and freedoms of the individual contained in this Chapter but subject to respect for the rights and freedoms of others and the public interest.

Though health rights are not explicitly stated under chapter five of the constitution, article 30 protects the rights of the sick from being denied medical treatment, information and other social benefits.¹⁹¹ In addition, article 34(2) mandates the President to present before the legislature an annual report on steps taken to ensure the realisation of the rights to good healthcare.¹⁹² However, the health rights mentioned in article 34(2) fall under the directive principle of state policy provisions of the constitution, which were generally regarded not to be legally enforceable in the past.¹⁹³

In contrast, a recent Supreme Court ruling held that the directive principles are legally enforceable ‘when they are read together or in conjunction with other enforceable parts of the Constitution’.¹⁹⁴ In this instance, the rights to good healthcare enumerated in article

¹⁹⁰ Constitution of Ghana art 12 (2).

¹⁹¹ Constitution of Ghana art 30 stipulates: ‘A person who by reason of sickness or any other cause is unable to give his consent shall not be deprived by any other person of medical treatment, education or any other social or economic benefit by reason only of religious or other beliefs’.

¹⁹² Constitution of Ghana art 34(2) states: ‘The President shall report to Parliament at least once a year all the steps taken to ensure the realization of the policy objectives contained in this Chapter; and, in particular, the realization of basic human rights, a healthy economy, the right to work, the right to good health care and the right to education’.

¹⁹³ *New Patriotic Party v Attorney-General* [1993-94] 2 GLR 35 SC.

¹⁹⁴ *Ghana Lotto Operators' Association v National Lottery Authority* (2008) JELR 68447 (SC) Supreme Court· ref no J6/1/2008 ·(23 July 2008)· Ghana 14/23.

34(2) read together with other articles in chapter five, such as rights to life closely linked to health, make it justiciable and enforceable in court, unlike article 37 of the Indian constitution, which states that the directive principles of state policy cannot be enforced in any court.¹⁹⁵ The Constitution of Ghana does not explicitly and directly make the directive principles non-enforceable. Even in India, where the directive principles are explicitly unenforceable, in the case of *Paschim Banga Khet Mazdoor Samity v State of West Bengal and Another*, the Supreme Court of India read the right to health into the right to life, noting that these rights are interrelated and indivisible.¹⁹⁶ Similarly, the Supreme Court of Uganda held that failure to provide healthcare facilities violate the right to life.¹⁹⁷

Additionally, article 33(5) of the 1992 Constitution¹⁹⁸ provided an avenue for such rights not guaranteed under chapter five and are enshrined in international treaties, conventions including provisions of international human rights instruments and national human rights legislation of other democratic societies applicable in Ghana.¹⁹⁹ Nevertheless, noting the supremacy of the Constitution of Ghana over other laws and the dualist nature of Ghana's jurisprudence discussed earlier, it is required that ratified international treaties be domesticated by an act of parliament to make them enforceable.²⁰⁰ However, non-domestication of these instruments do not make them null, and therefore international human rights law can play an essential role in this regard.²⁰¹

3.3.2 *The Persons with Disability Act 715 of 2006*

The Persons with Disability Act was adopted in 2006 to provide for persons with disabilities rights and establish a national council on persons with disabilities and other related matters.²⁰² The Act provides 'free

¹⁹⁵ Constitution of India (2019) art 37.

¹⁹⁶ *Paschim Banga Khet Mazdoor Samity & Ors v State of West Bengal & Anor* (1996) AIR SC 2426, (1996) 4 SCC 37.

¹⁹⁷ Constitutional Court of Uganda, Constitutional Petition No 16 of 2011.

¹⁹⁸ Article 33(5) states: 'The rights, duties, declarations and guarantees relating to the fundamental human rights and freedoms specifically mentioned in this Chapter shall not be regarded as excluding others not specifically mentioned which are considered to be inherent in a democracy and intended to secure the freedom and dignity of man'.

¹⁹⁹ Nyarko (n 184) 99.

²⁰⁰ *ibid.*

²⁰¹ *ibid.*

²⁰² Act 715 preamble.

general and specialist medical care, rehabilitative operational treatment, and appropriate assistive devices for persons with “total” disability’.²⁰³ As far as no further guidance is provided in the Act for the classification of disability on the ground of total or partial disability, the Act defines disability in article 59 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’.²⁰⁴

The definition of disability raises serious concerns as it limits disability to medical conditions where persons with disabilities are seen as objects of medical research and objects of charity.²⁰⁵ Typically, persons with disabilities in this context are viewed as a burden to society, people who need to be cared for and those who, in some extreme cases, deserve not to live among humans.²⁰⁶ In addition, they are considered as people who are cursed or a sort of punishment from the gods to their families and society.²⁰⁷ Similarly, providing an exhaustive list of examples of disabilities such as visual, hearing and speech is discriminatory. Thus, for instance, persons with intellectual disability and albinism will not be considered persons with disabilities in the strict sense of the Act.

In addition, the definition tends to locate the impairment or disability within the individual, disregarding the environmental and attitudinal barrier persons with disabilities face in their daily interaction with basic life activities.

The preamble to the CRPD conceptualised disability as ‘an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’.²⁰⁸

²⁰³ Act 715 art 31.

²⁰⁴ Act 715 art 59.

²⁰⁵ E Durojaye and S Nabaneh, ‘Human rights and access to healthcare for persons with albinism in Africa’ (2019) 7 African Disability Rights Yearbook 35, 35-58.

²⁰⁶ Ghana Association of Persons with Albinism (GAPA), ‘Ritual banishment and stigmatization of persons with albinism in Ghana. A contextual analysis report’ (GAPA 2019) 12 <<https://actiononalbinism.org/api/files/1564577071633r4nwwrgc26c.pdf>> accessed 8 July 2021.

²⁰⁷ EA Gyamfi, ‘Ghana – Revised country report’ (Centre for Human Rights, University of Pretoria Repository on Disability Rights in Africa) <www.rodra.co.za/index.php/country-reports-ghana/28-countries/ghana/245-ghana-revised-country-report> accessed 9 September 2021.

²⁰⁸ CRPD preamble para e.

This conceptualisation provides an essential ground for emerging and complex forms of disability to be recognised. It recognises the environmental and attitudinal barriers, promotes inclusion and protects the human rights of persons with disabilities. For persons with albinism, their disability becomes more visible because of environmental factors such as sunburn and discriminatory attitudes from society.

The definition of disability in Act 715 falls short of an inclusive recognition of disability as provided by the CRPD and the African Disability Rights Protocol. For example, article 1 of the African Disability Protocol defines persons with disabilities as:

those who have physical, mental, psychosocial, intellectual, neurological, developmental or other sensory impairments which in interaction with environmental, attitudinal or other barriers hinders their full and effective participation in society on an equal basis with others.²⁰⁹

The Persons with Disabilities Act is discriminatory. It limits the enjoyment of health rights to persons with ‘total’ disabilities who are incapacitated and cannot do anything on their own while depriving others of their health rights, a necessary right to persons with disabilities, including those with albinism. The Act also failed to address equality and non-discrimination, rights to life, the rights of women and children with disabilities, and awareness-raising.²¹⁰

3.3.3 *National Health Insurance Act 2012, Act 852*

The history of health insurance in Ghana dates back to 2003 with the National Health Insurance Act 2003, Act 650.²¹¹ The Act, which became operational in 2004, marked the end of the cash-and-carry system, which hindered access to healthcare for the poor and vulnerable in society. The National Health Insurance Act 2012, Act 852, an amendment to the previous Act 650, intended to provide primary healthcare through subscription and annual premium payments. However, to ensure access to health care for the poor and vulnerable in society, the Act in section

²⁰⁹ African Disability Rights Protocol art 1.

