

**A Comparative Review of Human Rights Approaches in Programming National Action
Plan for Protection of Human Rights of Persons with Albinism in Malawi**

**Dissertation submitted in partial fulfilment of the requirements of MPhil (Disability Rights
in Africa) Faculty of Law, Centre for Human Rights, University of Pretoria**

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Dedication

I dedicate this dissertation to persons with albinism in Africa, whom I have experienced and reviewed their heartbreaking stories with hope, strength and perseverance. My inspiration is that this dissertation will shine the light to the world as an opportunity for our voices to be heard and share our lived experiences as persons with albinism. I commit this work to God almighty for His love and wisdom, who will continue to watch and guide me in all the steps of my life.

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Throughout the dissertation I give all the glory and honour to GOD for His mercifulness

Abstract

Persons with Albinism as a public health condition are particularly vulnerable to witchcraft accusation and harmful practices across Africa. Stereotypes and superstitions surrounding them have led to attacks against the group. The purpose of the study is to highlight whether governments through National Action Plans have adequately addressed the human rights violations against persons with albinism. This includes how international and national legal instruments have informed the drafting of the National Action Plans and the enjoyment of rights and freedoms as stipulated therein. The main argument put forward is for the National Action Plans to adopt a human rights based approach with a particular focus on ensuring full participation of persons with albinism at all levels of implementation of the plans. The research also highlights the discussion about albinism as a disability and how it shapes governments response to the violation as a disability. Currently, National Action Plans have formed a normative framework or formal mechanism to conceptualise measures to respond to and monitor human right violations against persons with albinism. Hence the research demonstrates unexpected hardships such as attitudinal and environmental barriers during the implementation of National Action Plans. The emphasis is to ensure that persons with albinism are placed within a human rights discourse in the National Action Plans to ascertain whether they are afforded the equal protection of their rights.

Contents

Plagiarism Declaration.....	1
Dedication.....	2
Acknowledgments.....	3
Abstract.....	4
Acronyms.....	7
CHAPTER ONE : IMPACT OF RITUAL ATTACKS ON THE LIVES OF PERSONS WITH ALBINISM.....	8
1.1 Introduction.....	8
1.1.1 Defining Albinism	8
1.1.2 Persons with Albinism and Disability Discourse.....	9
1.2 Problem Statement.....	15
1.3 Research Questions.....	16
1.4 Methodology.....	16
1.5 Literature Review.....	17
1.1.5 Stigma and Discrimination against Persons with albinism.....	17
1.6 Significance of study.....	20
1.7 Limitations	21
1.8 Chapter outline.....	21
CHAPTER TWO : COMPARATIVE ANALYSIS OF APPROACHES TAKEN BY GOVERNMENTS IN DEVELOPING NATIONAL ACTION PLANS ON PERSONS WITH ALBINISM.	23
2.1 Introduction.....	23
2.2 Programming of Regional and National Action Plan triggered by attacks against Persons with albinism.....	23
2.3 National Action Plan on Persons with Albinism in Malawi	24
2.4 Tanzania National Action Plan for Persons with Albinism	29
2.5 The Mozambique Multi-Sectorial Action Plan to Address the Issue of the Protection of Persons Albinism.....	30
2.6 Nigeria Action Plan on Albinism.....	31
2.7 Uganda National Action Plan for Persons with Albinism.	33
2.8 Conclusion	34
CHAPTER THREE: LINKAGE OF INTERNATIONAL, REGIONAL AND NATIONAL LEGAL INSTRUMENTS IN PROGRAMMING NATIONAL ACTION PLANS ON PERSONS WITH ALBINISM.	36

3.1	36
Introduction.....	36
3.2 Access to affordable and quality healthcare and education services	36
3.4 Human Rights Monitoring, reporting and Research	41
3.5 Legislation, security and Administration of justice	44
3.5.1 The Disability Act.....	45
3.5.2 The National Policy on Equalisation of Opportunities of persons with disabilities.	46
3.6 Conclusion	50
CHAPTER FOUR : ADDITIONAL MEASURES TO ENSURE THE EFFECTIVE PROTECTION OF PERSONS WITH ALBINISM IN MALAWI	52
4.1 Introduction.....	52
4.2 Access justice measures	52
4.3 Non-discrimination and equality measures.....	55
4.4 Conclusion and recommendations	56
5. Bibliography	61

Acronyms

APAM	Association of Persons with albinism In Malawi
AU	African Union
ACHPR	African Commission on Human and Peoples' Rights
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organizations
CERD	International Convention on the Elimination of All Forms of Racial Discrimination
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CRC	Convention of the Rights of a Child
DRC	Democratic Republic of Congo
ICCPR	International Covenant on Civil and Political Rights
IAAD	International Albinism Awareness Day
MACOHA	Malawi Council for the handicapped
OCA	Oculocutaneous albinism
RAP	Regional Action Plan
TAS	Tanzania Albinism Society
TAF	The Albino Foundation
TEVETA	Technical, Entrepreneurial and Vocational Education and Training Act
UDHR	Universal Declaration of Human Rights
UN	United Nations
UTSS	Under the Same Sun
WHO	World Health Organization

CHAPTER ONE : IMPACT OF RITUAL ATTACKS ON THE LIVES OF PERSONS WITH ALBINISM

1.1 Introduction

1.1.1 Defining Albinism

Albinism is a congenital genetic condition characterised by the lack of melanin in the skin, hair, and eyes.¹ Similarly, it can be defined as a rare group of genetic disorders that cause the skin, hair, or eyes to have little or no colour. Albinism can occur in all racial or ethnic groups across the world.² There are various types of albinism, but the Sub-Saharan African region has significantly higher prevalence rate of the type called Oculocutaneous albinism (OCA) of one in every five hundred persons, with most countries in southern Africa having a prevalence rate of one in every one thousand persons.³ OCA is a type of albinism which involves lack of coloring (pigmentation) of the skin, hair, and eyes is characterised by a reduction in or absence of melanin.⁴ In Malawi, the predominant type of albinism is also OCA, with a population of persons with albinism estimated to be about 134, 636 representing 0.8 % of the total population of 17,563,749 persons in Malawi. The total population of persons with disabilities is estimated to be 1,556,670 persons representing a disability prevalence rate of 10.4 % of the population.⁵ The condition affects both genders with 49% male and 51% female, with majority living in rural areas 87% (117,480 rural) and 13% (17,156 urban).⁶ The national census conducted in 2018 has also shown that the population of persons with albinism is relatively young with 40% (53,304) under the age of nine years.⁷ Albinism

¹DP Lookingbill & B Leppard 'Actinic damage and skin cancer in albinos in northern Tanzania: findings in 164 patients enrolled in an outreach skin care programme' (1995)

²The National Organization for Albinism and Hypopigmentation, available at <http://www.albinism.org> NOAH-What-is-Albinism_2020_low-res.pdf (accessed 16 July 2022)

³ I Ero, S Muscati, A Boulanger & I Annamanthadoo 'People with Albinism Worldwide a Human Rights perspective' 2021

⁴AWN Roy & RM Spinks Real lives, Personal and photographic perspectives on albinism (2005) 12

⁵Disability Report '2018 Malawi Population and Housing Census' National Statistical office 2020 available at <https://undocs.org/en/A/RES/74/156> (accessed 11 April 2022)

⁶ National Statistic Office '2018 Malawi Population and Housing Census' (2019) 198

⁷ National Statistical Office (n 6 above) 199

is non-contagious and cannot be transmitted through contact and blood transfusions.⁸ It is therefore, safe to live, make friends and marry persons with albinism. The difference in the physical appearance in terms of the white skin color and light coloured hair has led persons with albinism to face derogatory names and discrimination in society.⁹ The majority of persons with albinism also have limited knowledge of their skin condition and understanding on the basic facts about albinism that would enable them to defend themselves using accurate information to enlighten the community.¹⁰ Consequently, persons with albinism fall in the trap of defining their identity and disability through speculation and interaction with a society that is equally ignorant about the albinism condition.¹¹ Therefore, it is contended that right from birth persons with albinism's rights are often not respected, protected and fulfilled. They are repeatedly, stigmatised, feared and excluded within their own homes. These negative biases against persons with albinism and lack of knowledge about albinism has led to further marginalisation of the group.

1.1.2 Persons with Albinism and Disability Discourse

Disability is a complex and multidimensional concept with over 15 % of the World's population having some form of a disability and the application of model of disability varies in practice, policy and programmes.¹² However, the Convention on the Rights of Persons with Disabilities (CRPD)¹³ provides that shift in understanding disability by championing human rights-based approach to disability that is extensively accepted with a multi-level perspective to achieve human rights of persons with disabilities, including those with albinism.¹⁴ In article 1, the CRPD¹⁵ defines persons with disabilities as those with long term physical, mental, intellectual and sensory impairments, which interact with environmental and attitudinal barriers, and resulting in limited participation in

⁸ United Nation Albinism Worldwide "Report of the Independent Expert on the Enjoyment of human rights by persons with albinism" A/74/190 para 5 available at A/74/190 - E - A/74/190 - (undocs.org) (Accessed 25 July 2022)

⁹ Amnesty International (2017) 'People with Albinism in Malawi' Amnesty International's written statement to the 34th session of the UN Human Rights Council, paras 2 & 7 available at <https://www.amnesty.org> (accessed 12 July 2022)

¹⁰ S Braathen 'Albinism in Malawi: A qualitative study on attitudes and beliefs' master thesis, University of Oslo, Oslo 2005

¹¹ Z Ramaekers 'The Power of rumors violence against persons with albinism in and Political crisis in Malawi' master thesis Leiden University, 2020 17

¹² World Health Organization 'World Disability Report' (2011) 3 available at <https://apps.who.int/iris/rest/bitstreams/53067/retrieve> (accessed 8 June 2022)

