Republic of Zambia
Ministry of Community Development
and Social Services

ALBINISM AND RIGHTS IN ZAMBIA:

AN EXPLORATION OF EXPERIENCES, SOCIOCULTURAL CONDITIONS AND ACCESS TO JUSTICE

STUDY REPORT

This study was commissioned with the support of the United Nations Children's Fund (UNICEF), the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, the Canadian High Commission in Zambia, the Ministry of Community Development and Social Services, and the University of Zambia.

Masauso Chirwa, PhD
and
Likando Kalaluka, SC

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ACKNOWLEDGEMENTS

The development of this research report has been a collaborative process involving many stakeholders. This is one of the first studies on albinism in Zambia and I am, therefore elated to be part of this milestone.

I would like to commend all the stakeholders who participated in this process for their constructive input. I particularly acknowledge the financial and technical support from UNICEF, the Canadian High Commission in Zambia, the Zambia Human Rights Commission, the UN Independent Expert on the Enjoyment of Rights by Persons with Albinism and the University of Zambia.

May I also thank the lead researchers Masauso Chirwa, PhD and Likando Kalaluka, SC for their support. Further, I would like to express my gratitude to the technical committee, line ministries, CSOs and members of staff from my ministry for their invaluable leadership.

The study was designed in a way that information obtained will be used for subsequent action, such as lobbying public policy personnel, influencing law, and raising awareness through community dialogue and sharing information on issues surrounding albinism. Further the report will help assess pathways to impact on interventions and services to people with albinism by Ministries, organisations of and/ for persons with albinism and other stakeholders while raising awareness to the public on stigma and rights violations of persons with albinism.

The report also provides relevant information about persons with albinism on access to justice and other social services. This study conducted provides a platform in informing the design of evidence-based programming while deepening the existing understanding of the position of persons with albinism concerning their rights to equality, life, dignity, privacy, and freedom from any form of violence.

It is my sincere hope that the collaboration exhibited in producing this document will continue even in the implementation process. I am confident that the various partners involved in disability inclusion programmes will continue to complement each other's efforts and co-ordinate their activities for the benefit of persons with disabilities in Zambia. My Ministry will endeavor to pursue the actualization of the enjoyment of rights in accordance with the agenda of transformation and social justice envisioned by the Constitution of Zambia, as amended in 2016.

Angela Chomba Kawandami
PERMANENT SECRETARY
MINISTRY OF COMMUNITY DEVELOPMENT AND SOCIAL SERVICES

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LIST OF ACRONYMS

CERD:	Convention on the Elimination of All Forms of Racial Discrimination
CRC:	Convention on the Rights of the Child
CRPD:	Convention on the Rights of Persons with Disabilities
FGD:	Focus Group Discussion
ICCPR:	International Covenant on Civil and Political Rights
ICESCR:	International Covenant on Economic, Social and Cultural Rights
MCDSS:	Ministry of Community Development and Social Services
NPA:	National Prosecutions Authority
PDA	Persons with Disabilities Act
UDHR:	Universal Declaration of Human Rights
UNC:	United Nations Charter
UNZA:	University of Zambia

| EXECUTIVE SUMMARY

Albinism is a rare, non-contagious, genetically inherited condition, which commonly results in the lack of melanin pigment in the hair, skin and eyes, causing vulnerability to sun exposure. Persons with albinism often appear much lighter in complexion because of an absence of pigment in hair or skin. A first of its kind, the study on albinism in Zambia was conducted in 2022 to understand the living conditions of persons with albinism in the country. Albinism is present in all ethnic and racial groupings worldwide, but the prevalence rates vary considerably, with sub-Saharan Africa bearing the heaviest burden of the condition. The prevalent rates are estimated to be one in 2,000 to 5,000 in sub-Saharan Africa. Given the sunny, tropical climate and limited health and healthcare amenities in many sub-Saharan African contexts, these high prevalence rates have profound implications. The social ramifications of albinism may be even more pronounced. Although there are no known studies done in Zambia documenting the social aspects of albinism, studies from other parts of the continent contend that people with albinism face multiple forms of social discrimination, stigmatisation, rejection, violence, and limited access to justice and healthcare. Additionally, studies show that they are often ridiculed, ostracised, and excluded in their workplaces, schools, communities and families. In the most brutal instances, individuals are mutilated, trafficked and killed.

While there is an increasing awareness, literature indicates that persons with albinism should be regarded as people with disabilities who suffer from various discriminatory practices in Zambia, and there is a lack of documented evidence about these underlying perceptions. Therefore, the study aimed at achieving the following:

i. To explore the socio-cultural conditions surrounding people with albinism in Zambia.

ii. To understand the experiences of people with albinism regarding access to education, employment, healthcare and justice.

iii. To identify the barriers and opportunities to access justice for persons with albinism, including within the police, prosecutors and judiciary.

iv. To provide evidence-based recommendations on pathways to impact and how these can be utilised to address stigma and rights violations of persons with albinism in Zambia.

This study adopted a mixed methods approach in collecting data used in developing this report. Through a survey, in-depth interviews and desk review of lived experiences of persons with albinism and society's perspectives of persons with albinism, and factors that preclude persons with albinism from accessing justice were systematically analysed. From collated emerging themes, inferences were made on measures that ensure access to justice for violations of the rights of persons with albinism. The study was conducted in four provinces of Zambia, namely Lusaka, Western, Northern and Eastern provinces. The four provinces represented the urban/rural divide, with Lusaka being the urban province and the other three being rural. This enabled us to have a holistic picture of albinism in Zambia.

This study found that discrimination and stigma against persons with albinism were rife. People relate albinism to bad omens, curses and ghosts or claim that it was a result of the mother's adulterous relations. Conversely, the body parts of persons with albinism have been regarded as a source of wealth and prosperity. These myths have aroused hate, fear or ambivalence. As a result, those with albinism are vulnerable and exposed to multiple forms of discrimination and violations of their rights, such as physical attacks, sexual violence, lack of access to education, health and employment. This study found that violence against persons with albinism was fuelled by cultural practices and misconceptions, and women were more vulnerable to attacks. This was often reflected in healthcare settings where discriminatory practices manifested against persons with albinism.

There are several international laws and standards that affirm the rights of people with albinism. The key ones include:

1. United Nations Convention on the Rights of Persons with Disabilities (CRPD): This convention was adopted by the United Nations General Assembly in 2006. It sets out a framework for protecting the rights of people with albinism, including their right to education, employment and full participation in society. The Convention on the Rights of the Child spells out the rights of the child regardless of their condition.
2. Universal Declaration of Human Rights (UDHR): The UDHR, adopted by the United Nations General Assembly in 1948, is a foundational document for human rights. It recognises the inherent dignity and worth of all human beings, including those with albinism.
3. International Covenant on Economic, Social and Cultural Rights (ICESCR): it recognises the right of all people to education, work and adequate living standards, regardless of their disability.
4. Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW): This convention recognises the rights of women with albinism to education, employment and equal treatment under the law.

The Government of the Republic of Zambia signed and ratified the United Nations Convention on the Rights of Persons with Disabilities in 2008 and 2010, respectively, as a commitment to improving the welfare of persons with disability in general. In addition, the country has put in place several laws on people with disabilities, including the:

1. The Constitution of Zambia: The Constitution of Zambia provides for the protection of human rights and fundamental freedoms, including the rights of persons with albinism. The Constitution prohibits discrimination based on race, colour, sex, religion, or other status and guarantees equal protection under the law.
2. Persons with Disabilities Act: The Persons with Disabilities Act of 2012 recognises albinism as a disability and provides for the protection of persons with albinism. The Act prohibits discrimination against persons with disabilities, including those with albinism, and provides for their full participation on an equal basis with others.
3. Penal Code: The Penal Code of Zambia criminalises violence and other forms of abuse against persons with albinism. Section 89 of the Penal Code provides for the offence of causing harm to any person, while Section 224 provides for the offence of kidnapping. Both offences are punishable by imprisonment and other penalties.
4. Human Rights Commission Act: The Human Rights Commission Act of 1996 establishes the Human Rights Commission, which is responsible for promoting and protecting human rights in Zambia. The Commission is empowered to investigate complaints of human rights violations, including those against persons with albinism.
5. Office of the Public Protector (Ombudsman's institution of Zambia which replaced the office of the investigator

general) as provided for under article 243 of the amended Act no. 2 of the 2016 Constitution of Zambia is mandated to promote and safeguard the interests of individuals in their quest to receive a public service that is just and fair.

6. The Children's Code Act of 2022. It criminalises all forms of child abuse.

Discrimination against persons with albinism is a serious human rights issue, and addressing it requires a multifaceted approach. The following were the recommendations based on findings that could help stop discrimination against persons with albinism:

1. Education and awareness: Education and awareness-raising campaigns are crucial to challenge stereotypes and myths about albinism. Such campaigns should be targeted at schools, communities and the media.

2. Enact and enforce laws and policies: Governments should enact and enforce laws, policies and guidelines (with costed implementation frameworks) that protect the rights of persons with albinism and ensure they have access to education, healthcare and employment opportunities.

3. Provide support and services: Governments, non-governmental organisations, and other stakeholders should provide support and services to persons with albinism, including access to healthcare, education and employment opportunities.

4. Promote social inclusion: Efforts should be made to promote the social inclusion of persons with albinism in all aspects of society, including education, employment and social activities.

5. Encourage positive representation: The media should be encouraged to represent persons with albinism positively and accurately rather than perpetuating negative stereotypes.

6. Empower persons with albinism: Efforts should be made to empower persons with albinism by providing them with education, training, and support to become leaders and advocates for their rights.

7. To ensure that the right to health of persons with albinism is respected, protected and fulfilled, it is necessary to promote awareness about albinism and its associated health risks, provide affordable and accessible health care and medication, and address discrimination and stigma. In addition, the government, international organisations and civil society should work together to ensure that the right to health of persons with albinism is respected and fulfilled.

8. Therefore, the government must also introduce health education programmes aimed at educating persons with albinism about the health risks associated with their condition. An awareness of the causes of albinism and the measures that can be taken to prevent skin cancer, for example, will undoubtedly enhance the health of persons with albinism and reduce the risk of complications associated with the condition. Therefore, not only are basic health awareness education programmes for persons with albinism crucial, but programmes to educate people on clinical aspects of albinism will undeniably influence the way society perceives persons affected by this condition. These programmes could begin by targeting places of employment, community centres, schools and hospitals.

The study highlights key findings about the conditions of persons with albinism. This research on albinism has shed light on the various challenges faced by people with the condition, including stigma, discrimination and health risks. However, more effort is needed to address these challenges and promote the rights and well-being of people with albinism in Zambia.

| CHAPTER 1

INTRODUCTION

This report is the product of an initiative by the Ministry of Community Development and Social Services (MCDSS), the Canadian High Commission and the Zambia Human Rights Commission with financial support from UNICEF Zambia. This was the first study on albinism in Zambia. Led by the University of Zambia, the study was conducted to understand the living conditions of persons with albinism in the country. This study in Zambia draws on the experience of a series of similar studies undertaken in southern Africa as well as on international developments in the field of albinism. The study thus forms part of a growing body of evidence about the living situation of persons with albinism in low- and middle-income contexts.

1.1 Background

Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people regardless of race, ethnicity or gender. The condition is characterised by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment in the skin, hair and eyes.[1] Albinism often results in two congenital and permanent health conditions: visual impairment to varying degrees and high vulnerability to skin damage from ultraviolet rays, including skin cancer.

Albinism is present in all ethnic and racial groupings worldwide, but the prevalence rates vary considerably, with sub-Saharan Africa believed to have the highest prevalence. The prevalence rates are estimated to be one in 2,000–5,000 in sub-Saharan Africa. Given the sunny, tropical climate and limited health and healthcare amenities in many sub-Saharan African contexts, these increased prevalence rates have profound implications. With limited protection from the sun's ultraviolet light and skin cancer screening for early detection and treatment, few people living with albinism in sub-Saharan Africa survive to age 40 years.[2]

Although there are no studies done in Zambia documenting the social aspects of albinism, there are a few studies from other parts of the continent contending that people with albinism face multiple forms of social discrimination, stigmatisation, rejection, violence, and limited access to justice and healthcare. Additionally, studies show that they are often ridiculed, ostracised and excluded in their workplaces, schools, communities and families. In the most brutal instances, individuals are mutilated, trafficked and killed for their body parts, which are erroneously viewed as having special powers. Moreover, women and children with the condition also face discrimination disproportionately based on gender and age.

In many cases, these traditional myths, beliefs and superstitions about albinism have motivated different forms of attacks on persons with albinism, including violently shaving off hair and mutilation of ears, limbs, fingers and genitalia.[3]

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[1] Franklin, A., Lund, P., Bradbury-Jones, C., & Taylor, J. (2018). Children with albinism in African regions: their rights to 'being' and 'doing'. *BMC international health and human rights*, *18*(1), 1-8.

[2] Bradbury-Jones, C., Ogik, P., Betts, J., Taylor, J., & Lund, P. (2018). Beliefs about people with albinism in Uganda: A qualitative study using the Common-Sense Model. *PLoS One*, *13*(10), e0205774.

Furthermore, the physical appearance of people with albinism has been the object of erroneous beliefs and myths influenced by superstition, witchcraft or both. Witchcraft-related myths have fostered acute marginalisation, social exclusion and physical attacks. Related harmful practices include accusations of witchcraft, killing, maiming, rape, grave robbery, trafficking in persons and trafficking in body parts.[3]

1.2 Rationale: Albinism in Zambia

In Zambia, the population of persons with albinism may not be adequately captured. The population in rural areas is higher than in urban areas. Lusaka province has the highest population of persons with albinism, while North-Western province has the lowest.[4]

Literature from countries, such as Malawi, Tanzania, South Africa and Zimbabwe suggests that there are a lot of cultural beliefs, stereotypes, stigma and superstitions surrounding albinism, which threaten the lives and survival of persons with albinism. However, knowledge about the social conditions of albinism gained from studies done in other countries may not be imported into the Zambian context on account of social, cultural, religious and geographical differences. Consequently, little is known about the experiences of people with albinism concerning social interactions, socio-cultural conditions, access to healthcare and access to justice in the Zambian context. This is what motivated the conceptualisation of this study.

People with albinism are entitled to protection under the Convention on the Rights of Persons with Disabilities (CRPD) based on their visual impairment and vulnerability to skin damage and skin cancer. According to the CRPD, "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." The CRPD also explains, "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." In interpreting these provisions in relation to albinism, the CRPD has made it clear that persons with albinism fall within the definition of persons with disabilities due to their visual impairment and susceptibility to skin damage and skin cancer as well as associated environmental and attitudinal barriers.[5] This is also the position of the United Nations Independent Expert on the enjoyment of human rights by persons with albinism.[6]

The CRPD establishes the right of people with disabilities to enjoy their lives in the same way as other people, to access justice, and to enjoy the rights to freedom, privacy and security. It also prohibits all forms of discrimination against persons with disabilities, both direct and indirect discrimination, and recognises that accommodation of persons with disabilities is regularly required to expedite the achievement of equality. In addition, the CRPD obliges state parties to perform certain affirmative duties, including taking legislative and administrative measures that promote the human rights of persons with disabilities, eradicate discrimination and ensure that the public and private sectors respect persons with disabilities. The United Nations 2013 Annual Report of the Human Rights Council reaffirmed this position by stating that states should adopt specific measures to protect and preserve the rights to life and security of persons with albinism as well as their right not to be subject to torture and ill-treatment, and ensure their access to adequate health care, employment, education and justice.[7] In 2015, the United Nations established the mandate of the United Nations Independent Expert on Albinism to advance and promote the rights of persons with albinism. Since then, the

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[3] Taylor, J., Bradbury-Jones, C., & Lund, P. (2019). Witchcraft-related abuse and murder of children with albinism in Sub-Saharan Africa: a conceptual review. *Child abuse review*, *28*(1), 13-26.

[4] Zv. Tanzania, CRPD/C/22/D/24/2014, para 7.3

[5] Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Right of persons with albinism to the highest attainable standard of health, A/HRC/37/57, 20 December 2017, para 25

[6] Harpur, P. (2012). Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities. *Disability & Society, 27*(1), 1-14.

[7] https://www.ohchr.org/en/special-procedures/ie-albinism/reports

mandate has developed and elaborated several international standards which set out these rights in more detail.[8]

The International Convention on the Elimination of All Forms of Racial Discrimination raises concern about racial discrimination based on people's skin colour. Persons with albinism are hyper-visible in many environments —particularly where most of the population has darker skin tone—thus they are particularly vulnerable to stigmatisation and discrimination. A persistent lack of awareness and ignorance about the condition has contributed to stigmatisation, stereotyping and prejudice. People with albinism are subjected to name-calling, verbal abuse and physical attacks, which the United Nations Independent Expert on albinism has stated may amount to hate crimes. Harmful myths and misconceptions about albinism "have the effect of stripping persons with albinism of their humanity, paving the way for exclusion and attacks." These myths and misconceptions provide a rationale for discrimination and present ostracism and exclusion as natural.[9]

This study provides much-needed knowledge on cultural myths and prejudices, and exposes the discrimination experienced by persons with albinism when they access social services in Zambia. It integrates the voices of persons with albinism and has been designed, developed and carried out with the inclusion of organisations of persons with albinism in Zambia. This is critical because a lack of understanding of public perceptions, cultural beliefs and life experiences of persons with albinism may lead to the development of institutional and national interventions that neither benefit persons with albinism nor fully understand their circumstances.