²¹⁰ Gyamfi (n 207).

²¹¹ RK Albassan, E Nketiah-Amponsah and DK Arhinful, ‘A Review of the National Health Insurance Scheme in Ghana: What Are the Sustainability Threats and Prospects?’ (2016) PLoS ONE 11(11): e0165151 <<https://doi.org/10.1371/journal.pone.0165151>>.

29 exempts some categories of the population from premium payment, including children, pregnant women, the elderly above 70 years, categories of differently-abled persons to be determined by the Minister responsible for Social Welfare.²¹² Persons with albinism are not recognised or classified as belonging to the ‘differently-abled’ group. Therefore, the benefit the Act intends eludes persons with albinism in Ghana.

3.4 INSTITUTIONAL FRAMEWORK ON THE RIGHTS TO HEALTH FOR PERSONS WITH ALBINISM IN GHANA

Healthcare provision in Ghana has five levels of facilities or providers. These include health posts and community-based health planning services (CHPS) compounds, health centres/clinics and polyclinics, district hospitals, regional hospitals and tertiary or teaching hospitals. CHPS compounds and health posts provide primary health care and first aid in rural areas and are managed by nurses and midwives. In smaller towns, health centres and clinics have physician assistants and laboratory technicians who handle minor cases and referrals from CHPS compounds. District hospitals and polyclinics provide secondary preventive and curative healthcare services. They serve as the first point of contact for peri-urban and urban communities. At the same time, the regional and teaching hospital provides high level preventive and curative care, with most being referral cases from the lower levels. Finally, private facilities provide care either as specialist caregivers or general healthcare providers.

According to the CESCR, the right to health in all its forms and at each healthcare provision level has four essential elements, including availability, accessibility, acceptability and quality (AAAQ).²¹³ Therefore, these four elements will be employed to assess the institutional framework on the right to health for persons with albinism in Ghana. This will help provide a clear understanding of the access to healthcare available to persons with albinism in Ghana especially considering their unique healthcare needs discussed in chapter two.

²¹² National Health Insurance Act 2012 Act 852.

²¹³ CESCR ‘General Comment No 14’ (n 165) para 12.

3.4.1 Availability

Availability of well-resourced and functioning public health and healthcare facilities, goods and services, and health-related programmes and information are crucial to the enjoyment of rights to health for Ghanaians with albinism. Per their condition, which comes with multiple specialist healthcare needs, persons with albinism need specialist care such as dermatological and eye care services for a regular skin screening, early detection and treatment of skin problems, including skin cancer and eye-related problems. Currently, Ghana can only boast of 23 dermatologists serving over 30 million people, and most of them are located in urban areas such as Accra and Kumasi.²¹⁴ This means access to dermatological services by persons with albinism will be challenging, especially for those in rural areas whose daily survival needs depends on farming and other outdoor activities

Skin cancer is the primary cause of morbidity and mortality among persons with albinism in Sub-Saharan Africa.²¹⁵ Therefore, governments are expected to make adequate provisions to ensure these individuals are provided with available facilities to treat this deadly disease. However, this is not the case in Ghana. The country has only three radiotherapy facilities – Korle-Bu and Komfo Anokye Teaching Hospitals and a privately-owned Sweden Ghana Medical Center.²¹⁶ Sunscreen is a luxury and can only be found in supermarkets and malls at an exorbitant price. Therefore, this essential product is unavailable to persons with albinism in Ghana. In health facilities, no provision is made for it as they are generally considered cosmetic products and used mainly by expatriates.²¹⁷

²¹⁴ E Smith-Asante, 'Only 23 dermatologists in Ghana; Rabito plans a rescue' (*Graphic Online*, 16 October 2018) <www.graphic.com.gh/news/health/only-23-dermatologists-in-ghana-rabito-plans-a-rescue.html> accessed 24 September 2021.

²¹⁵ SE Emadi and others, 'Common malignant cutaneous conditions among albinos in Kenya' (2017) 31(1) *Med J Islam Repub Iran* 7 <<https://doi.org/10.18869/mjiri.31.3>>.

²¹⁶ EW Fiagbedzi and C Ahadzie, 'Radiotherapy in cancer treatment in Ghana: from the past to present' (Radiotherapy in Cancer Control Plans) <https://humanhealth.iaca.org/HHW/RadiationOncology/ICARO2/E-Posters/04_FIAGBEDZI.pdf> accessed 1 September 2021.

²¹⁷ W Thompson-Hernández, 'The Albino Community in Ghana: "I'm Motivated to Believe That I Can Survive"' (*The New York Times*, 9 June 2018) <www.nytimes.com/2018/06/09/world/africa/living-with-albinism-in-ghana.html> accessed 24 July 2021.

Similarly, eye care services and counselling and clinical psychological support services are inadequate and beyond the reach of this population. Moreover, mental health is not integrated into the general healthcare system. Instead, these services are provided by specialised institutions called psychiatric hospitals, which have a severe stigma. Factors such as inadequate personnel, lack of knowledge on skin cancer by health personnel and person with albinism alike, late presentation of cases at health facilities²¹⁸ and inadequate healthcare facilities, goods and services worsen the enjoyment of the right to health of persons with albinism in Ghana.

3.4.2 Accessibility

Access to health facilities, goods and services such as skin cancer treatment facilities, dermatological, ophthalmological and counselling services, and sunscreen products are crucial to the enjoyment of rights to health by persons with albinism. The state must ensure these services are accessible to everyone, including persons with albinism. Physical accessibility is essential to persons with albinism as they are most vulnerable to attacks. Health facilities, goods and services must be within reach for these individuals to avoid further exposure to the sun and attack in their attempt to visit these healthcare facilities.

As indicated earlier, cancer facilities in Ghana are located in cities far from the reach of persons with albinism, as in the case of other services peculiar to their health. Persons with albinism living in other parts of the country have to travel long distances to Accra or Kumasi to access these services. This brings to mind economic accessibility as most persons with albinism, and their families cannot afford these services and the cost of transportation to these facilities and sunscreens, contact lenses and other visual aids, sunglasses and protective clothing due to poverty.²¹⁹ This leads to discrimination, marginalisation and social exclusion faced by this group because of their condition, which further reduces their chances of quality education and the consequential unemployment status and low standard of living.

²¹⁸ V Vanderpuye and N Adorkor Aryeetey, 'Cancer radiotherapy in Ghana' (*Cancer Control*) <http://cancercontrol.info/cc2016/cancer-radiotherapy-in-ghana/> (accessed 1 September 2021).

²¹⁹ Ero and others (n 170) 79.