¹³ Adopted by the United Nations (UN) General Assembly A/RES/61/106 on 13 December 2006 and entered into force 3 May 2008 available at <https://www.ohchr.org/EN/HRBodies/CRPD> (accessed 27 June 2022)

¹⁴ E García Iriarte 'Models of Disability' (2016) Disability and Human rights global perspective at 16

¹⁵ CRPD (n 13 above) art 1

society. On the other hand, in paragraph (p) of its Preamble, the CRPD talks about multiple forms of discrimination on the basis on race, color, birth and status.¹⁶ Persons with albinism face stigmatisation, rejection and misconception due to their skin color.¹⁷ The Committee on the Elimination of Racial Discrimination has recognised persons with albinism as a group facing racial discrimination due to their physical appearance of the skin that makes them to be stigmatised and discriminated on the basis of colour.¹⁸ The International Convention on the Elimination of All Forms of Racial Discrimination (CERD)¹⁹ defines racial discrimination as any distinction, exclusion, restriction or preference based on race, color which has impairing effect on enjoyment of human rights and freedoms.²⁰ Thus, albinism brings restriction in society, causing a disabling environment. Persons with albinism have long-term physical impairment (lack of melanin in the skin that predisposes them to sun damage or skin cancer) and sensory impairment (lack of melanin in the eye causing visual difficulties) which in interaction with societal barriers create disabling factors including negative attitudes, stigma, and discriminations in the community. Thus, the physical difference in the skin pigmentation is regarded as deviant and labeled abnormal, hence attracting myths and erroneous beliefs that have led to great discrimination and targeted killings of persons with albinism.²¹ Often, persons with albinism are judged based on their impairment and associated fear that restrict them from sharing their lived experiences, skills, abilities and interests as they exercise their rights. There is increasing recognition of albinism as a disability at individual level as well as in laws in various countries,²² hence, this research focuses on the understanding and interpretation of international human rights instruments as they relate to rights

¹⁶ CRPD (n 13 above) Preamble (p)

¹⁷P Lynch, P Lund & B Massah 'Identifying Strategies to enhance educational inclusion of visually impaired children with albinism in Malawi, (2014) International Journal of Education Development at 226-234 available at www.elsevier.com/locate/ijedudev (accessed 12 July 2022)

¹⁸United Nation Committee on Elimination of Racial Discrimination 'Concluding observations on the combined fourth to eighth periodic reports of South Africa' CERD/C/ZAF/CO/4-8 (2016) paras 20 & 21 available at (undocs.org) (accessed 24 June 2022)

¹⁹Adopted by the United Nations (UN) General Assembly A/RES/2106/XX on 21 December 1965 and entered into force 4 January 1969 available at <https://www.ohchr.org/en/professionalinterest/pages/cerd.aspx> (accessed 22 June 2022)

²⁰ CERD (n 19 above) art 1

²¹ Human Rights Council, Preliminary Study on the Situation of Human Rights of Persons Living with Albinism, U.N. Doc. A/HRC/AC/13/CRP.1 (2014) 79 available at (undocs.org) (accessed 22 June 2022)

²² A Franklin, P Lund, C Bradbury-Jones & J Taylor 'Children with albinism in African regions: their rights to 'being' and 'doing' (2018) BMC International health and human rights

of persons with albinism as a type of disability. As is the case with other types of disabilities, the research affirms the position that due to the impairment, persons with albinism need specific support and measures to eliminate discrimination and ensure an enabling environment for their full inclusion in society. The researcher acknowledges that not everyone accepts the narrative that albinism is a disability. Nevertheless, the researcher asserts that albinism is a disability, and argues that the positioning of albinism within disability should be viewed as strategic in the context of sharing experiences of impairment by persons with albinism within the disability movement. The researcher views this as particularly necessary for persons with albinism based on conceptualisation of impairment within the CRPD.

Several anthropological and sociological perspectives have informed the definition of disability. Although there are several models of disability, this research focuses on three models namely medical model, social model and human rights model. It is observed that these models of disability have provided a foundation for understanding disability in international human rights law and systems that will be useful for understanding the rights of persons with albinism.²³ Firstly, the medical model is based on the functionality of body organs and status.²⁴ It highlights that, disability is as a result of the malfunctioning of the body and how the body interacts with its environment. Therefore, the focus is on biological functioning of the body and its limitation or restriction to function as 'normal' due to loss of functioning of body structure.²⁵ Secondly, the social model defines disability as not just in the individual functioning but also the society's behaviours, attitudes, environment that have historically restricted persons with disabilities.²⁶ The perceptions of society have excluded persons with disabilities from participating in mainstream community life. Thirdly, the human rights model acknowledges the human dignity, impairment as part of human diversity, different layers of identity, life circumstance and experience of persons with

²³T Degener 'Disability in Human rights Contest' (2016) Law Journal Department of Social Work, Education and Diaconia, Protestant University of Applied Sciences at 2 available at <https://doi.org/10.3390/laws5030035> (accessed 24 June 2022)

²⁴B Turner 'Disability and the Sociology of the Body' (2001) in Gary L. Albrecht, et al (eds) Handbook of Disability Studies

²⁵J Susman 'Disability, stigma and deviance. Social Science & Medicine' (1994) 36 issue 1 at 15–22

²⁶ RP Cheng 'Sociological Theories of Disability, Gender, and Sexuality: A Review of the Literature' [2009] Journal of Human Behaviour in the Social Environment

disabilities, but also offers room for minority and cultural identification.²⁷ Although all the three different models of disability focus on prohibiting equality on the basis of stereotypes, prejudices and stigma against persons with disabilities, it is argued that medical model correspond more to formal equality, social model to substantive equality and human rights model to transformative equality.²⁸ In General comment No 6 the CRPD Committee has interpreted formal equality as combating direct discrimination, negative stereotypes and prejudices while substantive equality deals with indirect discrimination, structural and power relationship of persons with disabilities. It further defines transformative equality as inclusive equality that addresses the participation, accommodation, redistribution of resources, human dignity, combating stigma and intersectionality dimensions of persons with disability.²⁹ It is important to note that both anthropological and sociological perceptions on disability have explored stigma and discrimination by the society as fundamental elements that reduce the status of persons with disabilities and increase inequalities. This has helped to enhance the understanding of human rights and multiple inequalities based on disability, gender and intersectionality.³⁰

In response to increased attacks against persons with albinism across Africa and the urgent need for preventive measures, the African Commission on Human and Peoples Rights (the Commission) made Resolution 263 on the Prevention of Attacks and Discrimination against Persons with Albinism which called upon States Parties to take all measures necessary to ensure the effective protection of persons with albinism and members of their families. The Commission, further called on States Parties to ensure accountability through the conduct of impartial, speedy and effective investigations and prosecution into attacks against persons with albinism and effective measures to eliminate all forms of discrimination against the group.³¹ Nevertheless, there is still increased vulnerability to attacks among women and children with albinism who are often considered weak

²⁷ T Degener ‘A new Human rights model to Disability’ (2017) The United Nations convention on the rights of persons with disabilities: A commentary

²⁸ Cheng (n 26 above) 2

²⁹ Committee on Rights of Persons with Disabilities “General Comment No 6 on Equality and non- discrimination” UN Doc CRPD/C/GC/6 (CRPD General Comment No 6) of April 2018 at paras 9,10 & 11 available at (undocs.org) (accessed 3 May 2022)

³⁰DL Brunnsma, KE Iyall Smith & BK Gran ‘Sociology and human rights resituating the discipline’ (2013) in David L. Brunnsma, et al (eds) Handbook of Sociology and Human Rights

³¹African Commission on Human and People’s Rights, Resolution 263: Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism (2013) available at (achpr.org) (accessed 18May 2022)

targets.³² Thus, persons with albinism are deprived of their human rights and freedoms as provided in the CRPD such as article 5 on equality and non-discrimination, article 10 on right to life, article 14 on liberty and security and article 15 on freedom from torture, cruel and degrading treatment. Furthermore, article 6(1) of CRPD requires States to recognise the multiple discrimination faced by women with disabilities, which includes women with albinism.³³ The CRPD recognises that women, girls and children with disabilities are at greater risk of abuse, violence, neglect and exploitation of these groups and call upon for their increased protection.³⁴

In Malawi, over the past eight years there has been extensive international, regional and national attention on albinism due to systematic violations of human rights that have led to persons with albinism constantly living in fear, trauma and dire need of assistance to restore their dignity.³⁵ This follows the widespread media coverage of alleged killings of persons with albinism for their body parts which are harvested for use in witchcraft and charms because they are mistakenly believed to create wealth. An Amnesty International report ‘We are not animals to be hunted or sold’ stated that human rights violations and abuses against persons with albinism in Malawi range from widespread societal discrimination that is evident in name calling in public, exclusion from access to public services, including education, work and health.³⁶ The report, further highlights the extreme forms of violence against persons with albinism that includes ritual killings, body parts harvesting, abductions, exhumation of grave yard and many missing persons with albinism.³⁷ Both children, young people, women and men with albinism in Malawi are targeted by the attackers. Other factors influencing the commission of these crimes include the promise of huge monetary rewards for the offenders, strong belief in witchcraft, and the perception of persons with albinism as unwanted and a burden to their poor families. However, the biggest factor of these attacks

³²Amnesty International (2018) ‘End Violence against people with albinism Toward effective criminal justice system for people with albinism in Malawi’ 3

³³ CRPD (n 13 above) arts 6(1), 10, 14 & 15

³⁴Committee on Rights of Persons with Disabilities “General Comment No 3 on Women and girls with disabilities” UN Doc CRPD/C/GC/3 (CRPD General Comment No 3) of November 2016 at paras 53 & 54

³⁵United Nations General Assembly ‘Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on her Mission to Malawi’ (2016) A/HRC/34/59/ paras, 58, 59, 60 available at: <https://undocs.org/A/HRC/34/59/> (accessed 30 March 2022)