Ultimately, the evidence in this report helps assess pathways to impact, which can be utilised by MCDSS, organisations for persons with albinism and other stakeholders to assist citizens in being aware of the stigma and rights violations of persons with albinism (for instance, mutilation) and how this can be changed. The study also provides relevant information about persons with albinism's access to justice and other social services such as health, education and employment. The information is also expected to directly feed into the works of government institutions, such as the Ministry of Health, Ministry of Education, Ministry of Justice, Ministry of Local Government and Rural Development, and the Association of NGOs for Persons with Albinism. This will inform the design of evidence-based programming. In this regard, this research deepens the existing understanding of the position of persons with albinism concerning their rights to equality, life, dignity, privacy and freedom from any form of violence. In addition, giving meaning to the rights must be done against the background of the agenda of transformation and social justice envisioned by the Constitution of Zambia, as amended in 2016. Thus, the research was designed in a way that information obtained will be used for subsequent action, such as lobbying public policy personnel, influencing law, or even holding community dialogues and sharing information with television and radio stations on the issues surrounding albinism.

1.3 Objectives

i. To explore the socio-cultural conditions surrounding people with albinism in Zambia.

ii. To understand the experiences of people with albinism regarding access to education, employment, healthcare, and justice.

iii. To identify the barriers and opportunities to access justice for persons with albinism, including within the police, prosecutors and judiciary.

iv. To provide evidence-based recommendations on pathways to impact and how these can be utilised to address stigma and rights violations of persons with albinism in Zambia.

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[8] Mladenov, T. (2013). The UN Convention on the Rights of Persons with Disabilities and its Interpretation. Alter, 7(1), 69-82.

[9] Mladenov, T. (2013). The UN Convention on the Rights of Persons with Disabilities and its Interpretation. Alter, 7(1), 69-82.


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| CHAPTER 2

ZAMBIA COUNTRY PROFILE

2.1 Demographics

Zambia is a landlocked country situated in southern Africa, and has one of the fastest-growing populations. According to the Preliminary Census of Population and Housing Report of 2022, the population grew at a rate of 3.4 per cent per annum between 2010 and 2022, and now stands at over 19 million. The rural population grew at an average annual rate of 3.4 per cent during the 2010–2022 period. Urban areas recorded a decline in the growth rate from 4.2 per cent to 3.5 per cent in the period 2010–2022. There are 73 ethnic groups in Zambia.[10]

2.2 Economy

The country's economy is largely based on mining, agriculture and tourism. Mining is the backbone of Zambia's economy, accounting for more than 70 per cent of the country's export earnings. Copper is the main mineral export, and Zambia is one of the largest copper producers in the world. Other minerals mined in Zambia include cobalt, gold and silver.

Agriculture is the largest employer in Zambia, employing over 70 per cent of the population, and accounts for about 20 per cent of the GDP. The main crops include maize, cotton, tobacco and sugarcane.

Zambia has increased its spending on social sectors, such as education, health and social protection. According to the 2023 National Budget, social sector spending increased to 30.5 per cent in 2023 from 23.5 per cent in 2022. The government allocated 14 per cent of its budget to the education sector, 10.4 per cent to the health sector, and the allocation to social protection went up by 30 per cent to K8.1 billion in 2023 from K6.2 billion in 2022.[11] This increase in allocation to social sectors was meant to safeguard the lives and livelihoods of especially the most vulnerable citizens, such as persons with disabilities. It is, however, worth noting that the COVID-19 pandemic has placed additional strain on Zambia's already limited resources and has had a significant impact on the country's economy. As a result, government spending on social sectors may have been affected.

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[10] ZamStats (2022) 2022 Census of Population and Housing. Preliminary Report. GRZ Publication

[11] Zambia Institute for Policy Analysis (2023) An Analytical Brief of the 2023 Social Sector Budget. ZIPA Publication


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BUILDING SOCIAL PROTECTION FLOORS IN AFRICA
TRANSFORM

| CHAPTER 3

LITERATURE REVIEW OF ALBINISM IN AFRICA

Albinism is a genetic condition that affects the production of melanin, the pigment that gives colour to the skin, hair and eyes. In some countries in Africa, albinism is often stigmatised, and people with albinism face discrimination, prejudice and even violence. Beliefs about albinism in Africa are diverse and often rooted in cultural and traditional beliefs.[12] In this literature review, we will explore the research conducted on beliefs about albinism in Africa and their implications for people with the condition.

Many African cultures have traditionally associated albinism with superstition and witchcraft, leading to discrimination, social exclusion and even persecution. For instance, in Tanzania, people with albinism have been targeted for their body parts, which are believed to bring wealth and good luck. This has resulted in a high number of attacks, mutilations and murders of people with albinism in the country.[13]

Research on albinism in Africa has focused on various aspects of the condition, including the genetic causes, the prevalence, and the social and health implications. For example, a study conducted in Ghana found that the prevalence of albinism in the country was 1 in 2,000, which is higher than the estimated global prevalence of 1 in 15,000. The study also found that people with albinism in Ghana faced social and economic challenges, such as limited access to education and employment opportunities.

Another study conducted in Nigeria explored the perceptions of albinism among healthcare workers and the general population. The study found that many healthcare workers had limited knowledge of albinism and often stigmatised people with the condition. The general population also held negative perceptions of albinism, associating it with superstition and witchcraft.

A study conducted in Tanzania found that people with albinism were viewed as inferior and cursed,[14] and many believed that their condition was caused by witchcraft or a curse. These beliefs have contributed to the stigmatisation and discrimination of people with albinism in Tanzania. Similarly, a study[15] conducted in Nigeria found that many people believed that albinism was a punishment from the gods or

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[12] Brocco, G. (2016). Albinism, stigma, subjectivity and global-local discourses in Tanzania. *Anthropology & medicine*, *23*(3), 229-243.

[13] Hong, E. S., Zeeb, H., & Repacholi, M. H. (2006). Albinism in Africa as a public health issue. *BMC public health*, *6*(1), 1-7.

[14] Kajiru, I., & Nyimbi, I. (2020). The impact of myths, superstition and harmful cultural beliefs against albinism in Tanzania: A human rights perspective. *Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad*, *23*(1).

[15] Ikuomola, A. D. (2015). Socio-cultural conception of albinism and sexuality challenges among persons with albinism (PWA) in South-West, Nigeria. *AFRREV IJAH: An International Journal of Arts and Humanities*, *4*(2), 189-208.

a curse. The study also found that people with albinism were often seen as inferior and were subjected to discrimination and social exclusion.

In contrast, another study conducted in Nigeria found that some people believed that people with albinism had special abilities, such as the ability to see ghosts or predict the future. Another study in Tanzania found that many people believed that albinism was caused by supernatural forces or witchcraft.[16] The study also found that some people believed that albinism was contagious, leading to the isolation and social exclusion of people with the condition. Similarly, a study conducted in Malawi found that many people believed that albinism was a curse or punishment from the gods.[17] The study also found that some people believed that albinism was caused by incest or adultery. Beliefs around the causes of albinism can have significant implications for people with the condition. These beliefs can lead to stigmatisation, discrimination and even violence against people with albinism.[18]

Beliefs about albinism also vary across different ethnic groups and regions. For example, a study conducted in South Africa found that among the Zulu people, albinism was associated with royal lineage and spiritual powers.[19] In contrast, among the Xhosa people, albinism was associated with negative beliefs, such as being cursed or being the result of incest.[20] In addition, promoting genetic counselling and testing can improve understanding of the genetic basis of albinism and reduce the stigma associated with the condition.

In terms of health, people with albinism are more susceptible to sunburn, skin cancer and vision problems due to their lack of melanin. Sun protection is essential for people with albinism, but it can be challenging to access in many parts of Africa, where sunscreen, protective clothing and hats are often expensive or unavailable.

In conclusion, albinism in Africa is a complex issue that affects people's health, social status and human rights. Research on albinism in Africa has shed light on the various challenges faced by people with the condition, including stigma, discrimination and health risks. More efforts are needed to address these challenges and promote the rights and well-being of people with albinism in Africa.

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[16] Masanja, M. M., Imori, M. M., & Kaudunde, I. J. (2020). Lifelong agony among people with albinism (PWA): Tales from lake zone in Tanzania. *Journal of Social and Political Sciences*, *3*(2).

[17] Baker, C., Lund, P., Massah, B., & Mawerenga, J. (2021). We are human, just like you: Albinism in Malawi–implications for security. *Journal of Humanities*, *29*(1), 57-84.

[18] Kiluwa, S. H., Yohani, S., & Likindikoki, S. (2022). Accumulated social vulnerability and experiences of psycho-trauma among women living with albinism in Tanzania. *Disability & Society*, 1-22.

[19] Blankenberg, N. (2000). That rare and random tribe: Albino identity in South Africa. *Critical Arts*, *14*(2), 6-48.

[20] Kerr, R., Manga, P., & Kromberg, J. G. R. (2020). Children with oculocutaneous albinism in Africa: Characteristics, challenges and medical care. *South African Journal of Child Health*, *14*(1), 50-54.

| CHAPTER 4

METHODOLOGY

This study adopted a mixed methods approach in collecting data used in developing this report. Through a survey, in-depth interviews, desk review of lived experiences of persons with albinism and society's perspectives of persons with albinism, and factors that preclude persons with albinism from accessing justice were systematically analysed. From collated emerging themes, inferences were made on measures that ensure access to justice for violations of the rights of persons with albinism. This process was consultative in nature, as various stakeholders were involved in deciding on the parameters of the study. Among those consulted included persons with albinism, organisations representing persons with albinism and the MCDSS.

4.1 Study sites

The study was conducted in four provinces of Zambia, namely Lusaka, Western, Northern and Eastern provinces. The four provinces were chosen because they recorded the highest albinism prevalence rates in the 2010 census of population and housing, respectively. These provinces also recorded the highest reports of abuse of persons with albinism. The four provinces represented the urban/rural divide, with Lusaka being the urban province and the other three being rural. This enabled us to have a holistic picture of albinism in Zambia. The following were the districts sampled per province: Chongwe in Lusaka, Chipata, Lundazi, Chasefu, Katete and Sinda in the Eastern provinces; Mongu (Sefula) and Senanga in Western province; and Kasama in Northern province.

4.2 Data Collection

Data was collected from eleven levels:

I. **Desk review**: Necessary policy documents and legislation were reviewed, and critical inquiry was applied to understand existing judicial systems and legal processes—bureaucratic and structural—to examine their impact on the access to justice for persons with albinism while identifying strategies for practical policy reform.

II. **In-depth interviews with persons with albinism:** A non-probability sampling method was used to enroll persons with albinism as study participants. Both purposive and snowball sampling were used to recruit persons with albinism, and interest groups, such as the organisations for persons with albinism helped recruit other participants for the in-depth interviews. A total of 21 interviews with persons with albinism were conducted in all the study sites.

III. **In-depth interviews with carers of persons with albinism:** Twenty interviews were conducted with carers of persons with albinism to understand their experiences of the legal process, seen from the child´s as well as the parent’s perspective and to identify structural and cultural factors that they experienced in caring for persons with albinism. Of those carers interviewed, eight were males, while twelve were females.

IV. **In-depth interviews with representatives from organisations for persons with albinism:** Five persons were interviewed from organisations for persons with albinism. The purpose of these interviews was to understand the activities that they are engaged with to counter discrimination and other vices against persons with albinism.

V. **In-depth interviews with police officers**: Six in-depth interviews were conducted with police officers in Chongwe, Katete, Chasefu and Lundazi. We were unable to interview officers in some towns because of bureaucratic impediments.

VI. **In-depth interviews with officers from National Prosecutions Authority (NPA):** Two in-depth interviews were also conducted with prosecutors from the NPA in Katete and Mongu to understand their experiences of handling cases involving attacks against persons with albinism. We were unable to interview officers in some towns because of bureaucratic impediments.

VII. **In-depth interviews with judges and magistrates:** Two in-depth interviews were conducted with officials from the Judiciary in Chipata and Mongu. The interviews highlighted the officers’ experiences dealing with matters involving persons with albinism.

VIII. **In-depth interviews with officers from education:** Two in-depth interviews were conducted with officials from the district education boards in Katete and Mongu.

IX. **In-depth interviews with officers from health:** Three in-depth interviews were conducted with officials from health in Chongwe, Katete and Mongu.

X. **Focus group discussions**: A total of three focus group discussions were conducted with persons with albinism in Sefula; and four focus group discussions with community members in Sefula and Lundazi.

XI. **Questionnaire:** A total of 208 questionnaires were administered with members of public in the study sites.

4.3 Data processing and analysis

I. ***Quantitative data analysis*****:** Data from questionnaires was analysed using SPSS version 28. After data cleaning, data analysis was done using descriptive statistics (tables, pie charts, graphs, numerical narratives) to reveal the socio-demographic characteristics of respondents as well as those with positive and negative perceptions towards persons with albinism.

II. ***Qualitative data analysis*****:** NVivo was used to analyse qualitative data from key informants and FGDs. Thematic analysis in line with study objectives was utilised to interpret qualitative data from key informants and stakeholders. This was triangulated with quantitative data, which allowed the research team to complement findings from the survey with more in-depth qualitative data.

4.4 Quality of Research

The goal was to enhance the credibility of the whole data analysis process. Peer reviewing provided valuable second opinion on the meaning of data and proposed categories. The researchers exchanged transcripts that were anonymised for them to provide feedback to each other. The researchers also met in person to discuss the research process, focusing on, among others, the coding process. Some interviews were undertaken in local languages, which meant that the researchers had to transcribe in the local Zambian language, then translated them into English. The researchers at the Department of Literature and Language at the University of Zambia verified the quality of anonymised translation. This helped in ensuring that the translation was as accurate as possible. The researchers also used a member-checking process whereby some transcripts were sent back to the participants for them to determine accuracy. This is one of the most important techniques used to establish credibility of the findings.

4.5 Ethical Considerations

Ethical approval was obtained from the University of Zambia Research Ethics Committee. Participants had an opportunity to decline to participate in the study.

4.6 Limitations of the Study

The key documents and cases requested for the purposes of this assignment were either unavailable or inaccessible. These included police dockets containing cases relating to attacks against persons with albinism. As a result, it was not possible to report authoritatively on some key components of the assessment, such as how cases are handled from the police to court.

| CHAPTER 5

FINDINGS

This section focuses on the findings of this study. The first section focuses on the quantitative component of the study. Questionnaires were distributed to members of the public in the study sites with a view to knowing their understanding of, among others, the causes of albinism and their attitudes. The second section presents the findings from the qualitative component of the study.

Quantitative Results

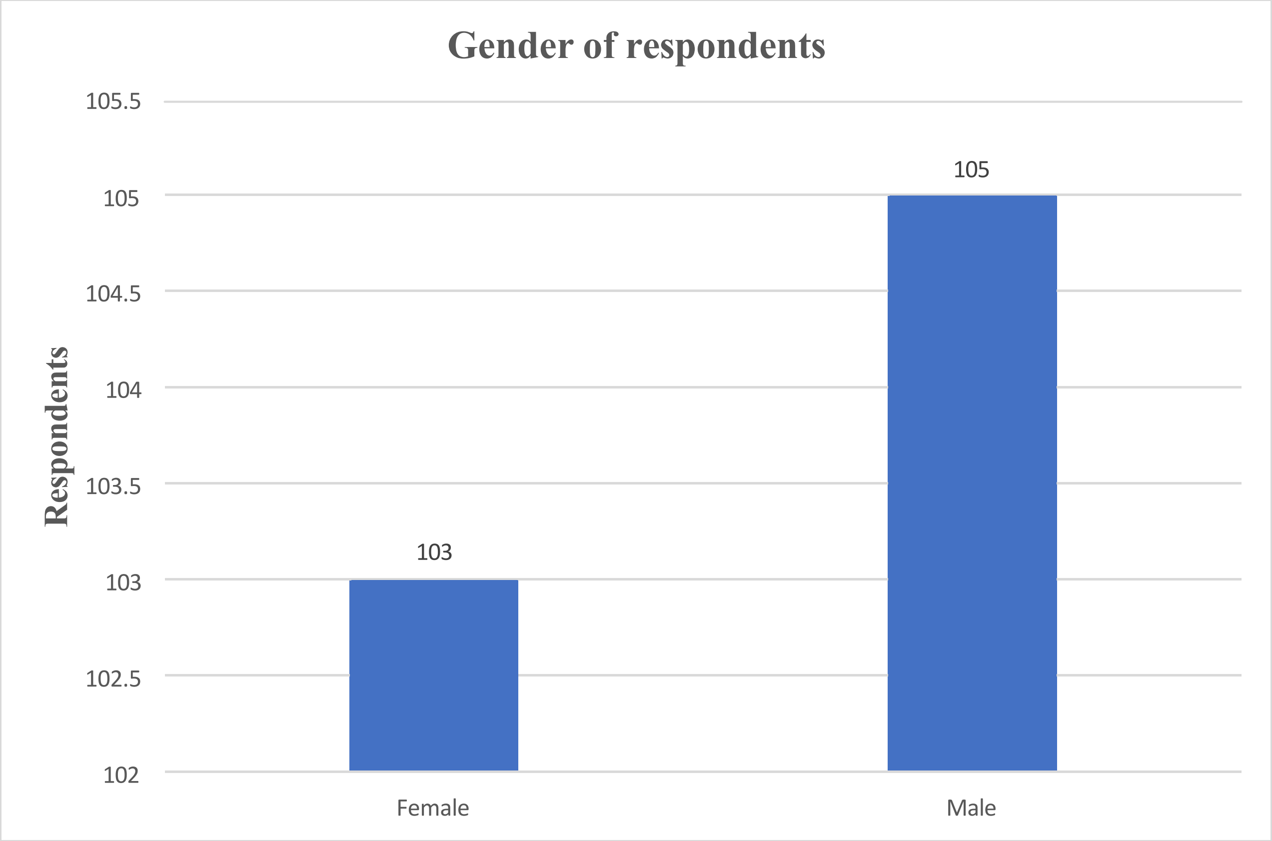

Figure 1: Gender of Respondents

Figure 1 shows the percentage of people by gender who responded to the questionnaire. Out of a total of 208 respondents who answered to the question on gender, 103 respondents were females, while 105 respondents were males.