Access to information on albinism and its relationship with skin cancer and other health challenges is lacking in the country. This makes it difficult for persons with albinism and their families to identify their problems and seek help. Also, paucity of knowledge among health workers coupled with superstition increases the deterioration of the health of persons with albinism in Ghana. For instance, Charles Assuming, a skin cancer patient, has to rely on the public through the media to raise enough funds to undergo radiotherapy and chemotherapy procedures to treat himself as there are no clear-cut policies on albinism in Ghana.²²⁰ Also, his condition deteriorated over the years due to wrong diagnoses.

Persons with albinism cannot access healthcare services, especially treatment for skin cancer, due to poverty and lack of government support. For example, the National Health Insurance Scheme (NHIS) does not cover skin cancer treatment, and the provision of visual aids is considered an exclusion from the benefits package of the scheme.²²¹ As a result, persons with albinism have limited access to social benefits from the government.²²² For instance, the District Assembly Common Fund dedicated to helping persons with disabilities in Ghana cannot easily be accessed by persons with albinism owing to a lack of recognition of albinism as a form of disability and lack of information on the processes of accessing this fund at the district level.

3.4.3 *Acceptability*

Persons with albinism need sunscreens and other sun care products as much as they need malaria drugs. This is because sunscreens form part of their daily routine usage as a measure of sun protection. Therefore, it is expected that health facilities, goods and services available to this population respect their basic health needs. However, available and accessible CHPS compounds to a person with albinism do not guarantee dermatological or ophthalmological services since there is a lack of such health professionals in these facilities. This means that

²²⁰ TV3 Ghana, 'News360' (*Facebook*, 12 June 2021) <www.facebook.com/TV3GH/videos/319502449804618> accessed 1 September 2021.

²²¹ National Health Insurance Scheme (NHIS), 'Benefit Package' <www.nhis.gov.gh/benefits.aspx> accessed 1 September 2021.

²²² Thompson-Hernandez (n 217).

the health facilities, goods and services, though available, do not respect and are insensitive to the life-cycle requirement and the health status of persons with albinism. Furthermore, travelling long distances in the sun to access health services may be counterproductive to the general well-being of persons with albinism. This instead increases their level of vulnerability to attacks and sunburns.

3.4.4 *Quality*

The healthcare quality available to persons with albinism in Ghana cannot be guaranteed. Experience revealed that persons with albinism who present advanced cases of skin cancer to tertiary health facilities have gone through the primary health care system. Reports of cancerous lesions and recurrent wounds treated as ordinary sores remain prominent among skin cancer patients with albinism. Wrong diagnoses and prescriptions coupled with a lack of financial resources to travel to tertiary healthcare centres militate against the enjoyment of the right to health by persons with albinism in Ghana. In addition, societal prejudices, myths and misconceptions about albinism mean that some health workers find it challenging to provide appropriate care to these individuals.

Quality of service delivery to persons with albinism is low due to their appearance, which some health workers find very repugnant. For instance, a 23 year-old man with albinism was left to die due to the offensive odour around him due to an advanced stage tumour of the head. In addition, discrimination, stigma and social exclusion faced by persons with albinism hinder access to quality health care, especially when healthcare workers exhibit these attitudes.²²³

²²³ Engage Now Africa, 'Albinism in Ghana' (8 December 2020) <www.youtube.com/watch?v=oNwGPbdmPIk&t=14s> accessed 26 August 2021.

3.5 CONCLUSION

International and regional human rights instruments guarantee the right to health of everyone, including persons with albinism. These standards further mandate state parties to adopt legislative and administrative measures to fulfil these rights. It is also clear from the discussion that Ghana, as a state party to these instruments, has made laws to provide for the vulnerable in society. For instance, article 29 of the 1992 Constitution of Ghana recognises persons with disabilities. Furthermore, in response to article 29(8), the legislative step led to the adoption of Act 715 in 2006. This Act provides free healthcare for persons with disabilities and, by extension, persons with albinism. Similarly, the National Health Insurance Act also provided free healthcare for these populations depicting respect for the obligations enshrined in international human rights law.

However, administrative actions required to translate these laws into policies and programmes for the benefit of persons with disabilities is lacking. For instance, the NHIS does not make adequate provisions for persons with albinism to derive maximum benefit as their health care needs are not covered. In terms of institutional arrangement on the rights to health of persons with albinism, several factors barricade AAAQ of health facilities, goods and services for this vulnerable group. Inadequate cancer treatment facilities, lack of access to the few existing ones, lack of financial resources and social supports, inadequate knowledge on albinism, the attitude of health workers toward persons with albinism coupled with lack of information, stigma, discrimination and social exclusion are among the barriers to access to health care for persons with albinism in Ghana.

4.

BEST PRACTICES IN HEALTHCARE PROVISION FOR
PERSONS WITH ALBINISM ACROSS AFRICA: LESSONS FOR
GHANA

4.1 INTRODUCTION

Melanin deficiency in persons with albinism predisposes them to health complications, including skin cancer, visual problems and mental health issues. For example, in Sub-Saharan Africa, skin cancer is the primary cause of morbidity and mortality among persons with albinism.²²⁴ Aside from this, persons with albinism have low vision of varying degrees. These visual issues commonly include nystagmus, photosensitivity, strabismus and reduced visual acuity. Furthermore, research indicates that persons with albinism are likely to develop mental health problems due to discrimination, stigmatisation and social exclusion.²²⁵ See chapter two for an elaborate discussion on the health needs of persons with albinism.

These health complications require deliberate, concrete and targeted solutions from both state and non-state actors to help prolong the lifespan of persons with albinism, especially in Africa. Several African states, in collaboration with NGOs and CSOs, have adopted and implemented various measures to safeguard the health of persons with albinism across the continent.²²⁶ These measures have produced desirable health outcomes for persons with albinism in those states.

²²⁴ PM Lund and JS Taylor, 'Lack of adequate sun protection for children with oculocutaneous albinism in South Africa' (2008) 8 BMC Public Health 225 doi:10.1186/1471-2458-8-225.

²²⁵ AA Afram, E Teye-Kwadjo and AA Gyasi-Gyamerah, 'Influence of social stigma on subjective well-being of persons with albinism in Ghana' (2019) 29(4) Journal of Community and Applied Social Psychology 323, 332, 332. <<https://doi.org/10.1002/casp.2403>>. accessed 26 August 2021.

²²⁶ See detailed discussion in the following section of this chapter.

Therefore, these measures are considered ‘best practices’ in health programmes for persons with albinism worthy of emulation by other African states. This chapter examines such ‘best practices’ and their importance to the health of persons with albinism. Moreover, they present valuable lessons that Ghana can draw from, adopt and adapt such practices to mainstream the health needs of persons with albinism within Ghana’s health sector.

4.2 BEST PRACTICES IN HEALTHCARE PROGRAMMES FOR PERSONS WITH ALBINISM

The right to the highest attainable standard of physical and mental health is essential and must be protected in itself and as part of the right to life. Health legislation, policies, programmes, facilities, goods and services must adopt ‘best practices’ to produce the desired result. According to the WHO:²²⁷

‘Best Practice’ is ‘knowledge about what works in specific situations and contexts, without using inordinate resources to achieve the desired results, and which can be used to develop and implement solutions adapted to similar health problems in other situations and contexts.