³⁶ Amnesty International Report ‘We are not animals to be hunted or sold’ (2016) Amnesty International available at <https://africanlii.org> (accessed 5 April 2022)

³⁷Amnesty International (n 36 above)

remains the demand for human body parts by witchdoctors for performing ritual ceremonies for their clients who believe in their practices.³⁸

There is continuing witchcraft accusations, ritual killings, mutilations, abductions and trafficking of body parts of persons with albinism recorded across 29 African countries, with over 759 reported cases signifying the serious threat to life and dignity of this vulnerable group as provided for under international human rights law.³⁹ With countries like Malawi, Tanzania, Democratic Republic of Congo (DRC) and Mozambique being most affected in the sub-Saharan African region. Tanzania is the historical hub of violence against persons with albinism with over 200 reported cases, DRC 70 cases and Mozambique 51 cases as of the year 2021. Since 2014, Malawi has registered various forms of attacks against persons with albinism, a total of 195 cases of attacks have been recorded, representing 26% of all attacks in Africa.⁴⁰ A report by Amnesty International indicates that the numbers of attacks may be higher as the figures are likely to only represent reported and documented cases due to the secretive nature of the attacks and failure to openly report the cases.⁴¹ The report of the United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism issued after her visit to Malawi in 2016, further shows that based on the increase of attacks and killings in Malawi, the attacks constitute a threat to life for persons with albinism.⁴² Persons with albinism are endangered, risk extinction and their body parts are targeted even in the graveyards. Hence the call for urgent action by the government of Malawi to end the atrocities.⁴³

Furthermore, the International Bar Association report issued in 2017 ‘Waiting to disappear,’ recommended that the government of Malawi strengthen legal protection, investigate, prosecute

³⁸ Chilungamo Programme (Justice and Accountability) European Union Final Report, Technical Assistance to conduct a research Study on the markets and criminal networks for body parts of people with albinism 2019

³⁹ Standing Voice Report ‘Reported human rights violation against people with albinism in Africa’ 2021 available at <http://www.standingvoice.org/> (accessed 4 March 2022)

⁴⁰ Standing Voice (n 39 above)

⁴¹ Amnesty International (n 36 above)

⁴² UN Human Rights Council ‘Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to Malawi’ 2016 at 10 available at A/HRC/34/59/ <https://undocs.org/A/HRC/34/59/> (accessed 5 May 2022)

⁴³ United Nations, Statement by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, Ms. Ikponwosa Ero, upon conclusion of her official visit to Malawi 2016 paras 2 & 3 available at <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=19903&LangID=E> (Accessed 9 June 2022)

and formulate Action plans that protect and address the needs of persons with albinism.⁴⁴ Correspondingly, in June 2017, the Amnesty International brief report, highlighted the fact that in spite of Malawi having a new legal framework, there are gaps in the criminal justice system in that need the urgent attention of government and civil society organisations. Some of the gaps include limited knowledge on albinism at all levels leading to systematic discrimination, poor quality of investigations, delayed prosecution of cases, lack of provision of psycho-social support to victims of attacks and social protection to persons with albinism.⁴⁵ The Independent Expert on the Enjoyment of Human Rights by Persons with Albinism report in 2016 further called for development of specific measures to prevent, protect, promote equality and eliminate non-discrimination against persons with albinism.⁴⁶

1.2 Problem Statement

In response to these gross human rights violations the government of Malawi and other countries including Uganda, Mozambique, South Africa, Nigeria and Tanzania responded by legislative reform, policy review and development of National Action Plans on Albinism (NAP) in order to address the atrocities perpetrated against persons with albinism. A National Action Plan is a blue print that guides how government responds to the atrocities against persons with albinism and advances the enjoyment of their human rights. However, some of the legislative, policy and programme responses are inadequate to effectively address the attacks and deep-rooted stigma as a human rights issue across the disability spectrum. The group continues to face abuse, increased vulnerability and struggle for social acceptance, resulting in limited opportunities to participate effectively and live independently along with a range of other physical or psychosocial limitations. Furthermore, there is knowledge gap on how the circumstances of persons with albinism overlap with human rights approaches in developing Malawi's National Action Plan, to ensure that it serves as a basis for policy guidance, learning experiences and advocacy to promote equitable representation of all relevant stakeholders.

⁴⁴ International Bar Association 'Waiting to disappear' (2017) international and Regional Standards for the Protection and Promotion of the Human Rights of Persons with Albinism report

⁴⁵ Amnesty International, People with albinism in malawi, written to the 34th session of the un human rights council (27 february -24 march 2017) available at <https://www.amnesty.org> (accessed 12 July 2022)

⁴⁶ United Nations (n 42 above) 2

1.3 Research Questions

This dissertation attempts to critically explore whether the National Action Plan in Malawi adequately protects the human rights of persons with albinism in the light of the interplay of the various barriers, which hinder their full participation and effective networking in programming action plan on an equal basis with others.

The main research question is, does the government's response through National Action Plans adequately deal with the killings, stigma and discrimination against persons with albinism?

The research focuses on answering the following specific subquestions:

- a. Does the National Action Plan provide an adequate framework for the protection of the rights of persons with albinism?
- b. How does the National Action Plan in Malawi conform to international human rights standards?
- c. What additional measures can Malawi adopt to ensure the effective protection of persons with albinism?

1.4 Methodology

The study adopts a desktop research method through literature review that critically analyses the effect of stereotypes and affirmative action by government in understanding the circumstances of discrimination against persons with albinism. The method also reviews National Action Plan formation processes and whether the government was consulting relevant stakeholders. It also compares National Action Plan development processes from other neighbouring countries across the southern African region, in order to get a regional and cross border understanding of the various approaches taken by governments in the development and implementation of the National Action Plans. Other sources consulted include internet sources, news paper articles and e-mail correspondence, published and unpublished materials, reports, textbooks, law review articles, general comments, journals and by obtaining physical copies of relevant official documents as they relate to the subject under of the research.

1.5 Literature Review

1.1.5 Stigma and Discrimination against Persons with albinism

There is adequate evidence on the social discrimination and stigmatisation towards persons with albinism due to lack of knowledge and etiologic beliefs. The lack of knowledge has brought social, psychological and medical burden to persons with albinism resulting in compromising their quality of life.⁴⁷ Often persons with disabilities experience poverty, institutional, environmental and attitudinal discrimination that has led to systematic marginalisation in laws, practice and customs.⁴⁸ Compounding this situation is the traditional beliefs that associates persons with disabilities and witchcraft, with the recent focus being widespread killings of persons with albinism.⁴⁹ This discrimination is deeply entrenched in societal practices, beliefs, witchcraft and stereotypes about persons with albinism.⁵⁰ Mainly these violations are as a result of harmful practices, accusations of witchcraft and ritual killings leading to persons with albinism suffering discrimination, stigmatisation, removal of body parts, torture, grave desecration and death.⁵¹ The killings of persons with albinism are influenced by traditional beliefs, misconception and myths. It is argued that often these atrocities are perpetuated by persons who have money to support the costs of such organised crime although some family members have been involved who also connive with the attackers with the motivation that they will financially benefit by selling body parts of their relatives with albinism. Frequently, the attacks have happened during the farming period and are a combination of several factors like poverty, corruption and the widely held belief that business can succeed through the use of magic, hence the association of body parts of persons with albinism with acquisition of wealth.⁵²

⁴⁷ ES Hong, H Zeeb & MH Repacholi 'Albinism in Africa as a public health' (2006) BMC Public health at 3 & 4

⁴⁸ R Yeo Including Disabled people in poverty reduction work: Nothing about us without us' (2003) World Development Vol. 31, No. 3 at 572

⁴⁹ N Groce & J MacGeown 'Witchcraft, Wealth and Disability: Reinterpretation of a folk belief in contemporary urban Africa' Working Paper Series: No. 30 at 11

⁵⁰ Human Rights Council, Report of the United Nations High Commissioner: Persons with Albinism, U.N. Doc. A/HRC/24/57 OHCHR Report 2013

⁵¹ United Nations 'The COVID-19 pandemic and harmful practices impacting Persons with Albinism: Accusation of witchcraft and ritual attacks' 2020

⁵² A Chavuta, S Chiwaya & M Mankhwazi, Investigation research on the abductions, killings & exhumation of remains of persons with albinism in Malawi, 2015

Traditionally, for persons with disabilities these negative beliefs have not only demonstrated a direct link between disability and witchcraft accusation due to social status, poverty and prejudice but also led to banishment, killings and physical violence in various communities. It is believed that the witchdoctors play a specialist role in performing witchcraft related rituals in secret and promotes charm erroneously believe to thier clients for good fortune to business.⁵³ These witchdoctors help foster the trade in body parts, trafficking and attacks against persons with albinism. However, it is also worth noting that in other communities persons with albinism are considered as a gift from God and accepted by families.

Across Africa, cultures have developed many myths and superstitions regarding persons with albinism making them social outcasts. Numerous cases of attacks against persons with albinism have been reported posing massive violation of human rights, particularly the right to life.⁵⁴ Interesting discourse on albinism and disability is the name calling and labelling that has also fueled discrimination and prejudice against persons with albinism. They are often called by derogatory names that construct a negative perception about albinism affirming the ideology that name calling can shape understanding of body of persons with disabilities and their relationship with the community.⁵⁵ Persons with albinism are labelled as ‘money’ fueling the negative image of their condition and advancing the perception that they are sub-human.⁵⁶ Similarly, Amnesty International’s report ‘Toward effective criminal justice for persons with albinism in Malawi’, showed that the mistaken perception that persons with albinism are not human beings and promised markets fosters the trade of human body parts and violates persons with albinism’s right to life, security and freedom.⁵⁷ Other authors have argued that such labelling and discriminatory language has power to further exclude and shape the perceptions of persons with albinism.⁵⁸

⁵³ Groce (n 49 above) 8, 11,15

⁵⁴Report of Independent Expert on the Enjoyment of Human Right by Persons with Albinism on the Regional Action Plan on Albinism in Africa (2017-2022) Human Rights Council (2017) 2 available at [OHCHR | A/HRC/37/57/](#) (Accessed March 15 2022)

⁵⁵ P McPherron & V Ramanatha ‘Language, Body, and Health’ (2011) Mouton de Gruyter Press

⁵⁶ J Corbett ‘Bad Mounthing: The Language of Special Needs’ (1996)

⁵⁷ Amnesty international Report ‘Toward effective criminal justice for persons with albinism in Malawi’ 2018

⁵⁸ N Gottlieb ‘Language and disability in Japan’ (2001) Disability and Society at 981-995 & N Singal “Doing disability research in a Southern context: challenges and possibilities” (2010) Disability and Society at 415-426

Therefore, the intersectional landscape of albinism means that persons with albinism are at crossroads of multiple discrimination in accessing various services that increases their vulnerability.