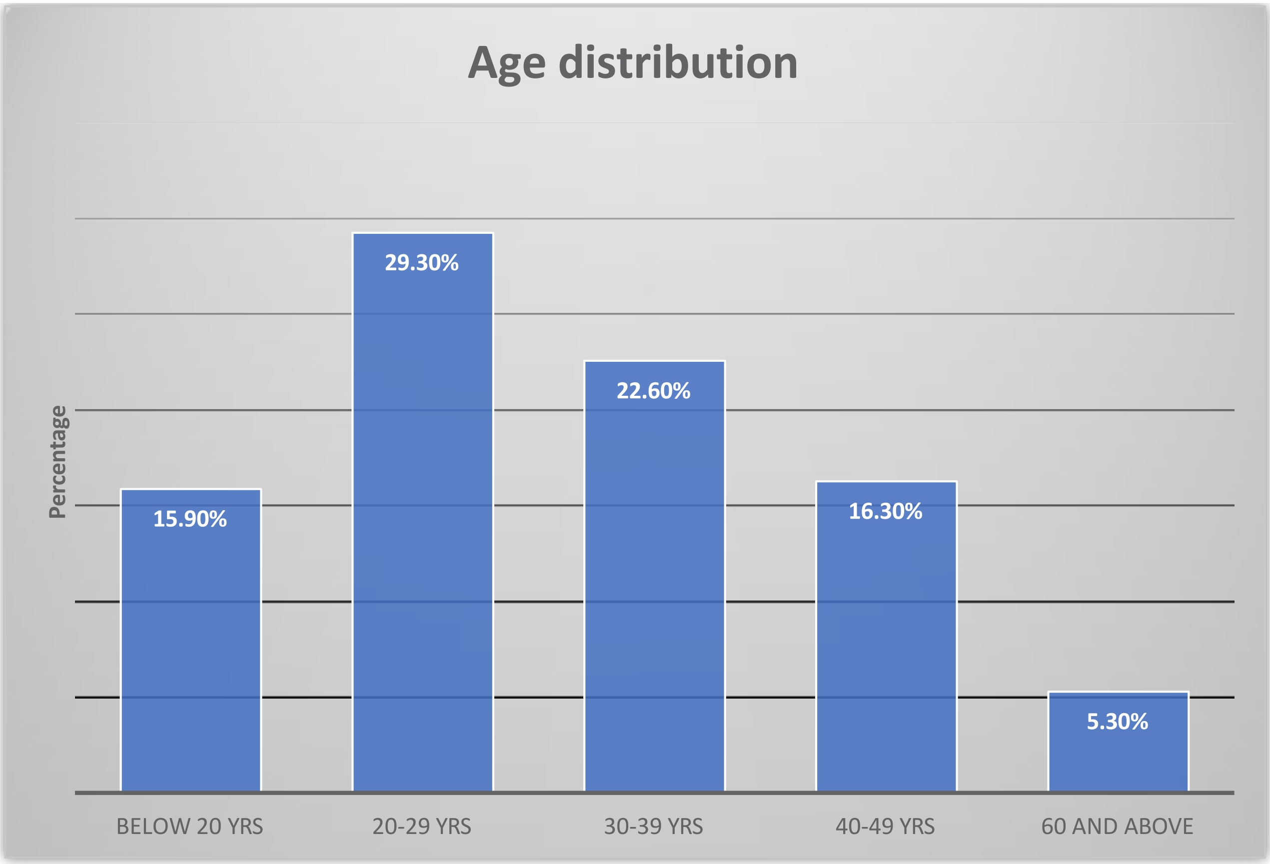

Figure 2: Age of Respondents

Figure 2 shows the age distribution between participants. Out of the 208 respondents, most participants were aged between 20 and 29 years, these represented 29.3 per cent of the total number of people who responded to the questionnaire. This age group was followed by those aged 30–39 years at 22.6 per cent. The least represented by age were participants aged 60 years and above at 5.3 per cent of the total number of the respondents.

Table 1: Age of respondents per district

		Age group						Total
		Below 20 years	20–29 years	30–39 years	40–49 years	50–59 years	60 years and above	
District	Kasama	9	23	24	12	8	7	83
	Mongu	1	0	3	21	12	3	40
	Senanga	20	0	0	0	0	0	20
	Chongwe	0	25	0	0	0	0	25
	Lundazi	0	5	17	0	0	0	22
	Katete	3	8	3	1	2	1	18
Total		**33**	**61**	**47**	**34**	**22**	**11**	**208**

Interestingly, in Chongwe only those aged 20–29 years responded to the questionnaire. Out of the six districts that were sampled for the quantitative component of the study, Kasama had the highest number of respondents at 83, followed by Mongu, where 40 people answered the questionnaire. The least number of respondents were in Katete, where only 18 people participated.

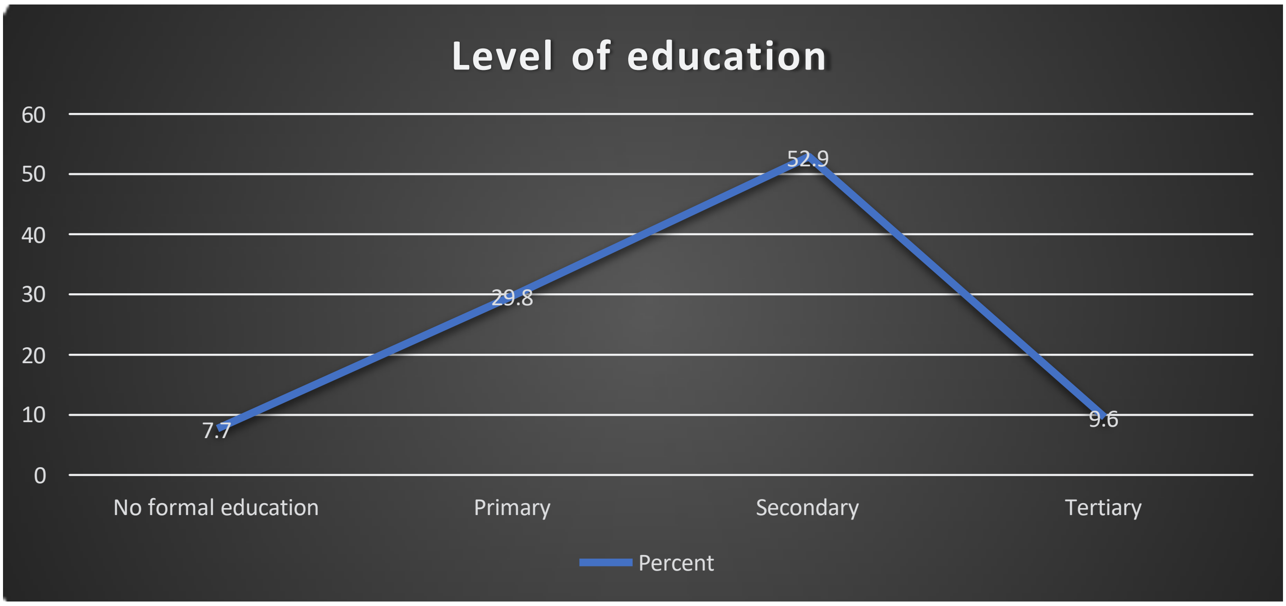

Figure 3: Level of education of respondents

Figure 3 above shows the highest level of education of the respondents in the study: 7.7 per cent of the respondents never attended school. Over half (52.9 per cent) attended and completed secondary school; 29.8 per cent attended or completed primary school. As for higher education, only 9.6 per cent reported higher than secondary school status.

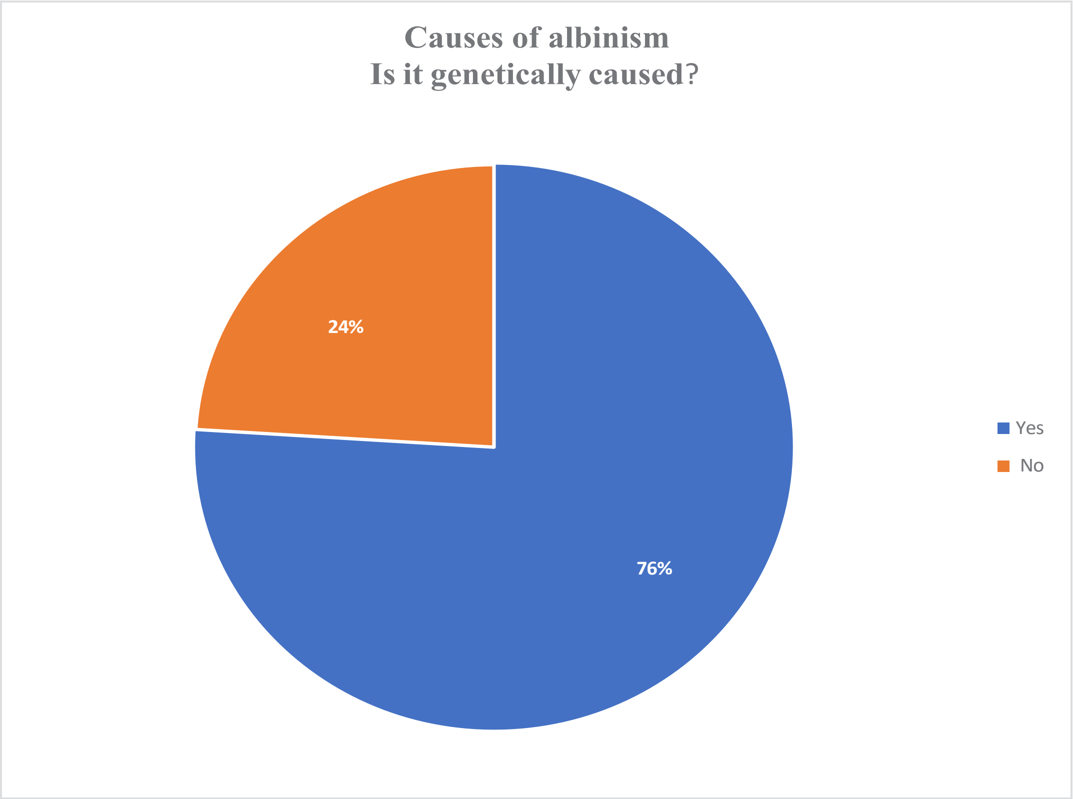

Figure 4: Beliefs about causes of albinism

When asked whether people with albinism were genetically caused, the study revealed that 76 per cent of the 208 participants who responded to the question believed that it was a genetic condition, while 24 per cent did not. This shows that most of the people who responded to the questionnaire were of the view that albinism was a result of a genetic condition.

Table 2: Age of respondents and their beliefs that albinism is a disability

Statement	**Response**	**Below 20 years**	**20–29 years**	**30–39 years**	**40–49 years**	**50–59 years**	**60 years and above**	**Total**
Albinism is a disability	Strongly disagree	12	32	18	13	8	2	85
	Disagree	13	16	23	11	4	6	73
	Neutral	2	9	2	3	2	0	18
	Agree	4	1	3	4	7	2	21
	Strongly agree	2	3	1	3	1	1	11
Total		**33**	**61**	**47**	**34**	**22**	**11**	**208**

The table above shows the age of respondents and their understanding of albinism as a disability. Across all the age groups, only 32 respondents (15.3%) agreed that albinism was a disability, while 18 (8.65%) were not sure. The proportion of those respondents who agreed with the statement were older respondents, in age groups of 50–59 years n=(8) and 40–49 years (n=7); only 6 respondents below the age of 20 years viewed albinism as a disability. These results show that very few young people who participated in this study understood that albinism was a disability.

Table 3: People per district and their beliefs that albinism is a disability

		District						**Total**
		Kasama	**Mongu**	**Senanga**	**Chongwe**	**Lundazi**	**Katete**	
Albinism is a disability	Strongly disagree	47	9	3	13	4	9	85
	Disagree	25	12	13	2	13	8	73
	Neutral	4	6	0	8	0	0	18
	Agree	3	10	4	0	3	1	21
	Strongly agree	4	3	0	2	2	0	11
Total		**83**	**40**	**20**	**25**	**22**	**18**	**208**

Table 3 shows that across the districts, only 32 respondents believed that albinism was a disability (15.38 per cent). Of these, 13 (6.25 per cent) were from Mongu, 7 (3.37 per cent) were from Kasama, 5 (2.40 per cent) were from Lundazi and the remaining were from Chongwe and Katete.

Table 4: Religious beliefs about albinism

Statement	Response	Very religious	Moderately religious	Somewhat religious	Not religious	Not religious at all	Non-response	Total
Albinism can be cured through spiritual intervention	Strongly disagree	66	44	10	8	0	1	129
	Disagree	34	11	9	0	1	1	56
	Neutral	5	1	1	1	0	0	8
	Agree	9	2	2	0	0	0	13
	Strongly agree	0	2	0	0	0	0	2
Total		**114**	**60**	**22**	**9**	**1**	**2**	**208**

Table 4 shows that 15 (7.2 per cent) respondents believed that albinism could be cured through spiritual intervention. All of these respondents identified themselves as religious. In contrast, 185 (89%) respondents who answered the question of whether albinism can be cured by spiritual intervention disagreed. Among these 174 were religious and 11 were not. Meanwhile, only 7 (3.4%) were neutral.

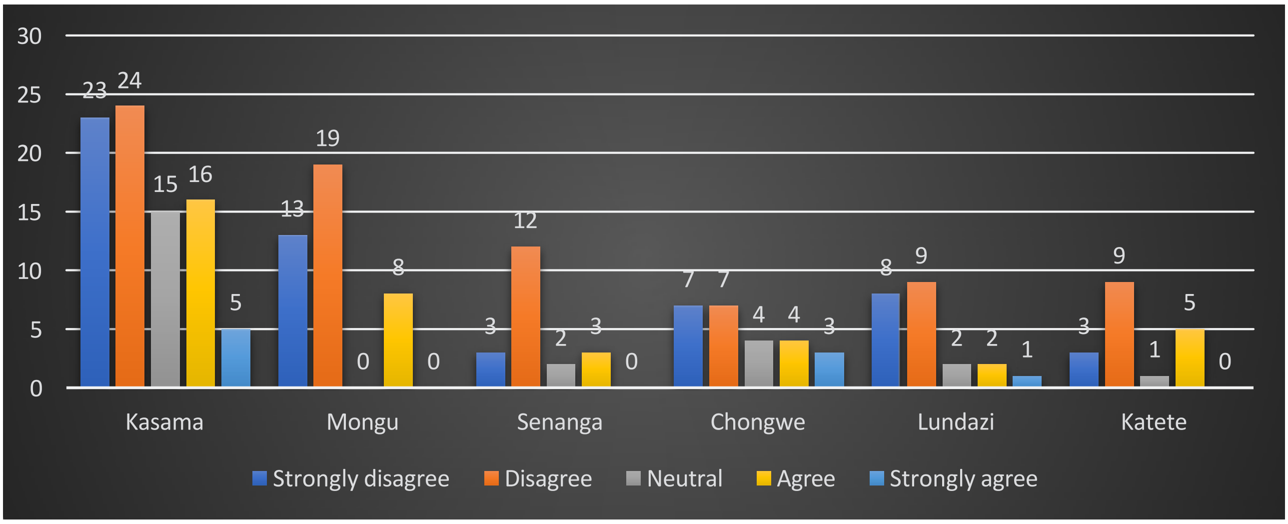

Figure 5: Beliefs about albinism being inherited.