In essence, ‘best practices’ in healthcare are not perfect solutions to health problems. Instead, those producing significant results leading to improved health outcomes for people in similar situations and contexts. As far as ‘best practices’ are not about perfection, they present valuable lessons to stakeholders to avoid unnecessary mistakes and adopt, adapt and implement such practices in similar situations.²²⁸ For instance, providing sunscreen products to persons with albinism at no cost or subsidised rates would be considered a ‘best practice’ since they help prevent sunburn, a precursor to skin cancer among persons with albinism in Africa.

Best practices in healthcare service provision for persons with albinism should focus on their physical and mental health. Physical healthcare services should pay attention to dermatological services such as preventing skin lesions. Recommended practice includes the supply

²²⁷ WHO Regional Office for Africa, *Guide for Documenting and Sharing ‘Best Practices’ in Health Programmes* (AFRO Library 2008) para 6.

²²⁸ *ibid* para 7.

of sun-protective products such as sunscreens, hats and protective clothing.²²⁹ In addition, regular screening for skin lesions and early detection and treatment of cancerous lesions should be conducted.²³⁰ Likewise, ophthalmological and optometric services are provided to enhance the eye health of this population.²³¹

Eye screening and prescription of appropriate lenses, including tinted sunglasses, are recommended and encouraged. Likewise, surgeries should be carried out on individuals with eye conditions requiring such services. Training healthcare professionals and integrating psychosocial support services reduce the mental health conditions persons with albinism face due to social factors.²³² Consultation with and engagement of this population in decision making concerning their health produce the most significant outcomes and encourage ownership of these policies and programmes.²³³ It is highly recommended that health policies and programmes targeting vulnerable populations, including persons with albinism, should not be isolated; instead, they should be integrated into general healthcare policies and programmes to avoid further discrimination and social exclusion.

4.3 LEGAL AND POLICY FRAMEWORKS

Health is a fundamental human right that needs strong protection under the law. In this regard, Article 12 of the ICESCR provide a comprehensive provision recognizing the right to health of everyone in international human rights law.²³⁴ Article 12(1) mandates state parties to the covenant to recognise the right of everyone to enjoy the highest attainable standard of physical and mental health.²³⁵ Article 12(2) obligates states to take appropriate steps, including legislative

²²⁹ Human Rights Council, 'Report of the Independent Expert on the enjoyment of human rights by persons with albinism' A/HRC/37/57 (2017) para 67.

²³⁰ I Ero and others, 'People with albinism worldwide. A human rights perspective' (United Nations 2021) 110 <www.ohchr.org/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf> accessed 24 July 2021.

²³¹ *ibid.*

²³² HRC 'Report of the Independent Expert 2017' (n 229) para 98(b).

²³³ CESCR, 'General Comment No 14: The right to the highest attainable standard of health' (2000) E/C/12/2000, para 17.

²³⁴ *ibid* para 2.

²³⁵ ICESCR art 12(1).

and administrative means to fully realise this right.²³⁶ To fulfil their international obligations, the state must ensure laws and policies are adopted to guarantee these rights. In addition, these legal frameworks require that relevant social support mechanisms be implemented to ensure equality and non-discrimination in both the public and private health sectors.²³⁷ Similarly, appropriate and effective remedies must be developed to address right violations.

For instance, in South Africa, section 7(2) of the 1996 Constitution imposes an obligation on the state to protect, promote, respect and fulfil all rights enshrined in the Bill of Rights, including the right to health as set out in section 27 of the Constitution. Section 27(1) of the Constitution provides the right to access healthcare services, while section 27(2) mandates the state to ‘take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights’.²³⁸ Accordingly, the National Assembly enacted the National Health Act in 2003.²³⁹

to provide a framework for a structured uniform health system within the Republic, taking into account the obligations imposed by the Constitution and other laws on the national, provincial and local governments with regard to health services; and to provide for matters connected therewith.

Section 4(2d) recognises persons with disabilities, including albinism, as a group of vulnerable individuals eligible for free health care under the Act.²⁴⁰

In March 2016, the Minister of Social Development gazetted the White Paper on the Rights of Persons with Disabilities. The white paper, among other provisions, recognises the rights of persons with disabilities, including their health rights.²⁴¹ Furthermore, in October 2012, South Africa adopted a conference resolution on albinism named

²³⁶ ICESCR art 12(2).

²³⁷ African Commission on Human and Peoples’ Rights, ‘Principles and guidelines on the implementation of economic, social and cultural rights in the African Charter on human and peoples’ rights’ para 7. accessed 28 August 2021, para 67(jj).

²³⁸ The Constitution of the Republic of South Africa 1996 ss 7(2) and 27.

²³⁹ Republic of South Africa, National Health Act 2004 No 61 of 2003.

²⁴⁰ *ibid* art 4(2d).

²⁴¹ Republic of South Africa, ‘White paper on the rights of persons with disabilities’ (Department of Social Development 2016).

the ‘Ekurhuleni Declaration on the Rights of Persons with Albinism’.²⁴² The declaration recognises the rights of persons with albinism and declares free health care for them. Further, the Ekurhuleni Declaration also provided free sunscreen products for persons with albinism in public health facilities across the country.²⁴³ This legal and policy framework provides a solid legal protection and safety net for South Africans with albinism.

Likewise, the 2010 Constitution of Kenya in article 43(1)(a) protects Kenyans’ rights to health,²⁴⁴ including persons with albinism though not explicitly mentioned. However, the 2018 proposed Persons with Disabilities Amendment Bill expressly mentions persons with albinism.²⁴⁵ Therefore, this Act will give this population adequate legal protection and provisions for their health rights if passed into law. Moreover, Tanzania’s Persons with Disabilities Act provides healthcare fee waivers for persons with disabilities, including albinism and further measures are in place to develop a guideline to this effect.²⁴⁶

Also, Nigeria’s National Policy on Albinism provides free healthcare, including prevention and treatment of skin cancer and eye care. Furthermore, other countries, including Uganda,²⁴⁷ Mozambique²⁴⁸ and Malawi,²⁴⁹ have developed National Action Plans on albinism to protect and prioritise the rights of persons with albinism. In addition, the Republic of Guinea has adopted a law on 30 April 2021 to protect and promote the rights of persons with albinism.²⁵⁰ These legal and policy

²⁴² Ekurhuleni Declaration on the rights of persons with albinism (27 October 2013) <www.gov.za/ekurhuleni-declaration-rights-persons-albinism> accessed 14 September 2021

²⁴³ *ibid.*

²⁴⁴ Constitution of Kenya 2010 art 43,1a.

²⁴⁵ HRC, ‘Visit to Kenya. Report of the Independent Expert on the enjoyment of human rights by persons with albinism’ (2019) A/HRC/40/62/Add.3.

²⁴⁶ United Nations Special Procedures, ‘Best Practices In the protection of human rights of persons with albinism. Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism’ (2020) (Presented to the 75th session of the General Assembly A/75/50343).