Low vision in persons with albinism affects their education outcomes in school.⁵⁹ Albinism is associated with low vision, due to nystagmus (involuntary eye movements) and photophobia (eye problems such as squinting and astigmatism).⁶⁰ The visual impairment in persons with albinism is life long present from birth and not progressive but varies in severity between individuals. Students with albinism face challenges like bullying, lack of inclusive teaching skills by teachers, lack of parental support and inaccessible learning materials. Owing to the visual impairment and their difference in skin appearance, they are a target of bullying and name-calling in education facilities. Thus, persons with albinism face double vulnerability due to the misconception that albinism is progressive and eventually leads to blindness. It is observed that this is a fallacy and persons with albinism should not be forced to learn Braille as they can use their residual sight.⁶¹

Disability is both a social and human rights issue, it is an umbrella term in which albinism falls as a result of impairment effect of the condition. In this regard an impairment is the functional limitation that leads to activity and participation restrictions within the individual in interaction with environmental barriers.⁶² The impairment in persons with albinism is the low vision and high risk to skin cancer which led to barrier of doing things that affect their daily lives and denial for their enjoyment of human rights like any other human being due to discrimination.⁶³ The protection of human rights of minorities and vulnerable groups like persons with albinism, requires active interplay of government structures beyond rhetoric. With the African region now prioritising human rights of persons with albinism in laws and programmes, it is important that prejudice and violations rooted in traditional superstitious beliefs are eliminated to ensure the protection and

⁵⁹ P Lund & P Lynch Promoting social and educational inclusion of young people with albinism in sub-Saharan Africa, Evidence from Malawi

⁶⁰ A Franklin, P Lund, C Bradbury-Jones & J Taylor 'Children with albinism in African regions: their rights to 'being' and 'doing' (2018) BMC International health and human rights

⁶¹ P Lund & P Lynch Education of children and young people with albinism in Malawi (2011) 3

⁶² Franklin (n 60 above)

⁶³ C Thomas 'How is disability understood? An examination of sociological approaches' (2004) Disability and Society, Vol. 19, No. 6 at 569–73.

promotion of enjoyment of the all human rights for persons with albinism. For persons with albinism this signifies that discrimination is deeply entrenched in societal practices, beliefs, witchcraft and stereotypes.⁶⁴

1.6 Significance of study

There is a significant amount of knowledge on albinism from a medical model that has taken forward lessons and best practices from the previous publications, medical research and disability projects in Africa. However, there is little knowledge on understanding of albinism from a human right model, with the rationale of exploring inequalities among persons with albinism, challenging misconceptions, myths and vulnerability surrounding them throughout the process of programming national action plan.

Therefore, the aim of the study is to contribute to the improved participation, implementation and coordination within development of national programmes responding to ritual attacks and harmful practices against persons with albinism. Specifically, the objective is to ensure governments adopts a human rights based approach in the development processes of National Action Plans. Thus, it is imperative that the research contribute to evidence-based interventions in the development of legislation, policies and programmes that conform to international human rights agreements and directly speak to the needs of persons with albinism as a special population group within their local context.

The research helps the government of Malawi to track progress towards the achievement of inclusive programming of the National Action Plan and targets set in the response strategies. Thus, increasing National Action Plan potential for inclusion, equalisation of opportunities and protection status within their communities, by responding directly to reducing inequalities in the enjoyment of political, economic, social and cultural rights. Inclusive processes in development of National Action Plan spotlight the need for the human rights field to be innovative in ensuring that government is effectively fulfilling its obligation and duty to promote and protect the rights of persons with albinism.

⁶⁴ Human Rights Council report (n 50 above)

1.7 Limitations

There was also lack of empirical data that could have added value to the research due to limited time for data collection and ethical clearance processes within the two years period of the master's programme. However, the research might contribute to wider knowledge of evidence on programming of action plans against ritual killings of persons with albinism, as Malawi is among the first countries in sub-Saharan Africa to develop a national plan on albinism as a measure of ending the atrocities. The scope of this study was limited only to a few countries that have developed National Action Plan and are experiencing attacks against persons with albinism in Africa. Finally, the processes of developing the National Action Plans may vary from one country to another based on the contextual specification, including political will, economy and the different roles of persons with albinism or their organisations is also unpredictable across different countries.

1.8 Chapter outline

The research is organised into four chapters.

Chapter one describes the background, problem statement, research questions, methodology of the research, literature review, significance of the study, limitations and chapter outline.

Chapter two introduces the process of programming National Action Plans based on the human rights model of disability. It provides a general overview of the process of developing National Action Plan in Malawi and other countries from a human rights perspective. The purpose of this chapter is to provide a theoretical framework for the development processes of National Action Plan and to examine involvement of various stakeholders. The main objective of this examination is to highlight the National Action Plan gaps and strengths that exist in Malawi and other countries, important is the approaches implemented by governments which this research intended to cover. It discusses the situation of atrocities perpetrated against persons with albinism in Malawi and across Africa. It includes a comparison of broader implementation of Regional Action Plan on Albinism in Africa and how it has informed the process of developing National Action Plans by various countries. Thus providing the historic and legal context of responding to the attacks against persons with albinism that facilitates their participation in advocacy at all levels.

Chapter three discusses the following areas, international and national human rights legal framework that promote and protect disability rights, particularly persons with albinism. It also explores regional, sub-regional and national instruments that safeguard and enhance the protection and promotion of the right of persons with albinism. It concentrates on the analysis of the right to participation, right to equality and non-discrimination, right to life, right of freedom from torture or cruel or inhuman treatment of persons with albinism in the programming of action plan. But also, as it relates to the right of persons with albinism to live independently and be included in community life. Furthermore, the chapter looks at the comparative approaches taken by governments in programming National Action Plans, effectiveness and factors that foster its impact on improving lives of persons with albinism.

Chapter four provides an analysis of the National Action Plan effectiveness and establishes additional measures that influence the interpretation and application of rights as guaranteed therein at the national level. Chapter four then proceeds to provide a summary of the all the chapters, thus providing a conclusion and recommendations.

CHAPTER TWO : COMPARATIVE ANALYSIS OF APPROACHES TAKEN BY GOVERNMENTS IN DEVELOPING NATIONAL ACTION PLANS ON PERSONS WITH ALBINISM.

2.1 Introduction

This chapter contextualises the situation of violations of human rights against persons with albinism that has led to the development of National Action Plans. It analyses how knowledge on attacks against persons with albinism and their identity has shaped the framing of pillars of National Action Plans. Furthermore, it looks at the involvement of persons with albinism as they make claims for their human rights, knowing that these deep-rooted social injustices require a unified voice and their self-representation in National Action Plan development processes. It also builds on the conversation on albinism as disability and how it has strategically been used as a means to bring albinism into the political, legal and policy spheres of National Action Plan at African Union level and national level. It highlights governments; political will to end the violations and increasing media reports of the ritual killings of persons with albinism that attracts urgent action by the international community and governments to respond to the attacks. Such international advocacy is necessary to inform the approaches taken by governments in developing NAPs and how various stakeholders were involved or contributed to the process. The Chapter focuses of analysis of the approaches taken by the governments in developing National Action Plan from Malawi, Mozambique and Tanzania as they share boundaries and were among the first countries in Africa to develop national action plans. On the other hand, Nigeria and Uganda are chosen as they have specific policy on albinism and recently adopt a national action plan in June 2022, respectively. It is observed that the development and adoption of National Action Plan remains the means to mitigate the impact of the harmful practices and witchcraft accusation against persons with albinism.

2.2 Programming of Regional and National Action Plan triggered by attacks against Persons with albinism.

The year 2019 is remarkable for promoting and protection of human rights of persons with albinism in Africa, as it marked when the Regional Action Plan (RAP) on albinism was considered

and subsequently adopted as a continent-wide policy as the plan of action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031) (Plan of action) by the executive council of the AU.⁶⁵ Thus, the Plan of action (2021-2031) replaced the regional action plan (2017-2021) and is incorporated into the larger disability architecture of the AU, thereby giving further legitimacy to the need to implement the measures contained therein. The AU further decided to create a position of special envoy to oversee and drive the implementation of the plan. Furthermore the AU developed and adopted implementation matrix of the Plan of action to end attacks and other human rights violations targeting persons with albinism as a way of ensuring that government in Africa are adopting such measures at national level.⁶⁶

Since the AU adopted the Plan of Action many governments in Africa are making progress towards adopting specific measures to end the attacks and discrimination targeted at persons with albinism. From here proceed to the the different National Action Plans.