Respondents in the study sites were asked if they were aware that albinism in children is inherited from their parents. The results show that 139 respondents (67%) disagreed that albinism is a hereditary condition, whilst 24 respondents (11.5%) were not sure. In contrast, only 47 (22.5%) correctly believed it is hereditary. In Kasama, 21 out of 84 (25%) respondents agreed that it was inherited from the parents. In other districts, those that agreed that albinism was inherited from parents were as follows: 8 (20%) from Mongu, 7 (28%) from Chongwe, 5 (28%) from Katete, 3 (15%) from Senanga, and 3 (14%) from Lundazi.

Findings from the qualitative component of the study

5.1 Cultural responses to the birth of a child with albinism

In Zambia, cultural responses to the birth of a child with albinism are varied, and unfortunately, negative beliefs and superstitions are still prevalent in some parts of the country. To some extent, their responses were shaped by their beliefs and their knowledge about albinism. When discussing their growing awareness that their child may have been a child with albinism, the participants shared their initial reactions, beliefs, thoughts and experiences about the condition of their child

with others. Their attitude varied from suspecting the involvement of witchcraft, attributing it to a medical condition or believing that it was the will of God.

In a focus group discussion (FGD) in Senanga district of Western province, participants reiterated the ancient unresolved mystery of the human albinism condition. It was also found that the joy of having a child changed to sorrow upon suspecting that the child had albinism.

> “
> At first, I couldn't accept it because, I mean, I didn't just accept it. I literally cried [...] I was disturbed because in my family there has been no case of anyone being born like this.
>
> **Mother – Senanga**

> “
> I can remember that day like it was just yesterday. I couldn't stop crying [...] there were days when I would lock myself in a room and cry and cry and cry. It was really hard to understand and accept that my child had a problem.
>
> **Mother - Mongu**

Other participants described their reaction to the child's condition as one of surprise and shock that they had not experienced before. During a FGD with carers of children with albinism in Sefula, it was found that women had limited educational attainment, lacked formal employment opportunities and thus had limited financial resources.

Similarly, mothers of students with albinism who were interviewed in Katete had either no formal education or were in informal employment. They reported that they had limited financial resources. Some mothers, as shown above, were widely responsible for the care of their children. Some mothers narrated that the fathers rejected their children with albinism and left the entire responsibility to them.

> “
>
> He rejected us both, the child and me. I felt lonely and miserable.
>
> **Mother, Kasama**

> “
>
> So, he didn't accept the child, I should say. He said that they didn't have such children in his family.
>
> **Mother, Sefula**

However, some partners were supportive of their spouses and children with albinism.

> “
>
> My husband accepted the child as a gift from God, and that there was nothing he could do if that was God's desire.
>
> **Mother, Chongwe**

> “
>
> Husband also believed that it was God's will that they had such a child.
>
> **Mother, Sinda**

Mercy was not abandoned by her husband when they had children with albinism. She says he was understanding and supportive. But she says that being a mother:

> “
>
> You lose a lot of friends because people are afraid of coming to your house and you have pretenders who are going to pretend that they are your friends but actually they are not. They will come only when they have a need and something like that.
>
> **Mercy, Chasefu**

Respondents in this study stated that in Zambia, when a child is born, it is a source of joy and happiness to family members, neighbours, friends and relatives. Because of such joy, neighbours, friends and relatives often visit the newborn with presents and good wishes. But myths and beliefs hold that when one encounters a person with albinism, then the person is subsequently likely to have children with albinism. In this study, we found that during these encounters, the person must spit to avoid having a child with albinism. For Bwalya, these myths and beliefs meant being a mother was exclusion, loneliness and a sacrifice that she had to make because:

> “People say children with albinism are born because of some mistakes that mothers had committed like having love affairs outside wedlock.

Bwalya, Kasama.

All research respondents acknowledged that the stereotypes were linking mothers of children with albinism with immorality and sin, which is harmful to their personal well-being.

5.2 Emotional and social effects of discrimination on persons with albinism

Discrimination against persons with albinism can have significant emotional and social effects on their lives. Albinism is a visible difference that sets people apart from the majority, and as such, persons with albinism may be stigmatised and marginalised in their communities. Persons with albinism in this study identified discrimination and fear as some of the factors that made them feel emotionally detached from other people. In most cases, they lived quiet and isolated lives at home, with little exposure and interaction with other people in the neighbourhood.

> “Nowadays you never know who your genuine friend or neighbour is. Sometimes, a close friend might be planning your execution.

Banda, Katete

> “We know we are still alive and secure, when we see the morning of a new day. Urban or rural environments are quite insecure for us.

Betty, Senanga

In all the districts, a key issue raised by traditional leaders as well as civic leaders was that most persons with albinism are suspicious of strangers owing to pervasive cases of unspoken or manifest prejudice against them. Persons with albinism across all the research sites said that they did not trust and/or take up jobs in towns and isolated places. This trend restricted their survival to activities around the household, homesteads and village trading centres, yet most opportunities are available in urban places away from their parental home.

Related to the above was gender-based violence. This was acknowledged by persons with albinism as being a challenge in all the districts sampled, and what was further acknowledged was that women were more vulnerable. Women with albinism faced gender-based violence and hate crimes in the form of rape. This meant that rape, which some women with albinism endured, were acts of hate against them.

One of the persons with albinism in Lundazi stated that some men proposed marriage to women with albinism not because they wanted them as partners, but because they wanted to win their trust so that, with time they would murder them (women with albinism) and use their body parts for rituals, in the hopes of becoming rich.

> **“ It's hard to trust men, they see us as 'sample', they will pretend that they love you, once you stay together for two or three years, you start trusting them, they will kill you and sell your body parts. So for me, marriage is out of question... I have heard of such stories"**

Mutemwa, Sefula

In Senanga and Chongwe, the respondents said that there were beliefs that having sex with a woman with albinism can cure certain diseases, including HIV/AIDS, which led to a rise in sexual violence against women with albinism. It was further acknowledged that women with albinism faced other forms of gender-based violence, such as domestic violence and sexual harassment. Research respondents, particularly the health workers, reported that the violence and hate crime that persons with albinism experienced were also subjecting them to the risk of contracting infectious diseases, such as HIV/AIDS and other sexually transmitted diseases. Persons with albinism, particularly women, spoke about threats of being raped and that these threats raised their anxiety about their personal safety, not only constraining their freedom of movement but also impeding their participation and/or retention in social activities.

> **“ Men say a lot of bad things. Some say I want to sleep with you...I do get afraid"**

Frida, Mongu

On the other hand, men with albinism in this research also admitted facing discrimination, but according to some women with albinism, men were perceived as having a higher status than women because of their gender hence, the discrimination they faced was of lesser severity.

> **“ In our culture, men, regardless of whether they have albinism or not, are seen as being superior to women.**

Sam, Katete

It is important to recognise that persons with albinism, regardless of their gender, are human beings who deserve to be treated with respect and dignity. One of the representatives from organisations for persons with albinism stated that efforts to raise awareness about albinism and combat discrimination and violence against people with albinism should consider the gendered aspects of the issue.

Another issue that was raised was that the discrimination and stigmatisation that persons with albinism experienced had a profound impact on their well-being. For example, persons with albinism reported low self-esteem and poor body image. Some persons with albinism interviewed mentioned that they felt ashamed or embarrassed about their appearance, and some avoided social situations. Some said that discrimination made them feel socially excluded and isolated, leading to feelings of loneliness.

> “During holidays when I go home, that is when I feel like people discriminate against me. When this happens, I feel anxious, depressed and isolated.

Learner, Sefula School

Some persons with albinism in this research reported experiencing fear and trauma because of the violence they were experiencing, as some respondents remarked:

> “There was a time I was coming from work, some boys started stoning me and calling me all sorts of names such as *‘Chidangwaleza icho’*. (a person with albinism)

Sam, Katete.

> “When she's going to school, people throw stones at her. Others call her ‘sample’, meaning her body parts can be sold and earn a person money.

Mother of a person with albinism, Katete

In Mongu, Lundazi and Chasefu, there were cases of persons with albinism being attacked, mutilated and killed, which induced fear and trauma. It is, however, important to recognise the emotional and social effects of discrimination against persons with albinism and work towards creating more inclusive and accepting societies. This can be done through education, awareness-raising, and advocacy efforts that promote the human rights and dignity of people with albinism.

5.3 Persons with albinism and their access to education

Access to education is a fundamental human right, and individuals with albinism should have equal opportunities to learn and develop their skills and knowledge. However, due to a lack of policies, or the enforcement of policies, aimed at ensuring persons with albinism receive the specific support they require in places of learning, most face barriers to accessing education and achieving their full potential. Learners with albinism reported experiencing attacks. This made them afraid of moving alone.

Due to the fear, some children and youth with albinism have been taken to special schools like Sefula, Magwero in Chipata and Kasama College of Education. Such schools were presumed to be more secure than having children with albinism walk daily to school within the villages.

> “I feel much safer here. We have a guard, and I don't really have the fear of being attacked the way I had before I came to this school. As you can see there are only people with disabilities and people with albinism at

this school. I feel accepted and safe.

Learners in an FGD, Sefula Special School

> **"Here we are okay, teachers understand us, and it's only people like me and those with disabilities at this school.**

Learners in an FGD, Sefula Special School

It was observed in this study that learners with albinism in special schools felt safer and accepted. However, it was acknowledged that learners with albinism in mainstream schools experienced discrimination and stigmatisation. Naomi, a female learner with albinism, talked about how she almost left school because of bullying and harassment. It was only after her neighbour, a friend she grew up with, moved into her class and defended her against bullying that she was able to continue with school and consequently made progress. Similarly, a male learner with albinism, reflected upon how he dropped out of school for three months because of the negative treatment he was receiving. He recounted his experience:

> **"I didn't like the way I was being treated by my friends and teachers. I almost stopped school because of the treatment I was receiving.**

Male learner in Lundazi.

What emerged from the perspectives of learners with albinism was that they were experiencing bullying and harassment, which were widely instigated by myths and beliefs about albinism, and this affected their smooth academic progress, and thus their inclusion in all phases of education. This meant that attitudinal barriers were among the factors that were limiting effective participation of learners with albinism in an inclusive school system. Other challenges acknowledged by learners with albinism included a lack of awareness and understanding among teachers and educational institutions on the specific needs of students with albinism, such as access to resources and accommodations necessary to support their learning, particularly in relation to vision problems, such as poor vision, nystagmus (involuntary eye movements) and photophobia (sensitivity to light).

> **"I have difficulties reading what the teacher writes on the board...I need help with the visual aid.**

learner with albinism, Sinda

Another issue raised, especially in Senanga, related to the myths that people with albinism have limited cognitive capacity. This made some parents refrain from taking their children with albinism to school, believing that it was a waste of resources, as the child could not adequately participate in education. Similarly, some teachers who believed in such myths made no effort to assist students with albinism with their learning processes.

> **"You see, you can only invest where there will be benefits.**

from a FGD participant, Senanga.

While the myth blames those with albinism for possible poor performance, it overlooks the limitation of learning and teaching facilities that the education system often provides for students with albinism who, as already mentioned above, often suffer from poor vision.

This study found that inadequate support from teachers had negatively impacted parents. Some parents started to believe that their children with albinism were incapable of doing well at school. This resulted in parents' believing that educating children with albinism was a poor investment and thereby justifying their decision not to invest in their children's education and legitimising the misrecognition of their learning abilities.

> **"He has poor sight hence he can't see clearly on the board...because of the limited resources that we have, his dad said that he will start school later. We decided to send his young brother to school instead.**
>
> **Mother, Chongwe**

According to the research respondents, the myth about persons with albinism's learning inabilities was discriminatory and a form of hate. Some parents of children with albinism stated that they feared becoming poor if they sent their children with albinism to school because it would mean spending substantial amounts of money buying uniforms plus other devices, which these learners needed to aid them at school. These parents thus thought that it was too risky to invest in a child with albinism.

> **"With these scarce resources, as parents, we need to be making wise decisions regarding the children we send to school. Others can be taken care of by their siblings.**
>
> **Febby, Chongwe**

This belief contributed to the widespread prejudice towards people with albinism owing to the false belief that they have limited cognitive capacity. It was also acknowledged that boys with albinism, in general, were favoured over girls with albinism because of the assumption that they may become breadwinners. This is unfortunate for a girl child with albinism. One representative from the organisation for persons with albinism admitted the following:

> **"There are a lot of myths around learners with albinism in the villages...it's our responsibility as NGOs to debunk these myths.**
>
> **Ackim, non-governmental organisation (NGO) official.**

Ackim noted that myths incite violence against persons with albinism at learning institutions threatens the safety of these learners. This has led to persons with albinism avoiding public places where they are prone to attacks.

Peter, a male learner with albinism in Sefula shared his school experiences. He reflected on his primary school experiences and recalled that:

> "
> I used to get offended by the way my fellow students were treating me. When I had just started school, no one wanted to get closer to me, but with time, they accepted me.

Peter, Sefula

Peter noted that myths incite violence against persons with albinism. Albinism-related violence in learning institutions was rife:

> "
> There are a lot of myths around learners with albinism in the villages...it's our responsibility as NGOs to debunk these myths.

Patrick, a non-governmental organisation (NGO) official.

In terms of study materials, in all the research sites, it was reported a lack of accessible material and reasonable accommodations in schools limits the ability of students with albinism to read books in small font or at a distance. Specific textbooks which have large print are required to ensure a comfortable reading and learning environment for persons with albinism. All students with the condition acknowledged the lack of large-print textbooks in all phases of their education, raising the need to have assistive devices or products to support their learning.

> "
> As a school we don't have books that are in large print to cater for learners with poor vision."

Teacher, Katete

5.4 The right to health of persons with albinism

Persons with albinism have the right to enjoy the highest attainable standard of physical and mental health, as recognised in international human rights law. However, there are numerous barriers which may hinder their ability to access health care and enjoy their right to health.

The participants in this study, particularly persons with albinism, acknowledged numerous barriers that they were encountering in accessing healthcare services. One of the main challenges highlighted was the lack of awareness and knowledge about albinism among some healthcare providers. This, at times, resulted in misdiagnosis and mistreatment of certain health conditions that are more prevalent among persons with albinism, such as skin cancer and visual impairments.

> "
> It's difficult for people like us when we go to the hospital, at times, we receive negative comments from the healthcare workers."

A person with albinism, Mongu

> **“I hardly find sunscreen at the hospital. Each time I go there, they tell me to go and buy…they don’t even have the courtesy of saying when the medicine would be available.”**

A Person with Albinism, Lundazi

Another challenge that was highlighted in this study was the high cost of treatment and medication for persons with albinism. Due to their sensitivity to sunlight, they require protective clothing, sunscreen and regular skin cancer screening which can be expensive and not easily accessible in some regions. Additionally, corrective lenses and other assistive devices, such as monocular and magnifiers may be needed to address visual impairments, which are not affordable for many persons with albinism.

> **“Sunscreen is beyond the reach of many persons with albinism, especially in this area. Most of us are farmers and you know we aren’t that productive because we can’t work in the sun for a long time.”**

Person with albinism, Katete

This study found that discrimination and stigma negatively impacted the right to health of persons with albinism. They reported facing attitudinal barriers in accessing health care due to discrimination, and the psychological impact of stigma affected their mental health. It was also discovered in all the study sites that lack of availability of specific healthcare services to persons with albinism occurred because, logistically, access to certain treatments was only available in larger health centres—for example, access to sunscreen (although it was rarely available) and support was often available only in urban centres and limited in remote areas. It was further learned that access to other healthcare resources and mental health services was often scarce and unevenly distributed in the study areas.

> **“There is insufficient access to eye-care specialists for us or other healthcare specialists.”**

Person with albinism, Katete

At one of the villages visited in Senanga, it was discovered that because of the unavailability of some healthcare services at health centres, families assumed the responsibility of providing alternative healthcare. They resorted to seeking healthcare through traditional healers.

Despite seeking healthcare services from traditional healers over healthcare providers, the research respondents, however, acknowledged that the traditional healers were unable to treat skin lesions and cancer.

> **“In most cases, when I go to the clinic, I hardly find medicine…Yes of course, traditional healers are an alternative.”**

Timothy, Sinda

Distance to health centres was also highlighted as one of the challenges that persons with albinism experienced. Also, persons with albinism, in many instances, could not afford to access healthcare, such as purchasing sunscreen and highly protective clothing, because where they resided had a dearth of these resources.