²⁴⁷ Government of Uganda, ‘National action plan for persons with albinism 2020-2025’ (2020) <<https://actiononalbinism.org/api/files/1625065386232ryivkhkrcrt8.pdf>> accessed 6 October 2021.

²⁴⁸ Republic of Mozambique, ‘Multi-sectoral action plan to address the issue of the protection of persons with albinism’ (2015) <<https://actiononalbinism.org/api/files/15681144716978ueh1iaje62.pdf>> accessed 6 October 2021.

²⁴⁹ Malawi Government, ‘National action plan on persons with albinism in Malawi 2018 – 2022’ (2018) <<https://actiononalbinism.org/api/files/15680987533626r6omtihg4.pdf>> accessed 6 October 2021.

²⁵⁰ Republic of Guinea, ‘Portant protection et promotion des droits des personnes atteintes d’albinisme en republique de Guinee’ (2021) <<https://actiononalbinism.org/api/files/162211107932296r4uadfyai.pdf>> accessed 6 October 2021.

measures in the examples above provide a legal shield to the rights of persons with albinism, including an attainable standard of physical and mental health. However, these laws also raise an additional set of questions as to how they will be translated into action that positively changes the lives of persons with albinism.

4.4 SOCIAL PROTECTION MEASURES

Social protection measures targeting the health needs of persons with albinism are essential to ensuring their attainable standard of physical and mental health. The weather conditions in Africa present the most significant challenges to persons with albinism, with increasing vulnerability for those close to the equator.²⁵¹ In addition, persons with albinism are highly susceptible to developing skin cancer upon sun exposure.²⁵² Therefore, states must put in place social interventions including dermatological, ophthalmological and psychosocial services that cater for the health needs of this population.²⁵³

Skin cancer prevention among persons with albinism should be a strategic priority for public health departments. To this end, sun-protective products, including sunscreen lotions, after-sun lotions, lip balm, wide-brimmed hats and long-sleeved shirts, should be available to this population at no cost or subsidised rates or included on essential drug lists as part of national health insurance schemes.²⁵⁴ For instance, in Tanzania, due to Standing Voice through its Skin Cancer Prevention Programme (SCPP), 95% of persons with albinism are practising sun protection measures leading to a reduction in the administration of cryotherapy.²⁵⁵ In addition, the continuous supply of these essential products increased sunscreen use among persons with albinism from 62% in 2017 to 89% in 2019, with over 5,900 beneficiaries.²⁵⁶ Since its introduction in 2017, the SCPP have supplied 400 wide-brimmed hats and 1,720 pots of sunscreen lotions to persons with albinism in Malawi.²⁵⁷

²⁵¹ TL Diepgen and V Mahler, 'The epidemiology of skin cancer' (2002) 146(61) *British Journal of Dermatology* 1, 2.

²⁵² Lund and Taylor (n 224) 2.

²⁵³ Ero and others (n 230) 83.

²⁵⁴ African Commission on Human and Peoples' Rights, 'Principles and guidelines on the implementation of economic, social and cultural rights in the African Charter on human and peoples' rights' para 67(bb). accessed 28 August 2021.

²⁵⁵ Standing Voice, 'Skin Cancer Prevention Program Annual Report 2018-2019' (2020) 12.

²⁵⁶ *ibid.*

²⁵⁷ *ibid.*

Persons with albinism in South Africa, Zambia and Kenya are also provided free sunscreens through government support initiatives. For example, in Kenya, over 4,000 persons with albinism are currently benefiting from the monthly allocation of sunscreen products through the National Albinism Sunscreen Support Program (NASSP).²⁵⁸ While, in South Africa, a study conducted among 111 school children with albinism indicated that 38% of the participants use sunscreen.²⁵⁹ However, only 12.2% of the participants had government-provided sunscreen lotion of sun protection factor (SPF) 15, which is below the recommended SPF for persons with albinism.²⁶⁰ Local production of sunscreen is vital to make the products available and accessible, including economic accessibility. Since 2012, the Kilimanjaro Sunscreen Production Unit under the Regional Dermatology Training Centre (RDTC) has delivered over 21,300 pots of Kilisun to persons with albinism across Tanzania.²⁶¹

Health facilities and dermatological services should be available and accessible to these individuals for regular screening, early detection and treatment of skin lesions. For example, mobile clinics in Tanzania and Malawi run by Standing Voice is a great example to be emulated by states to reach out to those in remote areas. Similarly, skin cancer screening and treatment provided by the RDTC in Tanzania have improved the health status of persons with albinism within the country. Likewise, the Nigerian government's free skin cancer treatment programme is worth emulating.²⁶² The Albino Foundation reported that over a thousand patients with skin cancer had gone through surgeries and other palliative care at no cost since 2007.²⁶³

Additionally, ophthalmological services providing eye care should be mainstreamed within the health sector with specific attention to the eye conditions of persons with albinism. These services should pay attention to the varying degrees of low vision and eye health of persons with albinism to ensure appropriate optical aids and assistive technology to improve their functional vision. Contact and prescription lenses and

²⁵⁸ National Council on Persons with Disabilities, 'Albinism (Support Program)' <<https://ncpwd.go.ke/albinism-support-program/>> accessed 11 September 2021.

²⁵⁹ Lund and Taylor (n 224) 4.

²⁶⁰ *ibid.*

²⁶¹ Standing Voice (n 255).

²⁶² HRC 'Report of the Independent Expert 2017' (n 229) para 81.

²⁶³ The Albino Foundation, 'Healthcare' <<https://albinofoundation.org/health-care/>> accessed 12 September 2021.

tinted sunglasses with UV protection are generally recommended to enhance their vision. For instance, more than 1,000 persons with albinism benefited from prescription glasses and other optical aids in Kenya as part of the NASSP.²⁶⁴

It is rather unfortunate to note that most health intervention initiatives by both government and NGOs focus primarily on physical health to the neglect of mental health for persons with albinism across the regions. However, it is worth noting the efforts of Standing Voice to provide public education to persons with albinism and their families, especially in areas of attack in Tanzania and Malawi, providing psychosocial support to these individuals. In Malawi alone, Standing Voice, in partnership with district health departments, has organised 87 health education and community sensitisation training events to create public awareness on albinism among persons with albinism and the general public, including CSOs.²⁶⁵

4.5 CAPACITY BUILDING FOR HEALTH PROFESSIONALS AND PERSONS WITH ALBINISM

The availability of skilled healthcare professionals is an essential element of a quality, effective and efficient healthcare system. To this end, capacity building plays a significant role in developing the required skill set needed by these professionals. To ensure persons with albinism enjoy the highest attainable standard of physical and mental health, there should be an adequate, available and accessible healthcare professional to provide the required services. Therefore, developing and strengthening the capacity of healthcare professionals to identify potential albinism cases and provide the necessary support services, including information, testing and counselling, must be prioritised.²⁶⁶

Training programmes for healthcare workers should include specific information on albinism, such as skin and eye problems and mental health concerns. For example, a training ‘manual on best practices on skin cancer treatment and management in Africa’ developed by Standing Voice is an excellent resource.²⁶⁷ The RDTC trains dermatologists and

²⁶⁴ HRC ‘Report of the Independent Expert 2017’ (n 229) para 76.