2.3 National Action Plan on Persons with Albinism in Malawi

The African Commission on Human and Peoples rights resolution 349 urged States Parties to ensure the effective protection, speedy and effective investigation and prosecution of attacks against persons with albinism. It also called on increased public awareness and education on albinism at all levels to eliminate all forms of discrimination.⁶⁷ In that regard, the Malawi government developed a national mechanism as a way of responding to the ritual attacks against persons with albinism as also provided in CRPD article 4(1) where it has taken measures to (a) adopt legislation and administrative measures, (b) modify laws and practices that constitute discrimination against persons with albinism.⁶⁸

⁶⁵African Union Executive Council “Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031’ 20, 31 available at <https://www.tralac.org/documents/resources/african-union/2959-35th-ordinary-session-of-the-executive-council-of-the-african-union-decisions-july-2019/file.html> (accessed on 6 July 2022)

⁶⁶African Union ‘Implementation Matrix Of The Plan Of Action To End Attacks And Other Human Rights Violations Targeting Persons With Albinism In Africa’ (2021–2031) 2019 available at <https://au.int> (accessed 2 June 2022)

⁶⁷ African Commission on Human and Peoples' Rights, 349: Resolution on the Attacks on Persons with Albinism in Malawi, available at <https://www.refworld.org/docid/5811e6814.html> (accessed 25 July 2022)

⁶⁸ CRPD (n 13 above) art 4(1) (a) & (b)

In February 2015, government adopted the National Action Response Plan on Albinism Atrocities to guide all national initiatives and coordinate resource mobilisation aimed at addressing human rights violations against persons with albinism.⁶⁹ The plan includes the following six pillars; education, awareness raising and reporting, Internal security, Investigative research, human rights monitoring and reporting, Administration of Justice and victim assistance, Legislation, and Empowering people with albinism. Although, the plan demonstrates the state's commitment to adopt measures to end the atrocities perpetrated against persons with albinism, implementation was slow and there was a lack of multi-sectoral approach, with no realistic targets and costed activities. The atrocities were not treated as an emergency situation hence there was drastic delays in the implementation of the plan and lack of financial resources committed to the implementation of the plan.⁷⁰ This led to non-existence stakeholder cooperation, poor communication and transparency in the implementation of the plan.⁷¹ It is observed that the plan only provided an operational framework as suggested by the name 'response plan' to guide government activities but did not translate into concrete actions in reducing the cases of attacks against persons with albinism.⁷²

Despite having the National Action Response Plan on Albinism Atrocities, it was observed that there were increased cases of attacks, hence in 2018, the National Action Plan on Persons with Albinism in Malawi (NAP 2018-2022) was adopted as a long-term response strategy with the aim of facilitating effective implementation and coordination of albinism response programming in Malawi. The plan also guides government and development partners with a multi-sectoral blueprint of priority areas to end the atrocities. Furthermore, it provides necessary resources for activities that will enhance measures aimed at promoting and protecting the human rights of persons with albinism. The plan has seven key focus areas including civic education, awareness raising and training, administration of justice and support of victims of attacks, safety and security of persons with albinism, human rights monitoring, reporting and research, mainstreaming and

⁶⁹ Malawi Government (2015) National Action Response Plan on Albinism Atrocities

⁷⁰ United Nations 'Malawi People with albinism face total extinction' – UN Expert calls for urgent response 2016 para 7 available at <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=19904&LangID=E> (accessed on 2 June 2022)

⁷¹ Malawi government (n 69 above) 57

⁷² M. Toumi, I Ero & H Tawata (2021) Regional action plan on ending attacks and human rights violations against persons with albinism in Africa above report at 13, 24,25,26 & 27

empowerment of persons with albinism, access to affordable and quality health care services, and access to equitable and quality education.⁷³

While the National Action Plan on Persons with Albinism in Malawi (2018-2022) as a successor of the National Action Response Plan on Albinism Atrocities (2015) signifies high level policy framework and commitment on albinism by government in Malawi, it is important to assess the extent of participation of persons with albinism and civic society in the development process of the pillars of the plan and how human rights approaches have been mainstreamed as long-term plan on ending atrocities by the government. The second National Action Plan was constructed to respond directly to the dilemma of the attacks and includes areas neglected in the first Action Response Plan, hence it has further developed the pillars. For instance, firstly, it identifies and addresses broader issues of violation of human rights and non discrimination such as access to affordable and quality education, where it recognises the vision impairment of persons with albinism as disability, negative attitudes, name calling, bullying as factors pushing learners with albinism to drop out of school. Secondly, it also highlights enviromental factors like non-inclusive teacher curricula and non-protective code of practice for school uniform as barriers to accessing education. Thirdly, on accessing equitable and quality health, it acknowledges the vulnerability of skin and eyes of persons with albinism due to lack of melanin as an impairment affecting their life. Thus, it provides the need for comprehensive prevention health program for persons with albinism focusing on quality and affordable dermatological and ophtamological services across all health facilities. Fourthly, it goes beyond to include increasing knowledge on albinism among health workers, access to sun screen and assistive devices as well as the need for rehabilitation and post rehabilitation to victims of attacks. The researcher argues that albinism is a peculiar condition in our community which may be affected by health, social, psychological, cultural, economic and religious factors. Somehow, there is a deliberate need for reasonable accommodation for persons with albinism to manage their condition through an inclusive plan. The second National Action Plan embraces the human rights based approach to disability in how it has fashioned its focus areas. However, it remains a challenge to clearly measure how the approach has been reflected during the implemetation stages of N ational Action Plan despite the government budgetary

⁷³ Malawi Government (2018) National Action Plan on Persons with Albinism in Malawi (2018-2022)

support in 2019/20 of MK400 Million towards its implementation and MK600 million for construction of housing for people with albinism and in 2021/2022 of MK 300 million and MK400 million respectively.⁷⁴

The National Action Plan is a stand-alone policy document for persons with albinism which from the beginning to the end of the consultations and drafting processes persons with albinism participated to ensure that their voice is heard. The process was led by government through the Ministry of Gender, Women, Children and Social Welfare which is the line ministry for disability affairs. The government conducted multi-sectoral consultations with ministries, agencies, departments, civic society organisations and development partners aiming at addressing the attacks against persons with albinism. In particular, persons with albinism were participating through the Association of Persons with Albinism in Malawi (APAM) which provided input in the consultation processes of developing the National Action Plan. As a civil society organisation (CSO), APAM's aim is to create equitable, enterprising, violence-free and healthy communities towards the improvement of lives and conditions of persons with albinism. It was the sole organisation championing human rights of persons with albinism through its lobby and advocacy activities to respect, promote and protect the rights of its membership in Malawi.

In 2015, APAM was appointed into the presidential Technical Committee on ending abuses of persons with albinism. The presidential committee was established as a national level coordinating hub for the National Action Plan and monitoring its implementation. The presence of APAM in the committee mainly contributed to active involvement of persons with albinism and their visibility in engaging government on the strategies and agreed pillars of National Action Plan. Although there is evidence of participation of persons with albinism at national level through APAM, it worth noting that the Malawi Human Rights Commission's National Action Plan monitoring report highlights gaps in the participation of persons with albinism during the implementation of National Action Plan at district level. These gaps include first, delays and inadequate funding for the institutions implementing National Action Plan activities, and lack of capacity in terms of knowledge and orientation of National Action Plan by implementing

⁷⁴ Ministry of Finance, Economic Planning and Development Malawi 'Budget Statement (2019/2020)' at 84 & 88 available at <https://actiononalbinism.org/en/entity/7r4k221hi72?page=32> (accessed 4 August 2022)

institutions. Second, there was limited involvement, coordination and communication between the various partners, including persons with albinism as rights holders and the implementing institutions at district level. Third, the APAM district committee members had limited capacity to effectively support the coordination and implementation of National Action Plan activities. Finally, the inactiveness and subsequent natural death of the National level Presidential Technical Committee in the office of President and Cabinet that was tasked with providing leadership and direction on National Action Plan activities has greatly contributed to the ineptitude in monitoring National Action Plan activities at district and national level.⁷⁵ It is observed that although there is evidence of government allocating funds to support National Action Plan activities, the failure to decentralise the funding to district council level renders the National Action Plan interventions ineffective as it only delays implementation of National Action Plan services in the community and poses a serious threat to the National Action Plan agenda of championing the enjoyment of freedom of persons with albinism in Malawi.

Therefore, it is argued that government's effort to prevent the attacks may only be achieved with the full participation of everyone at all levels, including the persons with albinism. The inclusion of persons with albinism in programme planning, implementation and monitoring of National Action Plan at all levels is a practical necessity if Malawi is to build a safe and responsive community without atrocities. With the ongoing review process of the next NAP (2022-2025) and resurgence of attacks against persons with albinism in Malawi, it is important to note that such a review process should be based on the protection and respect of individual and collective rights of persons with albinism. The author's view is that individual liberties of persons with albinism should not be interfered with in the context of implementation of interventions of the National Action Plan. Government should make deliberate efforts to allow persons with albinism to fully exercise their freedom to choose and make decisions about their lives throughout the implementation of National Action Plan activities. The National Action Plan transformed the approach taken by the first Response Plan by wresting the focus away from reactive response to the attacks, instead directed its focus on barriers in community fueling the violations. Additionally,

⁷⁵ Malawi Human Rights Commission (2021) Monitoring Implementation of the 2018-2022 National Action Plan On Persons With Albinism In Malawi report

the National Action Plan puts up government responsibility to continue prevention and protection measures that ensures persons with albinism enjoy their human rights on equal basis with others.