5.5 Access to justice for persons with albinism: The international and contextual legal framework

5.5.1 Historical context and the international bill of rights

The international protection for human rights for all persons, including persons with albinism, is primarily premised on the United Nations Charter (hereinafter referred to as "the UNC"), which is the founding treaty of the United Nations.[20] In Article 1 of the UNC, it is stated that one of the purposes of the United Nations is to promote and encourage respect for human rights and fundamental freedoms for all. Therefore, by becoming members of the United Nations, state parties undertake to promote and encourage the respect for human rights for all. However, the provisions of the UNC are not elaborate enough to ensure that human rights and fundamental freedoms are protected. In this regard, the Universal Declaration of Human Rights (hereinafter referred to as "the UDHR") was promulgated in 1948.[21] The UDHR is a morally and politically binding resolution of the United Nations, and while its text informs the Bill of Rights or constitutions of most nations, it has little or no legal force in terms of enforcement or protection of human rights.[22]

In pursuance of binding international treaties, the United Nations came up with two very important international human rights treaties in 1966, and these are the International Covenant on Civil and Political Rights (hereinafter referred to as 'the ICCPR'),[23] and the International Covenant on Economic Social and Cultural Rights (hereinafter referred to as 'the ICESCR').[24] The ICCPR expressly provides for the protection and enjoyment of a wide range of human rights, such as the right to a fair trial, equality and non-discrimination, and freedom from torture and other cruel, inhuman, degrading treatment or punishment. Enforceability is one distinguishing feature that sets apart the ICCPR and the ICESCR from the UNDHR. The ICCPR and the ICESCR have enforcement mechanisms that ensure the effective protection of human rights. For instance, the Human Rights Committee (hereinafter referred to as 'the HRC') monitors how state parties implement the ICCPR.[25] Further, the Optional Protocol to the ICCPR allows people to directly lodge complaints of human rights violations to HRC.[26] Equally, the Optional Protocol to the ICESCR establishes a complaint and inquiry mechanism like that under the Optional Protocol to the ICPCR.[27]

The UDHR, ICCPR and ICESCR collectively make up what has come to be known as the International Bill of Rights. To be binding, state parties must ratify the ICCPR and ICESCR. It is noteworthy that Zambia ratified both the ICCPR and the ICESCR on 10th April 1984.[28] It follows that Zambia is bound by both the ICCPR and the ICESCR. However, a careful perusal of the

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[21] United Nations Charter (full text), https://www.un.org/en/about-us/un-charter/full-text. 4 January 2023.

[22] United Nations General Assembly Resolution number 217 A, https://www.un.org/en/about-us/universal- declaration-of-human-rights. 6 January 2023.

[23] Marriane Schulze, 'A Handbook on the Human Rights of Persons with Disabilities; Understanding The UN Convention On The Rights Of Persons With Disabilities' file:///C:/Users/LK%20&%20Company/Downloads/holistic%20uncrpd%20manual.pdf. 6 January 2023.

[24] United Nations General Assembly resolution 2200A (XXI) 16 December 1966, International Covenant on Civil and Political Rights,mhttps://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant- civil-and-political-rights. 6 January 2023.

[25] United Nations General Assembly Resolution 2200A (XXI) 16 December 1966, International Covenant on Economic, Social and Cultural Rights, https://www.ohchr.org/sites/default/files/cescr.pdf. 7 January 2023.

[26] A body of independent experts that monitors implementation of the International Covenant on Civil and Political Rights by its States parties, https://www.ohchr.org/en/treaty-bodies/ccpr. 7 January 2023.

[27] United Nations General Assembly Resolution 2200A (XXI) 16 December 1966, https://www.ohchr.org/en/instruments-mechanisms/instruments/optional-protocol-international-covenant-civil-and-political. 7 January 2023.

[28] United Nations General Assembly Resolution A/RES/63/117, 10 December 2008, https://www.ohchr.org/en/instruments-mechanisms/instruments/optional-protocol-international-covenant-economic-social-and. 7 January 2023.

International Bill of Rights reveals that while it contains some progressive provisions as regards the pronouncements and enforcement of human rights, it does not have express provisions relating to the rights of persons with albinism and or persons with disabilities. At the most, the International Bill of Rights provided for the protection of human rights and forbade discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. The understanding was that persons with disabilities were covered under 'other statuses'. However, the right to access to justice was not expressly provided for. This means there are no procedural and other accommodations to ensure that the rights of persons with either disabilities or albinism firstly enjoyed their human rights on an equal basis with others and secondly that their human rights violations are sufficiently redressed.

5.5.2 The CRPD and the right to access to justice

With time, it became increasingly clear that human rights cannot effectively be enforced without expressly providing for the right to access to justice. In this regard, the CRPD, for the first time in an international instrument, expressly provided for the right to access justice, the gatekeeper right to all other human rights. Further, the CRPD is hailed as a paradigm shift from the medical model of disability to the social model of disability, whereby disability is seen as an interaction between an individual's impairment and the barriers created by society.[29] A medical model of disability is one that views impairment as a defect within an individual whose defects needs to be cured, fixed or eliminated.[30] The medical model creates a challenge in instances where the medical interventions fail to cure or fix the impairment as a result of which persons with such impairments are condemned to hopelessness, social exclusion, inhuman treatment and referred to in derogatory terms. Further, the medical model sees disability as a problem within a person, making it impossible for that person to enjoy his rights or fully participate in society.

On the other hand, the thrust of the social model of disability is to adapt the social and physical environment to accommodate persons with disabilities so they may enjoy their human rights on an equal basis with others. The social model has a human rights approach to disability. It recognises the impairment as normal in any society and considers the disadvantages the person with impairments has, the lack of appropriate support and a multi- faceted web of discrimination across all levels of society which in turn, often results in social and economic marginalisation and exclusion.

The CRPD, together with its human rights approach to human impairments (paradigm shift), is particularly useful in promoting, protecting and enforcing the rights of persons with albinism, seeing that albinism is incurable and requires the adaptation of the social and physical environment to enhance access to justice of persons with albinism.

According to Article 13 of the CRPD, state parties are required to take steps to ensure that the procedures by which persons with disabilities come into contact with the law, whether it be civil or criminal, should ensure that the barriers that hinder persons with disabilities from being availed the full benefit of the law are removed. Equally, steps should be taken to ensure that the built environment and societal norms and values are adjusted to ensure maximum participation of persons with disabilities.[31]

Unfortunately, the CRPD, with all its innovative provisions related to the right to access to justice, does not expressly mention persons with

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[29] United Nations Human Rights Treaty Bodies, https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=194&Lang=EN. 23 January 2023.

[30] European Union Fundamental Rights Agency, 'Choice and Controls: the right to independent living' (2012) p. 3 https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Ffra.europa.eu%2Fsites%2Fdefault%2Ffile s%2Ffra_uploads%2Fchoice_and_control_final_13.docx&wdOrigin=BROWSELINK. 26 March 2023.

[31] Office of the Developmental Primary Care, 'Medical and Social Models of Disability' https://odpc.ucsf.edu/clinical/patient-centered-care/medical-and-social-models-of-disability. 26 March 2023.

albinism. However, the peculiar circumstances persons with albinism find themselves in point to the fact that both their enjoyment of human rights, and the redress of their human rights violations, can mostly be achieved through the right to access justice as promulgated in Article 13 of the CRPD. This entails that persons with albinism should be availed of all amenities to ensure that they can access the courts and to participate in the court proceedings on an equal basis with others. Furthermore, there should be sufficient information, sensitisation and training of both persons with albinism and other members of the community. Information should flow freely in communities where persons with albinism live, especially on how to report human rights violations against persons with albinism, and how the violations may be dealt with within the available legal framework and the criminal justice system.

There is an equal need to make available such amenities as vision assistive devices and accommodative lighting in schools, health centres and other public buildings to ensure circumstances are created in these public facilities to ease vision or sight challenges for persons with albinism.

According to Article 5 of the CRPD, state parties are required to recognise that all are equal before and under the law, meaning that all persons are entitled, without discrimination, to equal protection of the law. With respect to persons with albinism, it means that the law should not be applied differently to persons with albinism than it is applied to all other persons. Suffice it to state that the law in the CRPD should not just benefit persons with disabilities and exclude persons with albinism. Equally, the application of the right of equality and non-discrimination in Article 5 and that of access to justice in Article 13 of the CRPD should be availed not only to persons with disabilities but also to persons with albinism and such other persons who require a reasonable accommodation to equalise opportunities and participation in their communities.

It is noteworthy that Article 5 (2) further enjoins state parties to prohibit discrimination because of a disability. To the extent that persons with albinism suffer visual impairments due to insufficient melanin pigmentation in their eyes means that albinism is a disability which brings persons with albinism within the confines of Article 5 of the CRPD. Article 5 (2) of the CRPD also pledges equal and effective protection against discrimination on all grounds. That there is to be equal and effective protection against discrimination on all grounds is significant. With respect to persons with albinism, it means that discrimination on the ground of albinism, with all its attendant offshoots, is prohibited. Therefore, persons with albinism are not to be discriminated against on the grounds of their skin colour and or visual impairments. Instead, they should be allowed to participate in the education system and economic, social and cultural affairs of their communities.

Article 19 of the CRPD provides for the right of all persons with disabilities to live in the community with full inclusion and participation, specifically to have access to the range of in-home, residential and other community support services, including personal assistance to avoid isolation and segregation. Persons with albinism usually suffer isolation and segregation on account of prejudicial and derogatory imputations and societal norms and values, and lack of in-home, residential and other community support services, such as protective clothing, sunscreen-appropriate light settings in public institutions, such as educational establishments.

Zambia ratified the CRPD on 10 February 2010,[32] but has not ratified the Optional Protocol to the CRPD.[33] This means that on account of its ratification of the CRPD, Zambia is subject to a peer review mechanism by other state parties whereby it is required to submit periodic reports to the CRPD Committee for discussion by the CRPD Committee members and other state parties. Article 1 (2) of the Optional Protocol to the CRPD reads:

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[32] Marriane Schulze, op. cit., p. 94.

[33] Disabled World, https://www.disabled-world.com/disability/discrimination/crpd-milestone.php#table1. 10 March 2023.

> ***"No communication shall be received by the Committee if it concerns a State Party to the Convention that is not a party to the present Protocol."***

The import of the foregoing provision is that no individual complaint may be lodged against Zambia with the CRPD Committee alleging violations of any of the provisions of the CRPD until Zambia ratifies the Optional Protocol to the CRPD. There is a need for Zambia to ratify the Optional Protocol to the CRPD to make the effective protection and enforcement of the CRPD rights effective. However, to the extent that the provisions of the CRPD have been domesticated in Zambia, the same are enforceable before Zambian courts.

5.5.3 The Convention on the Elimination of All Forms of Racial Discrimination

The main theme for the Convention on the Elimination of All Forms of Racial Discrimination (CEAFRD) is to eliminate all forms of racial discrimination,[34] and Zambia ratified the CEAFRD on 4 February 1972[35], and as such, the provisions of the CEAFRD are binding on Zambia. Article 1 of the CEAFRD defines racial discrimination as:

> ***"any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life."***

Persons with albinism usually have a distinctive skin colour which ordinarily results from the lack of or insufficient pigmentation in the skin, eyes or hair. It is a result of the distinctive colour that persons with albinism are subjected to racial discrimination. This brings persons with albinism under the auspices of CEAFRD.

The CEAFRD requires state parties to take special measures for the sole purpose of securing adequate advancement of certain racial or ethnic groups or individuals requiring such protection as may be necessary in order to ensure such groups or individuals equal enjoyment or exercise of human rights.[36] This provision requires that Zambia takes deliberate measures that will enable persons with albinism to enjoy their human rights and to ensure that violations of their human rights are effectively remedied. Therefore, Zambia is obligated under the CEAFRD not to rely on the general laws but to take special measures to ensure that racial discrimination, including against persons with albinism, is eradicated.

Article 2 (1) (a) of the CEAFRD mandates state parties to take effective steps to review national laws, regulations and policies and to rescind, amend or nullify such national laws, regulations and policies that have an effect of creating or perpetuating racial discrimination wherever it appears. Zambia, under this treaty is required to constantly review its laws, regulations and policies as to their effectiveness in combating racial discrimination against persons with albinism.

In Article 4, the CEAFRD requires state parties, including Zambia, to condemn all propaganda which attempts to justify or promote racial hatred and discrimination of any form and undertake to adopt immediate and positive measures designed to eradicate all incitement to, or acts of, such discrimination. This provision, among others, targets hate crimes or speech against persons with albinism. It also targets beliefs, myths or cultural practices which justify the attacks and dismembering, and sometimes killing, of persons with albinism.[37] The said propaganda (myths and beliefs) plays a significant role in excluding persons with albinism from society. Consequently, persons

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[34] Ibid.

[35] United Nations General Assembly Resolution No. 2106 (XX) of 21st December 1965, https://www.ohchr.org/sites/default/files/cerd.pdf. 28 February 2023.

[36] United Nations Treaty Collection, https://treaties.un.org/PAGES/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-2&chapter=4&clang=_en. 1 March2023.

[37] Ibid. article 1(4).

with albinism are forced to stay away from the education and health system and participate in the activities of the communities they are supposed to live in. Effectively, persons with albinism are racially discriminated against from every aspect of society. If Zambia can strictly adhere to its obligations under the CEAFRD, discrimination against persons with albinism would be minimised, if not eradicated altogether.

5.5.4 Convention on the Rights of a Child (CRC)

Non-Discrimination: the CRC upholds the principle of non-discrimination, which means that children with disability should not face any discrimination in accessing justice. They should have the same right to seek remedies for rights violations as any child.

Best interest of the Child: the CRC highlights the best interest of the Child as the principal consideration in all actions concerning children. This principle applies to children with disabilities as well, ensuring that their unique needs and circumstances are considered when accessing justice.

Participation and Expression of Views: the CRC stresses the right of the Child to express their views freely in matters affecting them. This includes ensuring their active involvement in decisions related to justice processes. For children with disability, this includes the provision of appropriate support to express their views and participate.

5.5.5 The regional legal framework for the protection of the rights of persons with albinism

On the African level, the rights of persons with albinism are protected under the persons with disabilities regional human rights instrument, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (the African Disability Protocol).[38] In its Preamble, the African Disability Protocol, the Heads of State and Government of the African Union express alarm at the maiming and killing of persons with albinism in many parts of Africa. It further has provisions on the right to access to justice,[39] reasonable accommodations,[40] non-discrimination[41] and equality[42], all of which are couched in similar terms as under the CRPD.[43] An innovative provision of the African Disability Protocol is perhaps the one relating to harmful practices found in its article 11.[44] The said Article 11 mandates state parties to take all appropriate measures and offer appropriate support and assistance to victims of harmful practices. In Article 1, harmful practices are described in the following terms:

> ***"include behaviour, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the human rights and fundamental freedoms of persons with disabilities, or perpetuate discrimination."***

It is noteworthy that the foregoing description of harmful practices is not only restricted to persons with disabilities; it also refers to any behaviour, attitudes and practices that generally perpetuate discrimination. The report has already shown that persons with albinism are usually subjected to myths, beliefs and other cultural practices and hate crimes, which inevitably lead to discrimination against persons with albinism. Consequently, persons with albinism are brought under the auspices of the African Disability Protocol not only on the basis that albinism is a disability but also because they are usually subjected to harmful practices which perpetuate discrimination. Suffice it to state that Zambia has not yet ratified the African Disability Protocol,[45] which in any event has not yet been brought into force on account of not

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[38] Muluka-Anne, op cit.

[39] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities, https://au.int/sites/default/files/treaties/36440-treaty- protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf. 1 March 2023.

[40] Ibid, art 13.

[41] Ibid, art 1.

[42] Ibid, art 5.

[43] Ibid, art 6.

[44] United Nations General Assembly Resolution Number 61/106(2006), op. cit.

[45] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities, op. cit.

having been ratified by a minimum of 15 member states of the African Union.[46]

Zambia ratified the African Charter on Human and Peoples' Rights,[47] popularly known as the Banjul Charter, and as such, Zambia is bound to uphold the human and peoples' rights protected under the Banjul Charter, including the right of every person to receive medical attention when sick.[48] This right to receive medical attention when sick is especially important for persons with albinism in that they usually lack basic supplies, such as sunscreen, cream sunglasses or hats to protect them from skin damage. Further, the Banjul Charter also provides for the right of persons with disabilities to special measures of protection in keeping up with their physical and moral needs.[49] Persons with albinism suffer physical attacks (including maiming and killings) and degrading and inhuman treatment, which rob them of their moral needs. The Banjul Charter, therefore, has a significant role to play in upholding and protecting the rights of persons with albinism.

Another important regional human rights instrument, which Zambia has ratified with key provisions that impact on persons with albinism, is the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, the Maputo Protocol.[50] Hereunder, the Protocol provides for the right of women with disabilities to dignity and freedom from discrimination,[51] and provides for the protection of women and girls from harmful cultural and traditional practices based on stereotyped roles of women and girls.[52] As stated above, persons with albinism, especially women, are victims of harmful cultural practices, which sometimes lead to their expulsion from the communities or being prevented from participating in the affairs of their communities.

5.5.6 The contextual legal framework: the Zambia legal framework and policies within the CRPD

An effective and comprehensive discussion of the Zambian legal framework for the protection and enforcement of the rights of persons with albinism should not only call into focus the statutes, regulations and policies that are collectively termed as national laws, but also include all those international and regional instruments that apply and have been domesticated in Zambia. Accordingly, the report will give a brief exposition of what is meant by the domestication of international and regional instruments in Zambia before a detailed discussion of the statutes, regulations and policies that constitute the legal framework for the protection and enforcement of the rights of persons with albinism.