²⁶⁵ Standing Voice (n 255) 34-40.

²⁶⁶ United Nations Special Procedures (n 247) 25.

²⁶⁷ A Sharp (ed), ‘Manual of Best Practice; Skin Cancer Prevention and Management for Persons with Albinism in Sub-Saharan Africa’ (Standing Voice 2019).

other healthcare professionals in Tanzania, including radiotherapists and surgeons. In addition, through its SCPP, Standing Voice provided basic dermatology training to community health nurses in Tanzania and Malawi.²⁶⁸ These community-based dermatologists provide primary screening for skin cancer among persons with albinism and administer cryotherapy treatment to remove skin lesions. Their services help in the early detection and treatment of skin cancer in both countries. For instance, the SCPP trained 12 dermatologists who provided services to 457 persons with albinism across two districts in Malawi.²⁶⁹

Furthermore, states must ensure that resources, facilities and skilled healthcare professionals provide the required services such as skin cancer screening, early detection and treatment for persons with albinism. For instance, healthcare professionals such as dermatologists, oncologists, radiotherapists, ophthalmologists, optometrists and other support staff should be readily available with adequate knowledge of albinism. In addition, other professionals such as psychologists and genetic counsellors should provide such services and information necessary to mothers of children with albinism at the point of delivery and regularly.

For instance, in South Africa, genetic counsellors at the public hospital provide counselling to mothers who give birth to children with albinism.²⁷⁰ These counselling sessions offer valuable information to these mothers on care for these children and where to receive healthcare services. The availability of psychologists in public hospitals serves a great deal by helping persons with albinism with psychosocial support services, hence reducing mental health conditions. However, such support services are generally lacking in the mainstream health sector. Where they are available, these services are provided by specialist health facilities. For example, psychosocial and mental healthcare services are provided by psychiatric hospitals in Ghana. Unfortunately, these health facilities are heavily stigmatised due to a lack of understanding of mental health issues. The stigma deters many from seeking services in such facilities. To avert this, mental health services should be integrated into the general healthcare system to encourage patronage.

Persons with albinism and their families should be trained to understand their condition and the care they need to be physically and

²⁶⁸ Standing Voice (n 255) 34-40.

²⁶⁹ *ibid.*

²⁷⁰ United Nations Special Procedures (n 246) 25.

mentally healthy. For instance, persons with albinism and their families should be trained on sun-protection measures and identify skin problems that require medical attention. Likewise, they can be trained to produce sunscreens using local materials. For example, the Kilimanjaro Sunscreen Production Unit teaches persons with albinism to make sunscreens in Tanzania locally. A similar practice is ongoing in Malawi and Ghana, led by Standing Voice and Engage Now Africa. The local production of sunscreens makes these products readily available and provides decent employment to them.

4.6 RESEARCH AND DATA COLLECTION ON ALBINISM

Data collection plays an essential role in planning goods and services, especially for the vulnerable in society. Data on albinism is a significant step to ensuring that the challenges associated with the condition are integrated into national development and strategic plans. Data is an accountability measure, especially in the wake of attacks targeting this population. Disaggregated data on albinism promote inclusive government planning, adequate delivery of goods and services, especially in healthcare and education. To this end, it is crucial government capture disaggregated data on persons with albinism through the population and housing censuses and other relevant surveys, especially those relating to access to healthcare.

Examples worth emulating in gathering data on albinism include Kenya's 2019 population and housing census, which put the total number of persons with albinism at 9,729, comprising 4,467 males and 5,261 females.²⁷¹ Malawi's 2018 population and housing census reported 134,636 persons with albinism, representing 0.8% of the country's population.²⁷² Other examples include Tanzania, with an estimated 0.04% of the country's population²⁷³ and Namibia, with 1,153 according to the 2011 population census.²⁷⁴ In Sierra Leone, the 2015 population

²⁷¹ Kenyan National Bureau of Statistics (KNBS), '2019 Kenya population and housing census, Volume IV; Distribution of population by socio-economic characteristics' (2019) 9.

²⁷² Malawi Government, '2018 population and Housing Census, Disability Report' (National Statistical Office 2020) 20.

²⁷³ United Republic of Tanzania, 'Disability Monograph' (National Bureau of Statistics 2016).

²⁷⁴ Namibia 2011 Census, 'Disability Report' (Namibia Statistics Agency 2016).

census indicated 501 persons with albinism representing 0.5% of the country's population.²⁷⁵ Statistical information captured by the national census is the starting point for identifying, planning, provision and delivering goods and services targeting this population.

Additionally, research and data collection on albinism are crucial to identify the prevalence rates and types and the health needs of this population.²⁷⁶ Research and data relating to albinism should also focus on the availability of relevant services to support their healthcare needs, barriers to accessing these services and healthcare professionals' capacity.²⁷⁷ Some academic research has estimated the prevalence rate of albinism in Nigeria, South Africa, Zimbabwe, Tanzania²⁷⁸ and Ghana.²⁷⁹ Continentwide, estimates indicate 1 in 5,000 to 1 in 15,000 persons with albinism in Sub-Saharan Africa.²⁸⁰ Other research targeting the health needs of persons with albinism, primarily skin cancer, was conducted in Togo,²⁸¹ Tanzania,²⁸² Nigeria,²⁸³ Uganda,²⁸⁴ Sierra Leone²⁸⁵ and Ghana.²⁸⁶ These research data provide an understanding of the condition and its associated healthcare needs to inform decision making targeting the population by public and private sector stakeholders.

²⁷⁵ FM Conteh and L Braima, 'Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone' (Lady Ellen Women's Aid Foundation/Open Society Institute for West Africa (OSIWA) 2018).

²⁷⁶ United Nations Special Procedures (n 246) 23.

²⁷⁷ *ibid.*

²⁷⁸ 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.

²⁷⁹ A Mwandida, 'Prevalence rate of albinism in Abura, Asebu Kwamankese district in Central region' (Master's thesis, African Institute for Mathematical Sciences, University of Ghana 2018).

²⁸⁰ Hong, Zeeb and Repacholi (n 278), 115.

²⁸¹ B Saka and others, 'Skin cancers in people with albinism in Togo in 2019: results of two rounds of national mobile skin care clinics' (2021) 21 *BMC Cancer*, 3 <<https://doi.org/10.1186/s12885-020-07747-8>>.

²⁸² SK Kiprono, MC Baraka and H Beltraminelli, 'Histological review of skin cancers in African Albinos: a 10-year retrospective review' (2014) 14 *BMC Cancer*, 157.

²⁸³ OO Awe and TA Azeke, 'Cutaneous cancers in Nigerian albinos: A review of 22 cases' (2018) 24 *Niger J Surg* 34, 35.

²⁸⁴ The OHCHR and Equal Opportunities Commission, 'Enhancing equality and countering discrimination against persons with albinism in Uganda' (2019) <https://uganda.ohchr.org/Content/publications/Albinism_Analysis_Report_2019.pdf> accessed 29 September 2021.

²⁸⁵ FM Conteh and L Braima, 'Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone' (Lady Ellen Women's Aid Foundation/Open Society Institute for West Africa (OSIWA) 2018).