2.4 Tanzania National Action Plan for Persons with Albinism

In Tanzania, according to the national Population and Housing Census conducted in 2012, it is estimated that it has a national population of 16,477 persons with albinism.⁷⁶ The Committee on the Convention on the Rights of Persons with Disabilities observed that there are several reported cases of violations perpetrated against persons with albinism and expressed concern about delayed access to justice as demonstrated by prolonged periods of handling complaints by the State Courts.⁷⁷ However, the government of Tanzania has taken several steps to ensure it adopts measures that will protect and promote human rights of persons with albinism. The United Nations Independent Expert on Albinism report on her visit to Tanzania in 2017, clearly showed that persons with albinism still live in fear and that the attacks remain a rampant. However, she noted positive measures taken by the government and civil society organisations to improve the situation of persons with albinism. Examples of positive steps taken by the government include the adoption and implementation of recommendations from various UN resolutions on the attacks against persons with albinism.⁷⁸

The government of Tanzania issued notice **No 110** on rules on judicature and application of laws (practice and procedure in cases involving vulnerable groups) in 2019 including those with albinism. In Section 2 under application it states that the rules are applicable in all court proceedings with the view of speeding up the determination of court cases involving vulnerable groups. The rules under interpretation have defined vulnerable groups as particular groups of people who are weak, marginalised and have traditionally been victims of violations and practices which include persons with disabilities among others. While Rule 4 set six months as the permitted

⁷⁶The United Republic of Tanzania ‘2012 Population and Housing Census: Population Distribution by Administration Areas’ National Bureau of Statistics (2021)

⁷⁷ Communication 7.4/2014, Mr X v Republic United of Tanzania, CRPD committee (31 August 2017) UN Doc CRPD/C/18/D/22/2014

⁷⁸ United Nations, Report of Independent Expert on the Enjoyment of Human Right by Persons with Albinism ‘Tanzania: Attacks on persons with albinism decline; local attitudes must change’ (2017)

period to finalise cases of vulnerable groups,⁷⁹ the author did not find any evidence on cases of persons with albinism as a vulnerable group that was finalised within the required time stipulated by the Law, despite the rules being adopted and passed.

As a way of continuously strengthening protective measures and effectively responding to the attacks, in the same year 2019, the government established a Coordinating Committee to guide the development of the National Action Plan for persons with albinism 2022 -2024 through a multi-sectoral consultation process with civil society organisations. The development process of the National Action Plan was led through the Persons with Disability Unit within the Prime Minister's Office. It is important to note that there was active involvement of the organisations that are working on protection and promotion of human rights of persons with albinism, such as Standing Voice, which also chairs the national albinism task force, Tanzania Albinism Society (TAS), and Under the Same Sun (UTSS), who played a key leadership role in providing evidence of the attacks and need for urgent action.⁸⁰

With ongoing threats and attacks against persons with albinism in Tanzania where a 5-year-old boy with albinism was murdered in May, 2021 in the Tabora region, it is worrisome to note that there has been a lack of political will and commitment by the government to adopt the plan as a government blueprint to guide national actions on eliminating harmful practices and attacks against persons with albinism. The delay in the adoption of the National Action Plan may lead to continued lack of coordination among stakeholders in the implementation of various measures to end the attacks.

2.5 The Mozambique Multi-Sectorial Action Plan to Address the Issue of the Protection of Persons with Albinism.

There have been continued reported cases of attacks against persons with albinism in Mozambique with a recent case of the murder of a young man with albinism aged 22 years old, in Mogovolas

⁷⁹ Republic of Tanzania 'judicature and application of laws (practice and procedure in cases involving vulnerable groups)' Notice No 110, 2019 available at [110 judicature and application of laws \(practice and procedure in cases\[12433\] Africa Albinism Network \(actiononalbinism.org\)](#) (accessed 14 July 2022)

⁸⁰ The United Republic of Tanzania (2019) 'National Action Plan for Persons with albinism' Prime Minister Office, Labour, Youth, Employment and Persons with Disability.

district, in the northern province of Mozambique on 16 May 2022.⁸¹ In an effort to combat the rise of attacks against persons with albinism and tackling the root cause of the attacks, in 2015, the government approved its first Multi-Sectorial Action Plan to Address the Issue of the Protection of Persons Albinism. The attacks were mainly reported in Northern and Central Mozambique where it borders with Tanzania and Malawi respectively.

Unlike in Malawi and Tanzania the consultation process and development of the action plan was led by the Ministry of Justice, Constitutional and Religious Affairs. This was the case as the plan was more focused on responding to the rise of attacks through legal protective measures, procedural celerity and the public sharing of judicial decisions.⁸² It is also observed through the legal and protective approach in the National Action Plan, other areas like humanitarian intervention, empowerment of organisations of persons with albinism and gender issues were omitted. The approach has led to the National Action Plan missing the broader human rights based approach in addressing the issues of attacks against persons with albinism. It is worth noting that at the time of the study the National Action Plan was under review to address the aforementioned gaps.

2.6 Nigeria Action Plan on Albinism.

Although Nigeria has not developed a National Action Plan, but it is the only country in Africa that has responded to the attacks against persons with albinism through a stand alone policy framework, National Policy on Albinism adopted in 2012 by government.⁸³ The multifaceted needs approach demonstrated the commitment by the government on the significance of the attacks and the need to have issues of persons with albinism specifically championed through a policy. The policy vision is to create a society where the survival, participation, protection and development of Persons with Albinism are adequately guaranteed. The policy goal is to guarantee

⁸¹ Club of Mozambique ‘Teenager with albinism killed for body parts’ Club of Mozambique 30 May 2022 available at <https://clubofmozambique.com/news/teenager-with-albinism-killed-for-body-parts-in-mogovolas-mozambique-217846/> (accessed 2 June 2022)

⁸² Republic Of Mozambique (2015) ‘Multi-Sectorial Action Plan to Address the Issue of the Protection of Persons Albinism’ Ministry of Justice, Constitutional and Religious Affairs.

⁸³ Nigeria Government (2012) National Policy on Albinism available at <http://albinofoundation.org/wp-content/uploads/2017/04/National-Policy-on-Albinism.pdf> (accessed 30 June 2022)

the welfare and rights of persons with albinism. Particular of interest is one of the policy objective of the National Action Plan that focuses on participation, as it aim to secure institutions of persons with albinism participation in the interventions and partnerships in addressing the challenges they face and their specific needs.

The development process was also led by government with close and active participation of The Albino Foundation (TAF) which is the main civil society organisation of persons with albinism in Nigeria. The main aim of TAF is to advocate for the inclusion, respect and recognition of persons with albinism in all spheres of life.⁸⁴ Although the TAF has registered about 12 cases of attacks it is observed that the majority of persons with albinism still face severe discrimination, stereotypes and about 41 % experience psychological or mental health problems.⁸⁵ Similarly, a 2018 survey report has revealed that (96%) of persons with albinism in Nigeria experience some form of discrimination and stigma, with (54%) of women with albinism experiencing more societal discrimination even within family or friends' circles than men with albinism (46%).⁸⁶

The author agrees with the criticism that the stand alone policy approach from the main disability policies may lead to dealing with the attacks in silos and relatively low budgetary commitments by government. Nevertheless, there has been noticeable steps, through civil society organisations like TAF, who have utilised the policy as a tool for high-level engagement with government and development partners that has contributed to achievement of the AU plan of action. There has also been regulatory and institutional improvement in promoting and protecting persons with albinism in areas such as education, health and political participation.⁸⁷ The approach of developing a policy has also helped to give legitimate power to the policy document and legitimate expectation among persons with albinism as a tool to provide guidance on mainstreaming albinism in other sector policies.

⁸⁴ The Albino Foundation available at <https://albinofoundation.org/wp> (accessed 27 June 2022)

⁸⁵ O Jaiyeola (2022) 'Living in Nigeria tough, we suffer discrimination – Albinos' available at <https://punchng.com/living-in-nigeria-tough-we-suffer-discrimination-albinos/> (accessed 21 June 2022)

⁸⁶ The Albino Foundation (2018) 'The Demographic, Geographic and Socioeconomic of survey of persons with albinism in Nigeria available at [Baseline-Survey-on-PWAs-in-6-states-and-FCT.pdf \(albinofoundation.org\)](#) (2 June 2022)

⁸⁷ Government of Nigeria (n 83 above) 20

2.7 Uganda National Action Plan for Persons with Albinism.

In Uganda, a report on 'Enhancing Equality and Countering Discrimination against Persons with Albinism' revealed numerous violations of human rights against persons with albinism in the country. The report highlighted that persons with albinism are facing discrimination as a result of myths, beliefs and superstitions in society. Women with albinism and girls face double discrimination as they are also sexually assaulted. There is exclusion of persons with albinism in government programmes and social services like education, health and safety net and lack of accurate official data on persons with albinism. Thus, the National Coordinating Committee (NCC) was established to oversee the development processes of developing a National Action Plan and consisted of relevant ministries, departments, agencies and representatives of organisations of persons with albinism. The Committee was working in collaboration with the National Council of Persons with Disabilities (NCPD), the council for all organisations of persons with disabilities established under the Persons with Disability Act 2019, to promote and protect the rights of persons with disabilities, including those with albinism. Thus, from the onset persons with albinism were included among the broader disability movement in Uganda.