Domestication of international and regional legal instruments

In the case of *Attorney General vs. Roy Clarke*,[53] the Supreme Court of Zambia had occasion to pronounce itself on the concept of domestication and held as follows:

> ***"[I]n applying and construing our statutes, we can take into account international instruments to which Zambia is a signatory. However, these international instruments are only of persuasive value unless they are domesticated in the laws."***

The above holding makes it clear that while the Zambian courts will consider the international and regional legal instruments to which Zambia is a signatory, the same are not binding and are of persuasive value only. In this regard, even though Zambia has not ratified the African

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[46] One Global Voice, African Charter Rights of Persons with Disabilities, the Protocol, https://oneglobalvoice.it/english/african-charter-rights-of-persons-with-disabilities-the-protocol/. 2 March 2023.

[47] Grace Antwi-Atsu, The African Disability Protocol: a call to leave no one behind, https://www.sightsavers.org/blogs/2021/08/the-importance-of-the-african-disability-protocol/. 2 March 2023.

[48] African Union, https://au.int/en/treaties/african-charter-human-and-peoples-rights. 11 March 2023.

[49] African Charter on Human and Peoples' Rights, art. 16.

[50] Ibid., art 18 (4)

[51] The Maputo Protocol, Adopted by the African Union on 11 July 2003, in Maputo Mozambique.

[52] Ibid., art. 23.

[53] Ibid., art. 2.

Disability Protocol,[54] persons with albinism can still rely on the progressive provisions of the African Disability Protocol to persuade the courts to enhance the protection of their rights. In such cases, the Zambian courts will apply the progressive provisions of the African Disability Protocol in determining a matter involving the protection and enforcement of the human rights of persons with albinism.

On the other hand, once an international or regional legal instrument is domesticated, it has the force of law the same way as a statute enacted by Parliament. Domestication takes the form of reproduction into national laws, of either part or the whole provisions of an international or legal instrument so that those domesticated provisions become part of the national law. For instance, Section 4 of the Persons with Disabilities Act (PDA),[55] adopted and reproduced most the general principles of Article 3 of the CRPD. Section 4 (a) and (b) of PDA among others, lists down the general principles as follows:

"(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
(b) Non-discrimination…"

The foregoing provisions have domesticated Article 3 (a) and (b) of the CRPD as the former are a reproduction of the latter. The effect of such a reproduction is that the reproduced provisions of the international and regional instruments are now part and parcel of a Zambian statute and as such have the force of law, just like any other statutory provisions in Zambia.

Constitutional prohibition of discrimination on the ground of albinism

The Constitution of Zambia is the supreme law of the land and if any other law is inconsistent with any of its provisions,[56] then that other law is, to the extent of its inconsistence, void.[57] This means that the Constitution is the grand norm by which all other laws are validated such that any law that is not consistent with is void. Part 3 of the Constitution consists of the Bill of Rights which seeks to recognise, promote and protect the fundamental human rights of all persons. Article 11 of the Constitution provides:

"It is recognised and declared that every person in Zambia has been and shall continue to be entitled to the fundamental rights and freedoms of the individual, that is to say, the right, whatever his race, place of origin, political opinions, colour, creed, sex or marital status, but subject to the limitations contained in this Part, to each and all of the following, namely:
(a) life, liberty, security of the person and the protection of the law;
(b) freedom of conscience, expression, assembly, movement and association;
(c) protection of young persons from exploitation;
(d) protection for the privacy of his home and other property and from deprivation of property without compensation…".

The foregoing provision recognises and guarantees that every person in Zambia is entitled to the fundamental rights and freedoms irrespective of his race, place of origin, political opinion, colour, creed, sex or marital status subject only to the limitations specified in Part 3 of the Constitution. Effectively, the Constitution prohibits discrimination on the grounds stated in Article 11. Further, Article 23 (2) and (3) of the Constitution states:

> *"(2) Subject to clauses (6), (7) and (8), no person shall be treated in a discriminatory manner by any person acting by virtue of any written law or in the performance of the functions of any public office or any public authority.*
> *(3) In this Article the expression "discriminatory" mean, affording different treatment to different persons attributable, wholly or mainly to their respective descriptions by race, tribe, sex, place of origin, marital status, political opinions colour or creed whereby persons of one such description are subjected to disabilities or restrictions to which persons of another such description are not made subject or are accorded privileges or advantages which are not accorded to persons of another such description."*

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[54] (2008) ZR 38.
[55] One Global Voice, op. cit.
[56] Act Number 6 of 2012.
[57] Constitution of Zambia, Chapter 1 of the Laws of Zambia, as amended by Act No. 2 of 2016.

In Article 23, the Constitution expressly prohibits the discriminatory treatment of any person, attributable wholly or mainly to that person's description by race, tribe, sex, place of origin, marital status, political opinion, colour or creed whereby such a person is subjected to disabilities or restrictions to which such other persons are not subjected to.

It is noteworthy that both Articles 11 and 23 of the Constitution do not expressly prohibit discrimination on the basis of albinism, and a question, therefore, arises as to whether discrimination on the basis of albinism is therefore allowed by the Constitution. The High Court for Zambia had occasion to pronounce itself on this question in the matter of Brotherton NO v Electoral Commission of Zambia.[58] In that case, notwithstanding that disability is not one of the grounds for which discrimination is expressly prohibited, the court held:

"That the Respondent has unlawfully discriminated against the Petitioner and other persons with disabilities represented by the organisation on whose behalf this action is brought contrary to Article 23 of the Constitution as read with Section 19 of The Persons With Disabilities Act."

By the same token, even if albinism is not one of the grounds upon which discrimination is expressly prohibited by the Constitution, subjecting persons with albinism to restrictions to which others are not subjected to, is discrimination. It, therefore, follows that discrimination against persons with albinism is effectively prohibited by Part 3 of the Constitution, notwithstanding albinism not being expressly listed in Articles 11 and 23 of the Constitution.

Statutory legal framework

Zambia has no specific laws that seek to promote, protect or enforce the fundamental human rights and freedoms of persons with albinism. However, as already stated, albinism qualifies to be a disability. The report demonstrates how the disability laws and other general laws enhance the protection and enforcement of the rights of persons with albinism.

(a) Persons with Disabilities Act and Albinism

The Persons with Disabilities Act (PDA) provides for the domestication of the CRPD and its Optional Protocol together with all other international instruments on persons with disabilities to which Zambia is a party, and in so providing, the PDA promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities.[59] This report has already demonstrated that albinism qualifies as a disability and as such the provisions of the PDA apply to persons with albinism. Section 3 of the PDA reads: *"Subject to the Constitution, where there is any inconsistency between the provisions of any other written law impacting on the rights of persons with disabilities as provided for in this Act or any other matter specified or prescribed under this Act with respect to persons with disabilities, the provisions of this Act shall prevail to the extent of the inconsistency."*

Section 3 (above) means that to the extent that the provisions of any other written law, except the Constitution of Zambia, are inconsistent with the provisions of the PDA, such other provisions of any other written law are void. Effectively, the PDA provides a single platform for the recognition and protection of human rights and fundamental freedoms of persons with disabilities and albinism. If it is established that there are certain provisions of any other written law that has an effect of, or inadvertently, undermines the human rights and fundamental freedoms of persons with disabilities or albinism, all that has to be shown is that such provisions of such other written law are inconsistent with any of the provisions of the PDA, then the provisions of the latter will prevail.

The significance of Section 3 of the PDA becomes clearer when one considers the fact that most laws in Zambia were promulgated before 2012

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[58] Ibid., art 1 (1).

[59] 2011/HP/0818.

(when the PDA was enacted), and as such, the said laws do not embrace the progressive provisions of the CRPD and its Optional Protocol together with other recent international instruments.

In its interpretation clause,[60] the PDA incorporates and domesticates several terms and principles that enhance the recognition and protection of the human rights of persons with disabilities and albinism. These include the definition of disability, discrimination, affirmative action, universal design etc., all of which ensure that legal amenities are available by which persons with disabilities and albinism enjoy their human rights on an equal basis with others. Further, the PDA in Section 4 adopts the principles that apply to persons with disabilities, which include recognition as persons before the law, respect for physical and mental integrity, full and effective participation and inclusion in society, respect for difference and acceptance of human divergency and humanity, equality of opportunity among.

The highlight principles are especially important for persons with albinism who are usually subjected to derogatory terms, physical attacks (including killings and maiming) and are sometimes forced into isolation and exclusion.

Section 6 of the PDA expressly prohibits several actions and stereotyping in that it prohibits the exploitation and subjecting of persons with disabilities and albinism to violence or degrading treatment while also prohibiting the calling of a person with disability any derogatory name on account of the disability of that person. Persons with albinism are usually subjected to violence and degrading treatment including being referred to by derogatory terms. Hence the provisions of the Section 6 of the PDA are critical in enhancing access to justice for persons with albinism.

Also worth noting is Section 8 of the PDA, which requires the courts in Zambia to take necessary measures to ensure that persons with disabilities have equal and effective protection and equal benefit of the law, without discrimination. Section 8 also requires that where a person with disability is a party to any legal proceedings, the adjudicating authority shall take into account the condition of the person with disability and provide procedural and other appropriate facilities to enable the person with disability to access justice and participate effectively in the proceedings. In this regard, where a person with albinism is required to for instance identify the perpetrator of physical violence or degrading treatment, the court is required to take into account the visual impairment of a person with albinism, which may present challenges of identification, without the court necessarily finding that the person with albinism has failed to identify the accused person.

Section 23 of the PDA mandates the minister responsible for education to designate public education institutions to provide necessary facilities and equipment to enable persons with disabilities to fully benefit from the public education institutions.[61] Further Section 23 (3) requires relevant state institutions at district levels, to make provision for an inclusive system of special education, where practicable, for persons with visual impairments. Persons with albinism usually need assistive devices and controlled lighting in both classrooms and libraries to enable them to fully participate in the educational institutions. The PDA therefore has provisions that enhance the protection and enforcement of the rights of persons with albinism, and also enhances their inclusion in society generally, including in education establishments.

(b) Penal Code Act (PCA)[62]

The PCA does not have any express provisions relating to persons with albinism and neither does any special provisions aimed at enhancing the rights of persons with disabilities nor albinism. Therefore, in mapping the legal framework for the protection and enforcement

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[60] No. 6 of 2012, op. cit., preamble.

[61] Ibid., section 2.

[62] Ibid., subsection (1).

of the rights of persons with albinism, this report relies on the general provisions of the PCA which also apply to persons with albinism.

Section 224 of the PCA provides that any person who, with intent to maim, disfigure or disable any person, unlawfully wounds or unlawfully attempts to strike any person with any projectile or spear, sword, knife or other dangerous or offensive weapon, commits a felon and is liable to imprisonment for life. Persons with albinism are usually subjected to attacks whereby they are maimed, and their body parts severed because of some erroneous cultural beliefs that the body parts of persons with albinism bring good luck to business, or for use in witchcraft. Section 224 may be employed to prosecute perpetrators of violence against persons with albinism.

Where death occurs because of such unlawful wounding and malice aforethought is established,[63] the perpetrators may be prosecuted and convicted of murder contrary to Section 200 of the PCA. The punishment for murder was death until 23 December 2022, when an amendment was enacted to reduce the punishment to life imprisonment.[64]

Under section 248 of the PCA, it is a criminal offence (misdemeanour) for any person to commit assault occasioning actual bodily harm on another person. Once such an offence is proved, the convict is liable to imprisonment for five years. Where the nature of the attacks on persons with albinism results in actual bodily harm, section 248 of the PCA may be used to bring the perpetrators to book.

In terms of section 130 of the PCA, it is a criminal offence for any person who among others, with the knowledge that the feelings of any person are likely to be wounded, commits any trespass in any place set apart for the performance of funeral rites or as a depository for the remains of the dead, or offers any indignity to any human corpse, or causes disturbance to any persons assembled for the purpose of funeral ceremonies. Because of the hostile cultural beliefs and witchcraft, the burial site (tombs) of persons with albinism are usually raided and their bodies dug out to remove their body parts. Section 130 of the PCA criminalises the trespass in any place set apart for the performance of funeral rites or depository for the remains of the dead or indeed offering any indignity to any human corpse.

The PCA also criminalises the use of insulting language by any person, which has the effect of provoking that person to break the public peace or to commit an offence against that person.[65] This provision is important as persons with albinism are usually subjected to insulting, pejorative and discriminating language, which may provoke persons with albinism to breach public peace, or even to commit an offence such as assault against the person who utters such insulting language. Persons with albinism must be accordingly protected in this regard.

Further, section 70 of the PCA provides:
"Any person who utters any words or publishes any writing expressing or showing hatred, ridicule or contempt for any person or group of persons wholly or mainly because of his or their race, tribe, place of origin or colour is guilty of an offence and is liable on conviction to imprisonment for a period not exceeding two years."

It is, therefore, a criminal offence to utter and publish words expressing or showing hatred, ridicule or contempt for persons with albinism. There is a need for public awareness and concerted efforts to enforce the crimes provided for under sections 70 and 179 of the PCA.

(c) Anti-Human Trafficking Act (AHTA)[66] and its subsequent amendment[67]

Persons with albinism usually suffer the fate of being trafficked to another place, either within or outside Zambia. The AHTA and its amendment

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[63] Cap 87 of the Laws of Zambia.

[64] Ibid., section 204.

[65] Penal Code (Amendment) Act No. 23 of 2022.

[66] Cap 87 of the Laws of Zambia, op. cit., section 179.

[67] No. 11 of 2008.

seeks to arrest such unlawful acts. According to Section 2 of the AHTA (as amended), trafficking in persons is defined as:

> *"means to recruit, transport, transfer, harbour, receive or obtain another person, within or across the territorial boundaries of Zambia, by means of the threat or use of force or other forms of coercion, abduction, fraud, deception, abuse of power or a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control of another person, for purposes of exploitation."*

On the other hand, Section 3 (8) of the AHTA (as amended) states that where the victim is trafficked for the purpose of the removal of the victim's body parts, the offender is liable, on conviction, to imprisonment for a term of not less than 25 years and not more than 35 years. The stiff punishment imposed on trafficking in persons where the purpose is to remove the victim's body parts is meant to deter would be offenders. Persons with albinism are usually subjected to trafficking for purposes of their body parts being removed and used for rituals and other harmful cultural practices.

(d) Witchcraft Act[68]

The Witchcraft Act provides for penalties for the practice of witchcraft,[69] and prohibits the practice, professing and naming of other persons as practicing witchcraft. Section 9 of the Witchcraft Act provides:

> *"Whoever, on the advice of any person pretending to have the knowledge of witchcraft or any non-natural processes or in the exercise of witchcraft or of any non-natural means, shall use or put into operation such means or processes as he may have been advised or may believe to be calculated to injure any person or any property shall be liable upon conviction to the punishments provided under section 4."*

According to Section 4 of the Witchcraft Act, the penalty for practising witchcraft is a fine of not more than 1,500 penalty units or to imprisonment with or without hard labour for any term not exceeding two years, or both. Effectively, any person who practices witchcraft as a witch doctor or witch finder, or who believes or shall put in practice any witchcraft or non-natural processes calculated to injure another person, commits a criminal offence. It follows, therefore, that a person who maims or in any way unlawfully wounds a person with albinism under the belief that the body parts of a person with albinism bring good luck or enhance business acumen commits an offence. It doesn't matter that such a person is merely following instructions.

It is important to understand that belief in witchcraft is not and cannot be a defence to protect the perpetrators from violence against persons with albinism. In the case of Patrick Mumba and others vs. The People,[70] the Supreme Court held:

> *"A message must be sent to witch finders when they conduct their business of pointing at people as responsible for death or other calamities, they are committing an offence under the Witchcraft Act and when the offence is followed by an assault, by a deterrent sentence must be imposed."*

It, therefore, follows that the Witchcraft Act prohibits any action or omission in furtherance of any witchcraft or cultural beliefs which result in injury to any person with albinism or any other person.

(e) Cyber Security and Cyber Crimes Act (CSCCA)[71]

Section 2 of the CSCCA provides:

> *"'hate speech and conduct' means verbal or nonverbal communication, action, material whether video, audio, streaming or written, that involves hostility or segregation directed towards an individual or particular social groups on grounds of race, ethnicity, antisemitism, tribalism, sex, age, disability,*

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[68] Anti-Human Trafficking (Amendment) Act No. 16 of 2022.

[69] Cap 90 of the laws of Zambia.

[70] Ibid., Preamble to Cap 90.

[71] (2004) Z.R. 202 (SC).

> *colour, marital status, pregnancy, health status and economic status, culture, religion, belief, conscience, origin."*

While albinism is not expressly listed as one of the particular social groups with respect to which hostility or segregation amounts to hate speech and conduct, it is covered under ethnicity, disability and colour. Therefore, any verbal or non-verbal communication or action that involves hostility or segregation directed towards persons with albinism amounts to hate speech and conduct.