²⁸⁶ Affram, Teye-Kwadjo and Gyasi-Gyamerah (n 225) 332.

4.7 CONCLUSION

Healthcare remains a primary concern for persons with albinism aside from the physical attacks and ritual killings. Since the right to health is closely linked with the right to life, and the weather conditions in Africa remain a threat to the survival of persons with albinism, governments across Africa must take stringent, deliberate, concrete and targeted steps to safeguard these rights. These steps must be coded in legal and policy frameworks and reflected in institutional setups for proper implementation, coordination and monitoring. However, there is little to no dedicated legal or policy frameworks safeguarding the rights to health of persons with albinism in Africa. There is a worrying trend of few government initiatives and supports for providing healthcare for persons with albinism across the continent.

Challenges of implementation cut across all the healthcare interventions, which are heavily driven by NGOs and CSOs. For instance, in Tanzania and Malawi, strong NGOs committed to saving the lives of persons with albinism make it possible to smooth these interventions with few challenges. However, inadequate resources, including financial and human resources, create difficulty for even strong NGOs with little government commitment. Moreover, it is evident that other aspects of health, such as mental health and vision care, are not adequately cared for due to the lack of proper coordination of the interventions. Most, if not all, interventions focus mainly on skincare to the detriment of other equally important ones, especially mental health. Governments across Africa must take the lead to protect, promote and fulfil their legal obligations under international human rights law with support from NGOs, CSOs and the international community.

5.

CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This research has explored how the right to access healthcare for persons with albinism is guaranteed under international and national legal frameworks. However, despite these legal frameworks safeguarding the right to health of persons with albinism in Ghana, numerous barriers hinder the full extent to which these individuals access these rights. Chapter two of this research discussed the full extent of albinism's healthcare needs, including physical and mental health conditions. In chapter three, the study highlighted the legal and institutional framework on the right to health. In addition, chapter four explored best practices in healthcare provision for persons with albinism across Africa. Finally, this chapter summarises the main findings of the research and suggests recommendations to remedy the same.

5.2 LEGISLATIVE AND POLICY ACCESSIBILITY TO HEALTH

This research found that Ghanaian laws, legislation and health policies do not recognise albinism as a public health concern with special healthcare needs. The 1992 Constitution provides the rights of persons with disabilities in article 29(4) protect them 'against all exploitation, all regulation and all treatment of discriminatory, abusive and degrading nature'. It further mandates parliament in subsection 8 to enact appropriate laws necessary to enforce the provisions in the constitution.²⁸⁷ This provision led to the adoption of the Persons with

²⁸⁷ Constitution of Ghana art 29.

Disabilities Act in 2006. However, Act 715 provides free healthcare for persons with ‘total’ disabilities, sharply discriminating against those with mild and moderate disabilities. In addition, the medical approach to disability adopted by the Act created a barrier to those whose disabilities are fuelled by attitudinal and environmental factors, such as persons with albinism.

In addition to the above, the National Health Insurance Act has no provisions recognising persons with albinism’s health needs. Further, the research revealed that skin cancer treatment and provision of optical or assistive devices and psychosocial support services are not included in the NHIS benefit package.²⁸⁸ This means that persons with albinism must pay to access these services. Furthermore, essential medicines or products such as sunscreens, after-sun lotions, lip balm and assistive devices are also excluded from the benefits package. Thus, aside from albinism and its needs not being mentioned in any legal or policy documents, Ghana cannot pinpoint a single policy document dedicated to the welfare of persons with albinism. This lack of legal recognition of albinism creates a barrier for persons with albinism to access healthcare proportionate to their basic health needs in Ghana.

5.3 ADMINISTRATIVE ACCESSIBILITY AND REASONABLE ACCOMMODATION

This research shows that the health sector’s institutional setup created accessibility barriers for persons with albinism. First, in terms of health facilities for skin cancer treatment, it has been indicated that Ghana has only three cancer treatment facilities across the country. Also, there are 173 facilities providing eye care services.²⁸⁹ Unfortunately, these facilities are located in the major cities of Accra and Kumasi, creating physical accessibility barriers. For instance, persons with albinism dwelling outside these cities have to travel long distances to access these facilities. Secondly, patients’ load on these facilities leads to delayed treatment of ever-growing skin cancer tumours. Furthermore, the cost of treatment that persons with albinism and their families cannot afford leads to discontinuing treatments since these costs are not covered under the NHIS benefit package.

²⁸⁸ National Health Insurance Scheme (NHIS), ‘Benefit Package’ <www.nhis.gov.gh/benefits.aspx> accessed 1 September 2021.

²⁸⁹ EK Amewuho Morny and others, ‘Assessing the Progress towards Achieving “Vision 2020: The Right to Sight” Initiative in Ghana’ [2019] *Hindawi Journal of Environmental and Public Health*, Article ID 3813298, 3 <<https://doi.org/10.1155/2019/3813298>>.

Health services and goods related to the health needs of persons with albinism are inadequate. The research revealed that persons with albinism do not have access to sunscreen lotions and other sun-protective products. Sunscreens are generally unavailable, and even if found in supermarkets, they are costly beyond what persons with albinism can afford. There is no effort from the government to make these products available and accessible to this population. There are only 23 dermatologists,²⁹⁰ 91 ophthalmologists, and 370 optometrists providing services for over 30 million Ghanaians, and over 70% of these professionals are in Accra and Kumasi.²⁹¹ The scarcity of these health professionals means access to adequate healthcare for persons with albinism is hindered, considering the number of patients to be served and the amount of time given to each patient for proper diagnoses and treatment. To avoid further stigma, persons with albinism needing psychosocial support services avoid accessing psychiatric hospitals due to the stigma associated with these specialist health facilities. Lack of prioritisation for prevention and treatment of skin cancer and lack of reasonable accommodation of the healthcare needs of persons with albinism hinders their access to an attainable standard of physical and mental health in Ghana.

5.4 INFORMATION ACCESSIBILITY AND SOCIO-CULTURAL BELIEFS AND PRACTICES

This research revealed that people with albinism in Ghana lack adequate information on their condition and health implications. Public education programmes do not include detailed information on albinism. Information inaccessibility to persons with albinism and their families make it difficult for them to make informed choices about their health and the kind of health facilities, goods and services available to them. For instance, public education posters, handouts and other materials come in small font sizes. Similarly, healthcare workers have limited knowledge of the condition.

²⁹⁰ E Smith-Asante, 'Only 23 dermatologists in Ghana; Rabito plans a rescue' (*Graphic Online*, 16 October 2018) <www.graphic.com.gh/news/health/only-23-dermatologists-in-ghana-rabito-plans-a-rescue.html> accessed 24 September 2021..

²⁹¹ Amewuho Morny and others (n 289) 3.

Some healthcare workers give wrong information to mothers of children with albinism or perpetuate myths related to the condition. For instance, the experience of Mavis Mensah, a mother of a child with albinism, at Tema General Hospital is a clear indication of a lack of knowledge on albinism by healthcare workers.²⁹² She narrated that the doctor who assisted her birth asked, ‘why is your child like this?’ This question was followed by nurses coming into the delivery ward to catch a glimpse of the child, make derogatory remarks and laugh.²⁹³ The nurses’ reactions paint a picture of societal prejudices and misconceptions about the condition fuelled by lack of information.