Viewed during the consultation processes, the role of organisations of persons with albinism was to ensure that they participated and influenced the selection of the priorities, strategies and activities for the National Action Plan. Another unique element of the Uganda National Action Plan is that it has specifically included objectives firstly, on participation of persons with albinism from the initial stages of all plans which are relevant to them and subsequently consulted during the implementation and monitoring of the plans. Secondly, on independence of persons with albinism to grow, develop and live independent life with dignity that will enable their effective participate in society. Finally, self-advocacy through building the self-confidence of persons with albinism and strengthening measures to facilitate their participation and amplify their voices in society.⁸⁸

The Regional Action Plan report of 2021, has provided progress by various governments in terms of the specific pillars and measures that have been adopted to end the human rights violations

⁸⁸ Republic of Uganda (2022) National Action Plan for Persons with Albinism 2020-2025

against persons with albinism. The scores in the report are only a representation of the number of measures governments have advanced to end the attacks during the reporting period, therefore they may not directly represents any recent measures adopted by governments across africa. According the the Regional Action Plan report, Malawi has made remarkable progress in ensuring that it adopts effective measures in ending the attacks. For instance, under the Prevention measures Malawi has scored 39,54%, Tanzania 26,13%, Uganda 19,88%, Mozambique 5.25%, Eswatini 4.84% and Ghana 4.17%. In term of protection measures Tanzania has scored 17.35%, Malawi 16.65%, Mozambique 14.40%, Eswatini 1.5%, Senegal 1.6 and Mauritius, Ivory Cost, Lesotho, Liberia, all at 1%. Under the accountability measures Malawi scored (15%), Tanzania (12%) and South Africa (3,17%), Ghana (1.67%), Zambia (1.5%) and Cameroon (1.17%), lastly, unders Equality and Non-Discrimination Malawi scored (40.16%), Nigeria (42.80%) and Tanzania (52.15%). Overall, over the period of 2017-21 Malawi has performed very well 28% towards implementation of the AU plan of Action pillars in ensuring that it adopted action and effective measures at different level in ending the attack, 23 % Tanzania and 19% Nigeria.⁸⁹

2.8 Conclusion

This chapter sought to examine the genesis and establishment of National Action Plans as tools for addressing the systematic violations of human rights and dominant discrimination narrative against persons with albinism. The discussion shows the success and gaps of National Action Plans in shaping the individual and group aspirations of persons with albinism and how the albinism-disability discourse informed the mainstream of albinism within the broader disability movement. Governments' political will and commitment created a platform for connections of various stakeholder to provide input during the drafting of National Action Plan. It shows the various approaches taken by government to ensure effective participation and representation of persons with albinism in the process of developing National Action Plans. It highlights the human rights violations persons with albinism are facing and the needed urgent response by governments. The chapter located participation and involvement of persons with albinism in the development of National Action Plans through their associations as a healing solution to endeavour their inclusion.

⁸⁹ Toumi, Ero & Tawata (n 72 above) 17

However, it also revealed the failure to fully represent persons with albinism during the implementation particularly, consultation was accessible mostly to national level members of the associations, but continued to demand their full involvement in the local level implementation phases. It is significant that persons with albinism are included at all levels of the consultation process and implementation of National Action Plans to ensure governments comply with human rights standards. Such representation will help to amplify their voice and facilitate the removal of barriers due to inaccessible service and environments in all the measures put in place by governments through National Action Plans for their enjoyment of freedoms.

The following chapter three will provide the international and national human rights instruments that support the protection of human rights of persons with albinism.

CHAPTER THREE: LINKAGE OF INTERNATIONAL, REGIONAL AND NATIONAL LEGAL INSTRUMENTS IN PROGRAMMING NATIONAL ACTION PLANS ON PERSONS WITH ALBINISM.

3.1 Introduction

Malawi has signed and ratified several United Nations and African Union human rights instruments aimed at promoting and protecting human rights, including the rights of persons with disabilities. These treaties have provisions that guarantee the rights of persons with disabilities and require state to report on their compliance with the treaties. The research looks at how these international human rights instrument forms an important role of promoting rights of persons with albinism, gaurantee right to security, liberty, participation in community life, independent living and protection from all forms of discrimination.

This chapter highlights how the various international legal instruments protect and promote the human rights and dignity of persons with albinism. It examines international human rights provisions that enable or limit opportunities for protection and promotion of human rights of persons with albinism. It explores ways on how the legal instruments interpretations shapes the framing of National Action Plan focus areas based on popular perspectives of albinism as a disability by majority of persons with albinism themselves and governments. But also, the benefit of utilizing the international human rights frameworks in developing National Action Plan pillars.

3.2 Access to affordable and quality healthcare and education services

The National Action Plan recognises the need to improve access to affordable and quality health care for persons with albinism as one of its pillars. In particular access to health facilities, sun screen lotion and assistive devices that may facilitate their enjoyment of freedoms. It also include the need for rehabilitation services and counseling for the victims of attacks.

In view of the right to access health care and ensuring privacy, article 25 of CRPD on health (d) provides that the duty of the health professional is to ensure dignity and autonomy of persons with disabilities to obtain free and informed consent and (f) prohibits discrimination to health care

services on the basis of disability.⁹⁰ While article 22 emphasizes the need for State to ensure privacy of persons, their health and rehabilitation information.⁹¹ Therefore, the National Action Plan provides access to health services that are responsive to the particular needs of persons with albinism that may facilitate their independence. As interpreted by the UN Committee on Economic Social Culture Rights (Committee on ESCR) General Comment **No 14** the State failure to put measures in laws and policies on right to health or treatment violate its obligation to respect health right for vulnerable or marginalised due to their disability.⁹²

It is worth, noting that the attacks have disproportionately affected the independent living and inclusion of persons with albinism, where majority of them failed to access services and some of their needs are not fully included in the albinism response strategies. Some of these factors have posed a challenge to their participate in social economic activities, lack of housing, inaccessible information, high transport to access health or education services and lack of personal assistants for fear of being attacked. General Comment **No 5**, defines independent living as the means by which individuals exercise their personal autonomy and choices over their life decisions. While inclusion in community means persons with disabilities live a full social life, improved access services like health will facilitate their participation in all spheres.⁹³ This is also underlined in resolution 106 on article 19 of CRPD that called for the State to put effective measure to facilitate independent living and inclusion in community of persons with disabilities. Article 19 of the CRPD provides a foundation for the protection and promotion of rights of persons with albinism. In particular, the article provides an opportunity for identifying specific measures that will ensure full inclusion of persons with albinism in community and their independent living as understood within the context of ritual attacks, discrimination, stigma, harmful practices and witchcraft accusations in the context of Africa. What it means is that persons with albinism right to independent living and inclusion in community has been violated by the physical attacks due to their skin condition, discrimination and stigma that has led to their oppression in the community. Therefore, persons

⁹⁰ CRPD (n 13 above) art 25

⁹¹ CRPD (n 13 above) art 22

⁹² Committee on Economic, Social and Cultural Rights “General Comment No 14 on Right to the highest attainable Standard of Health” UN Doc ESCR/C/GC/14 (ESCR General Comment No 14) of 11 August 2000 at para 22, 51 & 52 available at <https://docstore.ohchr.org/> (accessed 15 August 2022)

⁹³ United Nations Committee on Rights of Persons with Disabilities ‘General Comment No 5 on Living independently and being Included in Community’ UN Doc CRPD/C/GC/5 (CRPD General Comment No 5) of 27 October 2017 para 16

with albinism freedom of movement, personal relationship, daily routines, health, education and social life have been denied. Fear of being killed or abducted, has led to displacement and lack of control of day-to-day decision by persons with albinism and their family members as the group is constantly living in fear and threats to their life. General Comment No 1 of the CRPD Committee advised that the ability to make choices and live independently is critical to create community support mechanism for persons with disabilities to exercise their legal capacity.⁹⁴

The emphasis is that accessibility is the core principle of the CRPD as it cut across several articles of the Convention and in the absence of accessible services throughout implementation process of National Action Plan, it would be difficult to have equalisation of opportunities for persons with disabilities to live independently and participate fully in community. The CRPD article 3 general principle of accessibility,⁹⁵ as also provided in CRPD article 9 on accessibility talks about persons with disabilities living independently and fully participate in all aspect of life. It further, call upon states to eliminate all barriers to access to physical environment, transportation, information and communication technologies. Article 9 also prohibits discrimination in accessing premises and services on the basis of disability, which include sexual reproductive health services. It further provides the duty for the State to provide for reasonable accommodation to facilitate access to services and places by persons with disabilities.⁹⁶ Thus, for any persons with disabilities (like those with albinism) accessibility is a critical precondition for enjoyment of all human rights and fundamental freedoms.⁹⁷ The lack of accessible essential services, rehabilitation, assistive devices and information on National Action Plan processes on the basis of their disability has contributed to discriminatory practices that further restrict self-representation of persons with albinism in various activities, such as the human rights awareness campaign and tracking National Action Plan activities.

The National Action Plan has also align the pillars with the Malawi Vision 2063 (MW2063) has featured marginalised groups which include persons with albinism notwithstanding evident

⁹⁴ Committee on Rights of Persons with Disabilities “General Comment No 1 on Equal Recognition before the law” UN Doc CRPD/C/GC/1 (CRPD General Comment No 1) of 11 May 2014 at para 11, 45

⁹⁵ CRPD (n 13 above) art 3

⁹⁶ CRPD (n 13 above) art 9

⁹⁷ United Nations Toolkit on Disability in Africa, Accessibility, Division for Social Policy Development available at <https://www.un.org/esa/socdev/documents/disability/Toolkit/Intro-UN-CRPD.pdf> (accessed 12 June 2022)

inequalities in access to basic services and opportunities between persons with disabilities and the non-disabled that exist in Malawi. The Vision guarantees the provision and accessibility of quality education, skills development and decent work opportunities. One of the enablers of the Vision is effective governance systems and institutions, it talks about strict adherence to the rule of law. The Vision states that it shall ensure that human rights are respected, protected and realized in delivery of public services. It further promotes inclusivity, accessibility of essential services for marginalized groups and their active participants in the design and implementation of development plans. The Vision has put emphasis on ensuring that the rights and legitimate interests of the minority are recognized, respected and protected in accordance with the Constitution.⁹⁸

At the domestic level, the Constitution of Malawi does recognize the right to health as a principle in section 13 on healthcare, which provides for provision of adequate health care based on the needs of the Malawian society, regardless of status. Similarly, the Constitution provides in (article 19) dignity of all persons and section 20 prohibits discrimination and that all persons are, under any law, guaranteed equal and effective protection against discrimination on grounds of race, colour, sex, language, religion, political, disability, birth or other status or condition.⁹⁹ In addition, the Disability Act has expressly recognised the right to healthcare services for Persons with Disabilities in section 6(1) that call upon the Government to provide appropriate health care services designed to minimize and prevent the occurrence of more disabilities.¹⁰⁰ Whilst section 7 prohibits discrimination in accessing healthcare services.¹⁰¹