In terms of Section 65 of the CSCCA, any person who, using a computer system, knowingly without lawful excuse, uses hate speech commits an offence and is liable, on conviction, to a fine not exceeding 500,000 penalty units or to imprisonment for a period not exceeding two years, or to both. It is noteworthy that under the aforementioned Section 65, hate speech only relates to a person using a computer system and not to verbal communication, for instance. This means that a person who verbally communicates hostilities, or encourages segregation, against persons with albinism, will not be committing the offence of hate speech. Similarly, Section 69 of the CSCCA also creates an offence of harassment only if the person uses a computer system to intentionally initiate electronic communication with the intent to coerce, intimidate, harass or cause emotional distress to another person or group of persons. Section 65 and 69 of the CSCCA should be read against the backdrops of Sections 70 and 179 of the PCA, which does not make a distinction as to whether the offensive words are published using a computer system.

(f) Human Rights Commission Act (HRCA)[72]

The HRCA provides for the functions and powers of the Human Rights Commission (HRC), which is a body created under the Constitution.[73] Under the HRCA, the mandate of the HRC is, among others to investigate human rights violations and maladministration of justice. This means that perpetrators of violations of the human rights of persons with albinism may be reported to the HRC. The HRC also has powers to investigate the maladministration of justice should those charged with the administration of justice fail to do so. In investigating both human rights violations and maladministration of justice, the HRC may act either in its own motion or upon receipt of a complaint from any member of the public.[74]

The HRC has broad powers under Section 10 (2) and (4) to summon witnesses, order the release from detention, require any person to disclose any information within his knowledge and to recommend punishment of any officer found to have perpetrated human rights violations. Further, the HRC also has powers to order compensation of the victim of human rights abuse and to take such action as it considers necessary to remedy the human rights infringements.

It appears that despite the broad powers the HRC has, it does not seem to have enforcement powers, as can be seen in the HRC's lamentation with respect to the failure by Government to provide sunscreen to persons with albinism:

> *"We have been concerned about the complaints that there's inadequate support when it comes to the [sunscreen] lotion to protect their skin. The Human Rights Commission of Zambia has been engaging the government on this issue to ensure that there is adequate health and social welfare provided for persons with albinism."* [75]

Had the HRC had the enforcement mechanism, sunscreen would have been provided. It is noteworthy that the HRC has no mandate over a matter that is pending before courts of law.

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[72] No. 2 of 2021.

[73] HRCA, Cap 48 of the Laws of Zambia.

[74] Constitution of Zambia, op. cit., article 230.

[75] HRCA, op. cit., section 10 (1) (a) and (b).

Policy framework

Zambia has not promulgated any policy framework to deal with the rights and welfare of persons with albinism. A policy specific to persons with albinism is necessary similar to the National Policy on Albinism of Nigeria (NPAN).[7676] A albinism-specific policy is necessary to demonstrate political will and ensure that the rights of persons with albinism are not merely glossed over. The NPAN demonstrates a keen interest in the welfare of the rights of persons with albinism and takes time to explain the causes of albinism, thereby dispelling misconceptions and derogatory myths about albinism.[77]

In Zambia, the closest policy that has a bearing on persons with albinism is the National Policy on Disability, 2012 (NPD).[78] Although the NPD relates to persons with disabilities, it may also be applied to persons with albinism because the latter are similarly circumstanced with the former.

The NPD seeks to implement the fundament rights under the CRPD and the PDA and stresses the need to ensure that persons with disabilities enjoy their human rights on an equal basis with others and that no persons with disabilities should be discriminated against. Further, the NPD seeks to encourage the full participation of persons with disabilities in their communities.

Indeed, the NPD appears to endorse the innovative provisions of the CRPD and the PDA in seeking to enhance the rights of persons with albinism.

However, the good provisions of the NPD may not achieve much without concrete steps being made available to provide reasonable accommodation and other assistive devices and protective clothing necessary to allow persons with albinism to enjoy their human rights. This calls for strong budgetary provisions and support of persons with albinism through the social cash transfer system.[79]

According to Martha Khunga,[80] the cost of skin care products is very expensive, and sometimes sunscreen is out of stock. Martha lamented that 250mls of the sunscreen only lasts about two weeks and usually costs between K300 to K450 per tube, which is out of reach for most families. The fact that they are not being readily available creates room for exploitation in terms of pricing.

A good policy framework should be supplemented with good budgetary allocation and financial support to persons with albinism through the social cash transfer fund.

At the African regional level, the Executive Council of the African Union adopted a continent- wide policy known as the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031; AU Action Plan).[81] Among others, the AU Action Plan is significant as it forms the basis upon which member states may promulgate their national policies on persons with albinism.

5.5.7 Barriers to access to justice

Access to justice is a fundamental human right and essential for protecting citizens' rights and promoting the rule of law in Zambia. However, despite legal provisions that guarantee access to justice, a significant proportion of Zambians still face significant barriers to accessing justice. In particular, persons with albinism face significant access to justice barriers in seeking to protect their human rights and also in seeking to effectively prosecute those who violate their human rights. The barriers appear in both criminal and civil proceedings, and they are both structural (physical) and societal (attitudinal) in nature.

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[76] Chrispin Mwakideu, op. cit.

[77] Federal Ministry of Education, National Policy on Albinism of Nigeria 2019, https://education.gov.ng/wp- content/uploads/2022/07/REVIEWED-NATIONAL-POLICY-ON-ALBINISM-DESIGNED.pdf. 3 April 2023.

[78] Ibid., pp 10 and 11.

[79] National Policy on Disability, 2012, https://www.ilo.org/wcmsp5/groups/public/---africa/---ro-abidjan/---ilo- lusaka/documents/article/wcms_566928.pdf. 30 March 2023.

[80] Administered under the Social Protection Policy, 2014, https://www.social- protection.org/gimi/gess/RessourcePDF.action?ressource.ressourceId=54164. 3 April 2023.

[81] Mother to children with albinism.

Structural barriers

The failure by the State to provide facilities with assistive or adaptive devices is some of the structural barriers that hinder persons with albinism from access to justice.[8282] For instance, outdoor school or work activities in the scathing sun, without protective clothing will expose persons with albinism to cancer or skin diseases such that they will not participate in such school or work-related activities. If the lighting in a classroom coupled with the size or font used in writing of the classroom board is such that it is not legible to a person with albinism, then the whole classroom is a barrier to access to justice in so far as it relates to the right to education.

According to Article 13 of the CRPD, state parties are obliged to provide all amenities to ensure that persons with albinism are to enjoy their rights to education and health, including the right to access the courts of law and its procedures and process, in a manner that is not discriminatory and on equal basis with others.

Societal barriers

(a) Physical attacks, hate speech and stigmatisation

The physical attacks, hate speech and stigmatisation directed at persons with albinism means that they are ostracised or intimidated and discouraged from participating in the life of their communities. The resulting multi-faced systematic discrimination and the dehumanising treatment to which persons with albinism are subjected are de facto barriers to accessing access to justice.[83] Persons with albinism are usually ostracised or made to stay home to avoid attacks or ill-treatment. Social exclusion and prejudicial stereotyping necessarily inhibit integration into society, which leaves persons with albinism with limited knowledge of their rights and of the processes to be undertaken in seeking redress in cases of violations of their rights.

(b) Educational and economic exclusion

If persons with albinism do not fully participate in their communities, they won't be involved in the education system and in the employment sector. This will obviously affect their ability to be employed or to be self-employed. Without employment or any other income generating ventures, persons with albinism will not be able to engage a lawyer to seek damages in a discrimination case against a service provider for instance. In such cases, persons will be disadvantaged and will have to rely on legal aid services provided under the Legal Aid Act.[84]

The fact that the Legal Aid Board (LAB) has not decentralised to all provinces and districts in the country means that persons with albinism are unable to access justice especially in civil matters. [85]

(c) Witchcraft beliefs and practices

The fact that there are people who believe that body parts of persons with albinism may be used in witchcraft related activities, may also be a barrier to access to justice.[86] In this regard, beliefs in witchcraft may have a chilling effect on access to justice of persons with albinism in that some judicial and or law enforcement officers may be reluctant to prosecute perpetrators who are arraigned for alleged maiming of persons with albinism for fear of being bewitched by the accused persons. This may explain why there is a prevalence of reluctance by law enforcement

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[82] M. Toumi, I. Ero and H. Tawata, "Report: Regional Actional Plan for Ending Attacks and Human Rights Violations Against Persons with Albinism," p. 6. https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/RAP_Report_01-07_21_EN.pdf. 4 April 2023.

[83] Amnesty International, op. cit., p. 28.

[84] J Beqiraj, L McNamara and V Wicks, 'Access to justice for persons with disabilities: From international principles to practice', International Bar Association, October 2017. p.20. file:///C:/Users/lkala/Downloads/Access%20to%20justice%20for%20persons%20with%20disabilities_form%20 international%20principles%20to%20practice.pdf. 1 April 2023.

[85] Number 1 of 2021.

[86] Ibid., a body corporate under the Legal Aid Act whose main function is to administer a comprehensive legal aid system in Zambia and to provide legal aid in civil and criminal matters.

officers to prosecute such offences. This research showed that very few cases of alleged violations of the rights of persons with albinism are ever successfully prosecuted. In one case where assailants attempted to cut off the hand of a person with albinism, the police subsequently dropped the charges despite the victim identifying the voice of one of the assailants.

"In cases involving ritual crimes, especially in villages, most people know the possible suspects. The local authorities need to take these investigations seriously and incentivise people to come forward with information."[87]

There is need to do more in terms of sensitising communities on the importance of coming forward with evidence in cases involving the maiming of persons with albinism.

Legal barriers in the administration of justice and law enforcement

The law provides and guarantees the various fundamental human rights and freedoms to which all persons are entitled to. To achieve its objectives, the law consists of both the substantive and procedural law. The thrust of most laws is to provide for the substantive laws, such as the rights of persons with disabilities. In Zambia, the law does not expressly provide for the rights of persons with albinism, but it has been established that the law relating to persons with disabilities is sufficient to cover persons with albinism, since albinism is basically a disability.

However, where the law provides for the substantive laws but overlooks the right to access to justice, the ends of justice will hardly be met.[88] In such cases, the legal process and procedures may be barriers to access to justice. The Independent Expert on the Enjoyment of Human Rights by Persons with Albinism explained this situation by the following case scenario: where most of the attacks on persons with albinism involve the extraction/removal of and selling of body parts, and the law does not specifically recognise the offence of trafficking in body parts,[89] the law would not achieve its objective to punish the offenders and to discourage would be offenders.

The police system: the registration, investigation of cases, storage and utilisation of evidence in law enforcement agencies

It is important to note that the process of reporting a case to the police can vary depending on the nature of the incident and the police station. Some police stations may have specific procedures for reporting certain types of cases. Most police stations or posts, for instance, usually have the Victim Support Unit to deal with cases relating to domestic violence or sexual assault.[90] However, there are no similar units dealing with persons with albinism established by a statute or at all. This means that complaints to the police on human rights violations and physical attacks are dealt with just like any other criminal offence. The prevalence of attacks and murders of persons with albinism, whereby up to 10 persons with albinism are murdered every year,[91] suggests that there is a need to create a special unit or procedure to arrest these attacks and murders.

On the other hand, interviews with the police suggest that there is a dichotomy between the information that is either obtained from communities compared to what is shared in the newspapers. The position of the police is that there is almost always insufficient evidence in terms of what is contained in the witnessed statements given by potential witnesses to justify even taking the matter to court for

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[87] United Nations General Assembly, Human Rights Council, "Right to access to justice for persons with albinism: Report of the Independent Expert on the enjoyment of human rights by persons with albinism" p. 8. file:///C:/Users/lkala/Downloads/Right%20to%20access%20to%20justice%20for%20persons%20with%20albini sm.pdf. 3 April 2023.

[88] Mail & Guardian, 'No justice in Zambia for survivors of attacks against people with albinism,' https://mg.co.za/africa/2022-09-19-no-justice-in-zambia-for-survivors-of-attacks-against-people-with- albinism/. 4 April 2023.

[89] Ibid., p. 8

[90] Ibid.

[91] The Zambia Police (Amendment) Act No. 14 of 1999, section 53.

prosecution. People in communities usually make loose comments on the kind of evidence that is available but may not come forward to give formal statements to the police.

Some of the key challenges that affect the reporting of complaints of human rights violations against persons with albinism are as follows:

1. Fear of reporting crimes: People with albinism may be reluctant to report crimes against them due to fear of witchcraft, retribution, social stigma and lack of trust in the justice system. In some instances where a perpetrator supports the family, the perpetrator will not be reported to the police for fear of not having someone to support the family economically should the perpetrator be found liable and sentenced to imprisonment.

2. Lack of albinism specific offences in the PCA act and other relevant laws: Persons with albinism or their next of kins are usually hesitant to report violations of the rights of persons with albinism because there are no albinism specific offences in our statute books. Complainants are usually not too sure that the impugned acts are prohibited by law, or whether they will be entertained by the police on account of non-albinism specific offences.

3. Inadequate legal representation: People with albinism may face difficulties in finding lawyers who understand their condition and can effectively represent them in court.

4. Limited access to legal aid: Legal aid services in many African countries are limited, and people with albinism who cannot afford legal services may struggle to access legal aid.

5. Lack of sensitivity and understanding: Some justice system actors, including police officers and judges, may not be familiar with albinism and may not understand the challenges faced by people with the condition. The case in point is where the identification parade is undertaken where a victim with albinism is required to identify an assailant without considering that persons with albinism may have visual challenges. In such cases, the police should not insist on the identification parade but should instead adopt other means by which the person may identify the assailant.

6. Uncertainty and hesitation: These lead to delayed reports being made to the police, which ultimately result in changes in the circumstances and with the witnesses. Therefore, it's important to report incidents as soon as possible to help the police investigate and gather evidence effectively. The foregoing notwithstanding, the police take steps and measures to effectively investigate offenses or violations. The following are some of the measures that the Zambia police use to deal with cases involving attacks against persons with albinisms:

   a. *Investigations and follow ups on complaints:* The police have a system allocating and investigating reported complaints of human rights violations against persons with albinism. Where there is sufficient evidence, the police proceed to prosecute the offences. In one case, several suspects are currently being prosecuted by the police for attempted trafficking and selling of a young boy with albinism.[92]

      When investigating and prosecuting these offences, the police work with the National Prosecutions Authority (NPA) and other relevant agencies.[93]

   b. *Sensitisation and awareness campaigns:* The police work with

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[92] Chrispin Mwakideu, op. cit.

[93] Lusaka Times, "12 suspects apprehended for attempting to sell a 17 year old male living with albinism,' https://www.lusakatimes.com/2023/02/07/12-suspects-apprehended-for-attempting-to-sell-a-17-year-old- male-living-with-albinism/. 4 April 2023.

other organisations to create awareness about albinism and combat discrimination. The aim is to educate the public on the rights of persons with albinisms and the need to protect them from attacks, including to eradicate stereotyping and prejudice against persons with albinism. The police also seek to dispel rumours associated with witchcraft. Mr. Justice Charles Kafunda, a High Court Judge, at the Roundtable meeting to discuss the findings of the study on the obstacles to access to justice for persons with albinism maintained that the Witchcraft Act is not intended to protect those engaged in human rights violations as a defence against prosecution.[94]

c. Offering protection: The police provide protection to persons with albinisms who are at risk of attack. They may provide security personnel to accompany the person with albinism in public places or provide safe houses where the person with albinism can stay.

d. Arrest and prosecution: The police arrest and prosecute suspects involved in attacks against persons with albinisms. The suspects are charged with various offences, including assault, murder and kidnapping.

e. Collaboration with other agencies: The police collaborate with other agencies, such as the NPA and civil society organisations, to ensure that cases involving attacks against persons with albinisms are dealt with efficiently.

Though much still needs to be done, the Zambia police have taken significant steps to protect a person with albinism from attacks and prosecute those responsible for such attacks.

The prosecution system: the investigation of cases, storage and utilisation of evidence, reporting and understanding the needs of persons with albinism and fair prosecution of cases.

The NPA plays a crucial role in ensuring that criminal cases are prosecuted fairly and justly in Zambia. The NPA is headed by the Director of Public Prosecution (DPP), who is the chief prosecutor for the government.[95] According to the Constitution, the DPP has powers to institute and take over any criminal proceedings against any person and to discontinue any such criminal proceedings at any stage before judgment. The discretion the DPP has is crucial to the prosecution of the those who commit offences against persons with albinism. However, it is important that this discretion is exercised in a manner that advances the rights of persons with albinism.

In one case,[96] the deceased, Ernest Mtonga (a person with albinism) a resident of Mitete village in Lundazi, received a phone call from a known person (accused person) requesting to meet up with him. Since the accused person was well known to the deceased's family, the deceased went to meet him alone. The deceased never returned, and his body was found a month later by the dump site, with missing lower and upper limbs. Three months later, the accused person was found with body parts of a person with albinism. Initial reports are that the accused persons admitted to killing the deceased, but to have a water-tight case and to prove that the body parts belonged to the deceased, the police sent samples to Lusaka for DNA tests. However, the DNA test results went missing, and the state discontinued the subsequent criminal proceedings against the accused. The state could have proceeded with the criminal proceedings and relied on circumstantial evidence that the accused person was found with the body parts of a person with albinism and a few days preceding that a body of a person with albinism

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[94] National Prosecutions Act No. 34 of 2010.

[95] Held on 31 January 2023 at the Radisson Blu hotel in Lusaka.