In addition, socio-cultural beliefs and practices create barriers for persons with albinism to access healthcare. For example, the belief that persons with albinism are immune to diseases and illnesses and that they will die young discourages parents from taking adequate care of their children. Further, stigma and discrimination prevent mothers from taking their children with albinism to health facilities. It is also believed that recurrent wounds on persons with albinism are spiritual. For instance, patients with growing tumours recounted being taken to traditional herbalists for treatment, while others were wrongly diagnosed.²⁹⁴

Moreover, the attitudes of some healthcare workers towards persons with albinism are influenced by their perceptions, prejudices and myths they are exposed to in their community. For instance, in a video documentary, people indicated their discomfort in purchasing items sold by persons with albinism, while others do not want to do anything with persons with albinism, such as marriage or eating together.²⁹⁵ These attitudes reflect among healthcare workers, which create barriers to access healthcare for persons with albinism in Ghana. Also, discrimination, stigma, marginalisation and social exclusion against persons with albinism make it difficult for these individuals to present their health issues to health facilities for fear of further stigmatisation.

²⁹² Adonai StudiosGH, ‘My Colour’ (Albinism documentary, Thisability Episode 10, 2020) <www.youtube.com/watch?v=alu2g30CQKs&t=12s> accessed 24 August 2021.

²⁹³ *ibid.*

²⁹⁴ I Ero and others, ‘People with albinism worldwide. A human rights perspective’ (United Nations 2021) 12 <www.ohchr.org/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf> accessed 24 July 2021. 83.

²⁹⁵ Engage Now Africa, ‘Albinism in Ghana’ (8 December 2020) <www.youtube.com/watch?v=oNWGPbdmPik&t=14s> accessed 26 August 2021.

5.5 RECOMMENDATIONS

Considering the unique and peculiar health needs of persons with albinism, Ghana must ensure access to adequate healthcare commensurate to their health needs. For Ghana to meet its international obligations on the right to an attainable standard of physical and mental health for persons with albinism, the following measures, including legislative and policy, administrative and institutional measures and public education and training, must be instituted in collaboration with international development partners, NGOs and CSOs. Ghana can achieve these measures by learning from the best practices discussed in chapter four of the research while adapting them to fit the situation in Ghana.

5.5.1 Legislative / policy measures

- I. Amend the 1992 Constitution to include an explicit provision on the right to health. This provision can add up or replace article 30 on the right of the sick.²⁹⁶
- II. The government must fast-track the review and amendment process of the Persons with Disability Act of 2006 in line with the provisions of the CRPD²⁹⁷ and the African Disability Rights Protocol. These amendments will help the act to adopt a human rights approach to disability and recognise the challenges persons with albinism face.
- III. Review and amend the NHIS Act to make adequate provisions for the health needs of persons with disabilities. For instance, skin cancer treatment for persons with albinism, sunscreen products, assistive devices such as visual aids, wheelchairs, hearing aids and other essential medication should be provided at no cost or subsidised for persons with disabilities under the NHIS.
- IV. Review the Affirmative Action Bill to include persons with disabilities, especially women with disabilities including those with albinism.

²⁹⁶ Committee on the Rights of Persons with Disabilities, 'Initial report submitted by Ghana under article 35 of the Convention, due in 2014' (2019) CRPD/C/GHA/1.

²⁹⁷ Human Rights Council, 'Report of the Working Group on the Universal Periodic Review; Ghana' (2017) A/HRC/37/7.

- V. Adopt a national policy on albinism in Ghana. This policy should establish a National Albinism centre under the National Council on Persons with Disabilities (NCPD) in charge of albinism matters.
- VI. Adopt a national action plan on albinism in Ghana to mirror the AU Plan of Action on Albinism in Africa.²⁹⁸ This plan should be reviewed every five or ten years to respond to emerging issues affecting persons with albinism in the country.

5.5.2 Administrative and institutional measures

- I. Establish a National Albinism Centre under the NCPD to coordinate activities on albinism, including research, data collection, public education and training, psychosocial support services, provision and distribution of sun-protective materials to persons with albinism across the state.
- II. Conduct nationwide research on the prevalence rate of albinism, the health needs and other challenges associated with the condition.
- III. Collect data on persons with albinism. Specific questions on albinism should be included in the national census to capture disaggregated data on albinism in the country. This data will promote inclusive planning and adequate services to this vulnerable population.
- IV. Allocate an annual budget to the National Albinism Centre to procure essential medicine such as sunscreen products, research, and public education activities on albinism.
- V. Local production of sunscreens and other sun-protective products; produce and distribute sunscreen products locally and remove import charges on these products and other raw materials used in producing them. In addition, the local production will create decent employment for persons with albinism and make these products accessible to them.

²⁹⁸ African Union, 'Implementation matrix of the plan of action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031)' (2021).

- VI. Establish skin cancer and eye screening treatment centres at district hospitals. These centres should be responsible for the early detection and treatment of primary skin and eye conditions associated with albinism. Mobile skin cancer and eye screening clinics should be organised periodically by these centres in collaboration with the National Albinism Centre to provide services to those in rural communities. In addition, psychological support services should be attached to these clinics to offer psychological support to persons with albinism regularly.
- VII. Review the NHIS benefit package to include monthly free allocation of sunscreen products to card bearers of the scheme and ensure these products are made available in public health facilities across the country

5.5.3 Public education and training

- I. Organise intensive community and school-based sensitisation programmes to promote understanding of albinism. These programmes will help eliminate or reduce the myths, misconceptions and prejudices associated with the condition. As a result, discrimination, marginalisation and social exclusion will be reduced or eliminated. Public education should include traditional authorities/rulers, faith-based organisations, traditional healers and community opinion leaders. These programmes should focus on changing public perceptions of albinism and promote scientific understanding among the target population.
- II. Organise training and capacity building programmes for persons with albinism and their families on the condition as well as other employable skills to make them self-reliant
- III. Adopt albinism awareness month, during which nationwide public education activities can be organised to create a massive awareness of the condition. These activities include public lectures, seminars, workshops and dialogue sessions at various levels of engagement for multiple sectors, including health and education.

- IV. Adopt International Albinism Awareness Day (IAAD) for commemoration as an annual national event. The IAAD will serve as a national platform for deliberation on issues affecting persons with albinism and ways to address them.
- V. Implement innovative public education programmes through traditional media such as radio and television to discuss matters relating to persons with albinism. In addition, produce short films on albinism for both conventional and social media. These films should project diversity in society and promote the inclusion of albinism in every sphere of social life to eliminate discrimination and harmful cultural practices.

5.5.4 International cooperation

- I. The international community and international organisations in Ghana should collaborate with relevant government institutions and agencies to conduct research on albinism and gather relevant data to inform public policies to address challenges associated with the condition, including health and education.
- II. Collaborate with government institutions and agencies to adopt, implement and scale up best practices identified in chapter four of this research towards addressing the health needs of persons with albinism in Ghana.

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