[96] Constitution of Zambia, op cit., article 180.

was discovered with missing body parts. The onus would then have been on the accused person to explain how he could be in possession of the body parts. This case demonstrates that the way the DPP exercises the discretion under the constitution can have a significant impact on the protection and enforcement of the rights of persons with albinism. It is noteworthy that the functions of the DPP may be exercised by the DPP in person or by a public officer or legal practitioner authorised by the DPP or acting under the general or special instructions of the DPP. The DPP also operates under the auspices of the NPA.

The process of prosecuting a case by the NPA in Zambia typically involves the following steps:

1. Review: Upon receipt of the docket (dossier containing the police investigations), the NPA will review the case to determine whether there is sufficient evidence to prosecute. They will also consider the public interest in bringing the case to court. This process may constitute a barrier to access to justice as the NPA sometimes takes too long to review the docket such that the witness and the circumstances of the case on the ground may change to the detriment of persons with albinism.

2. Court proceedings: The case will be heard in court, and the prosecution and defence will present their arguments and evidence. The prosecution will be responsible for proving the guilt of the accused beyond a reasonable doubt. But this is usually hampered by the reluctance of witnesses to come forward and testify. In one case, a juvenile acted deceitfully to his brother, a child with albinism. The juvenile agreed to hand over his brother to people who promised him K200.00 in exchange for the young brother’s hands. While the young brother survived the gruesome ordeal in which he lost his hands, the family refused to allow the victim to testify against the elder brother because they did not want their son (elder brother to the victim) to be sentenced to imprisonment or to be fined, for the offence committed.

3. Sentencing: If the accused is found guilty, they will be sentenced by the court. The NPA will make recommendations on the appropriate sentence, taking into account factors such as the severity of the offence and any mitigating or aggravating circumstances.

Access to lawyers and legal aid/pro-bono services

(a) Access to Lawyers

In Zambia, most lawyers have concentrated their practice in Lusaka, Ndola, Kitwe and maybe Livingstone. Other provincial capitals or major towns only have at most one or two law firms. This means that most Zambians have limited access to lawyers. For persons with albinism, access to lawyers is even a greater challenge given the stigma, discrimination and ostracisation they are usually subjected to. Stigma, discrimination and ostracisation inevitably lead to exclusion from, among others, the education and economic system of society. This means that persons with albinism are the most vulnerable and disadvantaged in terms of their ability to access lawyers.[97]

On the other hand, the relevant constitutional framework for legal aid is focused on serving the legal needs of accused persons as opposed to victims of human rights violations. The constitution, in its Bill of Rights, provides that everyone charged with a criminal offence shall be afforded a fair hearing, adequate time and facilities for the preparation of his defence.[98] Further, Article 18 (2) (d) presupposes that the accused person will be granted legal aid in accordance with the law. The focus on the accused persons is premised on the fact that in criminal cases the state, through its resources, prosecutes the accused person through the NPA, and the victim, if alive, is merely the complainant. The understanding is that since the prosecution uses state resources, it’s the accused person that needs to be availed of reasonable time

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[97] Unreported criminal case.

[98] United Nations General Assembly, Human Rights Council, op. cit., p. 7.

and adequate facilities for the preparation of his defence. Therefore, persons with albinism who are mostly victims rely on the state lawyers of prosecutors in criminal proceedings.[99]

In civil matters, persons with albinism seek compensation or specific performances with respect to violations of their social and economic rights where they are discriminated against and denied employment, access to education or health facilities.[100] In such matter, persons with albinism are on their own with limited or no financial resources and are required to navigate their pursuit for justice. The lack or limited financial resources coupled with albinism specific statutory provisions, means that person with albinism sometimes are not even aware that their rights have been infringed upon.

(b) Legal aid/pro-bono services

The Legal Aid Act regulates the provision of legal aid in Zambia.[101] The Legal Aid offers comprehensive provisions on who can provide legal aid, to whom legal aid may be provided, how to apply for legal aid and what legal aid consists of. Since legal aid services can only be provided by a restricted cadre of service providers, legal practitioners,[102] legal assistants,[103] and paralegals,[104] the fact that these are not widely available countrywide means that persons with albinism would not have access to legal aid. In other words, there are much fewer legal practitioners, legal assistants and paralegals to meet the needs of those who need legal aid services. The geographical distance, together with the transport costs and lack of infrastructure (court buildings, legal aid clinics, etc.), can be a serious hurdle for persons with albinism to access legal aid.

While the said provisions of the Legal Aid Act are comprehensive and progressive, persons with albinism do not have access to this information. The information is simply not trickling to rural areas so that it may be accessed by all persons, including persons with albinism. With regards to persons with albinism, even where information about legal aid is made available, it may be inaccessible by persons with albinism on account of it not being available in appropriate formats, such as braille and other large fonts which are legible to the visually impaired, including persons with albinism.[105]

5.5.8 Opportunity for equitable and beneficial judicial outcomes

The current legal framework in Zambia for the protection of the rights and freedoms of persons with albinism may be described as ‘bittersweet’. Much needs to be done in terms of enacting albinism-specific legislation which is robust enough to not only enhance the rights of persons with albinism but also ensure that effective access to justice to punish those who attack, maim or in any way discriminate against persons with albinism. It is the criminal justice system that is responsible for the portion of the ‘bitterness’ as it has proved ineffective in arresting the barbaric physical attacks, maiming and brutal killings of persons with albinism. On the other hand, on account of the domestication of key international human rights instruments, key among them the CRPD, Zambia has a legal framework that may at least suffice to ensure that persons with albinism enjoy their human rights on an equal basis with others. Through the effective application of the CRPD rights of access to justice, equality and non-discrimination, reasonable accommodation, recognition as persons before the law and full and effective participation and inclusion in society, persons with albinism may enjoy human rights on an equal basis with others. Indeed, it is the human rights approach to addressing the welfare of persons with albinism that accounts ‘sweetness’ of the Zambian legal framework.

This current framework is, therefore, an opportunity for equitable and beneficial outcomes or judgments from the courts in

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[99] Constitution of Zambia, op. cit., article 18.

[100] United Nations General Assembly, Human Rights Council, op. cit., p. 5.

[101] Ibid.

[102] Number 1 of 2021, op. cit., section 5.

[103] Ibid., section 12.

[104] Ibid., section 15.

[105] United Nations General Assembly, Human Rights Council, op. cit., p 11.

Zambia. The courts in Zambia enjoy wide discretion to interpret the Constitution and others of the land. To demonstrate the discretion, reference is made to the Supreme Court decision in the case of Citibank Zambia Limited v. Suhaly Dudhia Appeal No.6 of 2022, where it was held:

> *"The purposive approach requires that judges look beyond the contents of the statute and discover the original purpose for the enactment of the legislation and its meaning should be defined from that purpose."*

The above decision of the Supreme Court was in reference to section 85 (3)(b)(ii) of the Industrial and Labour Relations Act, which reads:

> *"The Court shall dispose of the matter within a period of one year from the day on which the complaint or application is presented."*

The Supreme Court, in the Citibank case, ultimately held that the High Court may, in some circumstances, continue hearing the matter or dispose of a matter even after a period of one year. This said Supreme Court judgment in the Citibank case is of paramount importance because it demonstrates that if the words of the statute do not achieve the intended purpose of that statute, then the courts in Zambia may go beyond the contents of that statute and apply the purpose.

The approach the Supreme Court took demonstrates judicial activism and is important to achieve equitable and beneficial judicial outcomes for persons with albinism. Judicial activism refers to the judicial system where judges interpret the law not necessarily according to the letter of the law or the confines of already set precedents, but in a manner to reflect the contemporary challenges and values that affect the people.[106] Professor E.K. Quansah and Professor C. M. Fombad described judicial activism in the following terms:

> *"We intend therefore to use the concept in this paper to mean a situation in which judges go beyond their traditional role of interpreters of the Constitution and seek to give effect to contemporary social conditions and values."*

Judicial activism is particularly important with respect to protecting and enforcing the rights of persons with albinism, especially because Zambia does not have albinism-specific legislation. For instance, section 130 of the PCA reads:

> *"Every person who, with the intention of wounding the feelings of any person or of insulting the religion of any person, or with the knowledge that the feelings of any person are likely to be wounded, or that the religion of any person is likely to be insulted thereby, commits any trespass in any place of worship or in any place of sepulture or in any place set apart for the performance of funeral rites or as a depository for the remains of the dead, or offers any indignity to any human corpse, or causes disturbance to any persons assembled for the purpose of funeral ceremonies, is guilty of a misdemeanor."* (underlining ours)

A strict reading of Section 130 will show that the offence is only committed where the trespass on the burial places is done with the intention of "wounding the feelings of any person" "insulting the religion of any person" or "with the knowledge that the feelings of any person are likely to be wounded" or "that the religion of any person is likely to be insulted". Meaning that a person who trespasses on the burial places for any reason other than the listed reasons would not be captured under Section 130 of the PCA. Further, what is currently obtaining with respect to the corpses of persons with albinism, is that the trespasses on their burial places, while they may hurt the feelings of the relatives of the deceased persons with albinism, are intended to retrieve body parts.

Employing judicial activism presents opportunities to complement the shortfalls in the legal framework for the protection and enforcement of the rights of persons with albinism.

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[106] EK Quansah & CM Fombad 'Judicial activism in Africa: Possible defence against authoritarian resurgence,' p.3. http://www.ancl-radc.org.za/sites/default/files/Judicial%20Activism%20in%20Africa.pdf. 7 April 2023.


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| CHAPTER 6

RECOMMENDATIONS AND CONCLUSION

Discrimination against persons with albinism is a serious human rights issue, and addressing it requires a multifaceted approach. However, here are some recommendations that can help to stop discrimination against persons with albinism:

v. Education and awareness: Education and awareness-raising campaigns are crucial to challenge stereotypes and myths about albinism. Such campaigns should be targeted at schools, communities and the media.

vi. Enact and enforce laws and policies: Governments should enact and enforce laws and policies that protect the rights of persons with albinism and ensure they have access to education, healthcare and employment opportunities.

vii. Provide support and services: Governments, non-governmental organisations and other stakeholders should provide support and services to persons with albinism, including access to healthcare, education and employment opportunities.

viii. Promote social inclusion: Efforts should be made to promote the social inclusion of persons with albinism in all aspects of society, including education, employment and social activities.

ix. Encourage positive representation: The media should be encouraged to represent persons with albinism positively and accurately rather than perpetuating negative stereotypes.

x. Empower persons with albinism: Efforts should be made to empower persons with albinism by providing them with education, training, and support to become leaders and advocates for their rights.

xi. To ensure that the right to health of persons with albinism is respected, protected and fulfilled, it is necessary to promote awareness about albinism and its associated health risks, provide affordable and accessible health care and medication, and address discrimination and stigma. In addition, governments, international organisations and civil society should work together to ensure that the right to health of persons with albinism is respected and fulfilled.

xii. Therefore, the government must also introduce health education programmes aimed at educating persons with albinism about the health risks associated with their condition. An awareness of the causes of albinism and the measures that can be taken to prevent skin cancer, for example, will undoubtedly enhance their health and reduce the risk of complications associated with the condition. Therefore, not only are basic health awareness education programmes for persons with albinism crucial, but programmes to educate people on clinical aspects of albinism will undeniably influence the way in which society perceives persons affected by this condition. These programmes could begin by targeting schools and hospitals.

Other recommendations that this research makes in enhancing access to justice include:

i. Strategic ligation

There is a need to undertake strategic litigation in both civil and criminal proceedings. In civil proceedings, the idea would be to enforce the economic, social and cultural rights of persons with albinism who usually suffer discrimination and exclusion from employment, education and other social activities such as sports. Strategic litigation would also seek to create legal precedents that will benefit vulnerable persons with albinism. In criminal matters, strategic litigations will be in the form of seeking private prosecution or co-prosecution of cases of physical attacks, maiming, killings and trafficking in body parts of persons with albinism.

This will also help create precedents on the heinous crimes perpetuated against persons with albinism while also enhancing the visibility of the plights of persons with albinism. Currently, there are hardly any reported cases involving persons with albinism. Similarly, there are also very few cases that run the full length of court proceedings in both civil and criminal matters.

ii. Advocating for albinism-specific legislation and policies

Currently, the laws and policies in Zambia do not expressly provide for the rights of persons with albinism. Similarly, the criminal law system does not specifically criminalise the maiming or trafficking of persons with albinism or their body parts, yet, these heinous crimes continue to happen in Zambian communities. Albinism-specific legislation is critical in enhancing, protecting and enforcing the rights of persons with albinism and this also puts the plights of the persons with albinism on the national agenda.

iii. Domestication of international and regional human rights instruments that have a bearing on the rights of persons with albinism

This research has shown that the domestication of international and regional instruments has an effect of making the provisions of such international and regional instruments to be part of Zambian law. That way, the progressive provisions of international and regional instruments will form part and parcel of Zambian law.

There is also a need for Zambia to ratify the Optional Protocol to the CRPD to allow individual citizens to lodge complaints to the CRPD Committee should they not be satisfied with the manner the issues of albinism are being handled in Zambia.

iv. Judicial Activism

There is a need to conduct workshops, seminars or training for magistrates and judges of the High Court, Court of Appeal and Supreme Court on the protection and enforcement of the rights of persons with albinism. Such training and workshop will cultivate judicial activism in the judiciary. This also allows the magistrates and judges to appreciate both the human rights approach to albinism and the happenings in communities in Zambia.

v. Awareness and Sensitisation Drive

Concerted efforts by the government, civil society organisations and stakeholders are necessary to raise public awareness of the plights of persons with albinism. This research has shown that there is a need to disseminate information and carry out sensitisation activities about albinism. This is necessary so that the communities understand that albinism is not a curse or a bad omen, and that albinism does not cure diseases. This will help eradicate some of the prejudices, stigma and beliefs in witchcraft practices.

Further, awareness and sensitisation activities to enlighten persons with albinism of their rights and of the procedures to be undertaken to access lawyers, legal aid and also the courts of law. Persons with albinism and their significant others also need to be made aware of how to make complaints to the police to initiate criminal proceedings.

There is also a need to carry out sensitisation drives even for police officers and prosecutors as continuous professional development and to enhance the visibility of the plight and rights of persons with albinism.

vi. Social Cash Transfer

Persons with albinism are usually the most marginalised and vulnerable members of their communities in Zambia on account of the systematics and multi-faceted discrimination and exclusion from society. They are usually excluded from education, health and employment, which means that they are usually among the poorest in society. Therefore, it is important to lobby for persons with albinism to be included in social cash transfer. This is more so that because of their albinism, they incur additional expenses over and above others on skin protection and other assistive devices necessary to allow them to fully participate in societal activities.

vii. Infrastructure development

To enhance access to justice, there is need to lobby for infrastructure development in rural areas not only to remove structural barriers to access to justice (such as lack of court houses), but also to allow access to education, health and other amenities. The fact that persons with albinism must walk long distances impacts on access to justice and results in few cases either being reported to the police or civil proceedings being commenced relating to the rights of persons with albinism

Conclusion

This study highlights key findings about the conditions of persons with albinism. In Africa, albinism is a complex issue that affects people's health, social status and human rights. Research on albinism in Africa has shed light on the various challenges faced by people with the condition, including stigma, discrimination and health risks. However, more efforts are needed to address these challenges and promote the rights and well-being of people with albinism in Africa.

Despite huge strides in policy and legislation, the country still needs to respond adequately to the needs of people with albinism, who need help realising their social, economic, cultural and political rights. This is mainly due to the lack of equal opportunities and means to participate fully in all aspects of life. For example, many people with albinism do not have equal access to health care, education, social protection and employment opportunities. This situation also applies to Zambia.

For persons with albinism to enjoy their human rights on an equal basis with others, there is a need for the government to provide reasonable accommodation by taking necessary and appropriate steps to ensure that facilities and amenities are availed to persons with albinism in educational and health establishments and all other public institutions, including the provision of skin protection and other protective clothing. Failure to reasonably accommodate persons with albinism puts them at a disadvantage on the economic, social and cultural front, which leads to discrimination and social exclusion. The primary port of call, in terms of ensuring that persons with albinism enjoy their human rights on an equal basis with others, is the provision of reasonable accommodation. To ensure effective remedies to human rights violations, there is a need for access to justice for all persons with albinism by providing procedural and age-appropriate accommodations to enable them to participate in all legal proceedings involving or concerning them.

There is a lot to be done to ensure effective access to justice for all persons with albinism. Awareness and sensitisation programmes need to be undertaken to educate the general populace about the condition to dispel prejudicial beliefs that lead to discrimination, physical attacks, maiming and killings of persons with albinism. Similarly, more needs to be done to sensitise persons with albinism on the procedures and processes by which they can access the courts of laws to ensure the protection and enforcement of their rights.

All said, though largely untested, the access to justice with respect to the protection and enforcement of the rights of persons with albinism appear to be firmly rooted in the PDA (together with its domestication of the CRPD provisions). However, in terms of protection of persons with albinism from physical attacks, maiming and killings, and the effective prosecution and subsequent punishment of the perpetrators of violence, more needs to be done.


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CHAPTER 7

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