Notwithstanding the above enabling provisions with specific regard to persons with disabilities and access to health services, generally they are still facing challenges in accessing health services. Some of the limits that persons with albinism are experiencing in accessing health services in Malawi includes, Firstly, there is increased environmental barriers to access health such as lack of assistive devices, rehabilitation services and limited finance resource. There is still existing systematic exclusion and discrimination on how persons with disabilities access health services in

⁹⁸ Nation Planning Commission ‘Malawi Vision 2063’ 2000 30

⁹⁹ The Constitution of Republic of Malawi arts 13, 19 & 20

¹⁰⁰ Disability Act sec 6(1)

¹⁰¹ Disability Act Sec 7

Malawi.¹⁰² The researcher has observed the growing concerns on negative attitudes by health workers that contribute to stigma and discriminatory services towards persons with albinism. These stereotype behaviors may range from the lack of reasonable accommodation support, not given a priority or preferential treatment on long queues and derogatory terminologies. Secondly, majority of health facilities are not accessible to persons with disabilities with only 95% accessing government health facilities for their primary health care and 57% of the health facilities are accessible to persons with disabilities who use a wheelchair for their mobility, 24% medical staff had received no disability related trainings to cater for the communication needs of persons with disabilities in their health facilities and only 22% had access to assistive devices to support their access to health services.¹⁰³ For instant, Standing Voice report on skin skin cancer prevention program for persons with albinism has reveals that only 62 % of persons with albinism access dermatology services and 48% access the service in government facilities. The report has shwn limited knowledge on albinism by health workers and knowledge gap among persons with albinism on the use of sun screen lotion, with over 55% of persons with albinism applying sunscreen during the night.¹⁰⁴ Additionally, only 89% of persons with albinism are regularly receiving and use sunscreen, access skin cancer surgery and receive civic education on understanding albinism.¹⁰⁵ Thirdly, long distance to health facilities limits persons with albinism to access health services. High cost of transport, need for a personal assistant, lack of assistive devices such as prescribed glasses, magnifying glasses. As such, it can be argued that these hidden additional costs double the burden and make the services not affordable for persons with albinism, hence their right to health cannot be fully guaranteed.

Despite of the numerous challenges that limits persons with disabilities accessing to health services, there is still need for persons with disabilities aspirations as provided for in the CRPD be achieved as a way of alleviating such burdens. As highlighted by other authors, although the

¹⁰² Eide AH, Loeb ME, Nhwatiwa S, Munthali A, Ngulube TJ & Rooy G (2011) 'Living Condition Among People with Disabilities in developing Countries' in Disability and Poverty; A Global Challenge 66 available at <https://library.oapen.org/bitstream/handle/20.500.12657/31471/627775.pdf?sequence=1> accessed (4 June 2022)

¹⁰³ Malawi Human Rights Commission report (2018) 'Study on Access to services by persons with disabilities in Malawi' UNDP 68 -73

¹⁰⁴ Kilisun and Association of Persons with Albinism in Malawi (2017) 'Final report on Assessment on the situation of accessibility and availability of sunscreen lotion for persons with albinism in Malawi'

¹⁰⁵ Standing Voice Report 'Reported on National Skin Cancer Prevention Program for persons with albinism' 2019 available at <http://www.standingvoice.org/> (accessed 4 March 2022)

CRPD is enriched in the universality of human rights, it is important that persons with disabilities are not seen as victims but given the power to demand their right to health. Like the case in Malawi, persons with albinism feel that preferential treatment and priority consideration in health facilities would improve their access to health service. By getting the health service quicker, persons with albinism have more time to travel safely home, despite the long distances. The health care system in Malawi should consider the circumstances of patients with albinism attending the health facility and take into account the disproportionate burden they go through to get to the health facility. There is also a need to eliminate the negative attitude of health workers so that may have a significant influence on aspects of care and disability support services.

3.4 Human Rights Monitoring, reporting and Research

The National Action Plan focuses on the need to enforce the implementation of international human rights instruments for effective protection of persons with albinism. It looks at the need to gather adequate data on attacks and assessing human rights status of persons with albinism. In doing so, National Action Plan reaffirms the CRPD Article 4 which states the need to adopt all appropriate legislative, administrative and other measures for the implementation of the rights.¹⁰⁶ Similarly, article 1 of the Universal Declaration of Human Rights (Universal Declaration) states that all human beings are born free and equal in dignity and rights and article 3 guarantees that everyone has the right to life, liberty and security. Article 5 prohibits all forms of torture, cruel, inhumane and degrading treatment.¹⁰⁷ Thus the continued ritual attacks, abductions and trafficking of body part of persons with albinism violates the rights championed under the National Action Plan. There is a need to strengthen the human right monitoring systems to prevent more attacks and ensure compliance with human rights standards on the services that are provide to persons with albinism.

The African Union(AU) has made significant efforts through several resolutions and actions to ensure the protection and promotion of human rights of persons with albinism in the African region. The African Commission on Human and Peoples' Rights adopted a resolution ACHPR 263 in 2013 which raised deep concerned on systematic and widespread attacks, discrimination, stigma

¹⁰⁶ CRPD (n 13) arts 1 & 4

¹⁰⁷ Adopted by the United Nations (UN) General Assembly A/RES/217A(III) on 10 December 1966 and entered into force 23 March 1976 arts 1, 3 & 5 available at <https://www.ohchr.org/EN/UDHR> (accessed 20 March 2022)

and social exclusion directed at persons with albinism.¹⁰⁸ and resolution 373 which endorsed the Regional Action Plan on Albinism in Africa (2012-2021), which urges governments to take prevention, protection, accountability, equality and non-discrimination measures to address the attacks against persons with albinism.¹⁰⁹

In 2018, the African Union adopted the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (Disability Protocol) which has included issues of ritual killings and harmful practices that fuel attacks against persons with albinism in the context of African.¹¹⁰ The Disability Protocol was adopted in accordance with article 66 of the African Charter which states that special protocols may be established to supplement the African Charter where it is deemed necessary by state parties. The Preamble has also reaffirmed article 18(4) provision of the African Charter on Human and Peoples Rights (African Charter),¹¹¹ on the need for persons with disabilities to have the right to special measures of protection in keeping with their physical and moral needs. With regards to the attacks against persons with albinism first, article 1 of the Disability Protocol has defined harmful practices as traditional, religious, cultural and superstitious attitudes, behaviours and practices that perpetuate discrimination denial of human rights. Second, discrimination on the basis of disabilities is defined as distinction, exclusion and restriction based on disability which has an impairing effect and nullify the enjoyment of rights. Third, the Disability Protocol has innovatively reformulated definition of ritual killings as any killing of a persons motivated by beliefs for the purpose of using body parts for medicinal use, supernatural powers, prosperity and protecting the killer.¹¹² The Disability Protocol in article 7(2)(e) states that States Parties should take effective measures to ensure that it has policies that promote enjoyment of legal capacity by persons with disabilities.¹¹³ These provisions are unique

¹⁰⁸ African Commission on Human and Peoples 'Rights ACHPR/Res.263(LIV)2013 '263 Resolution on the prevention on attacks and discrimination against persons with albinism' (2013) available at [African Commission on Human and Peoples' Rights Sessions \(achpr.org\)](https://www.achpr.org/) (accessed 21 August 2022)

¹⁰⁹ African Commission on Human and Peoples 'Rights ACHPR/Res.373(LX)2017 '373 Resolution on the Regional Action Plan on Albinism in Africa (2017-2021)' (2017) available at [African Commission on Human and Peoples' Rights Sessions \(achpr.org\)](https://www.achpr.org/) (accessed 12 July 2022)

¹¹⁰ African Union (2018) Protocol to the African Charter on Human and Peoples 'Rights on the Rights of Persons with Disabilities in Africa available at [36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf \(au.int\)](https://www.au.int/) (accessed 8 July 2022)

¹¹¹ Adopted by the African Union (AU) General Assembly on 1 June 1981 and entered into force 21 October 1986

¹¹² Disability Protocol (n 110 above) art 1

¹¹³ Disability Protocol (n 110 above) art 7(2)(e)

to the Disability Protocol as issues of ritual killings and harmful practices are not defined in article 2 on definition in the CRPD. It is argued that the approach taken by the Disability Protocol is aimed at addressing the human rights violation as experienced by persons with disabilities in Africa. The Disability Protocol considered and exposes the specific practices and traditions that led to violation of human rights by the communities against persons with albinism that are particular to African context.¹¹⁴ Although the Disability Protocol is yet to be in force, the researcher support the views that the Disability Protocol will play a significant role in ending the attacks and supporting the impenetation of the National Action Plan once is forced.

Despite having the CRPD and the African Charter as treaties that have been ratified by majority of African governments, it is worth noting that there is still marginalisation and increased violation of human rights against persons with albinism across Africa. The general provision of the African human rights instruments has not adequately protected and promoted disability rights. It is argued that specific regional treaty like the Disability Protocol are helpful to address concerns and provides opportunities for solution to persons with disabilities in Africa that are not sufficiently addressed in international instruments. Its further noted that States Parties to the Charter would be more committed to comply to the obligation in African regional instrument in terms of enforcement and adopting legislative or administrative measures.¹¹⁵ The Disability Protocol recognises important aspect of human rights and different layers of identity for persons with albinism within the disability dscourse which is critical when formulating National Action Plan focus areas of interventions. The unique aspect of gender, age and sexual orientation experiences of persons with albinism has been neglected in National Action Plan, hence the need for a strong lobbying and advocating by the albinism movement during conslutation process for National Action Plan to consider these key aspects. The United Nations independent expert on the enjoyment of rights by persons with albinism acknowledges that although progress has been made towards ending the attacks by governments, the situation remain a serious concern due to

¹¹⁴ S Kamga ‘A call to the Protocol of African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities’ (2013) African Journal of International and Comparative Law Vol 23, issue 2 29 available at <https://www.eupublishing.com/doi/full/10.3366/ajicl.2013.0060> (accessed on 12 January 2022)

¹¹⁵ F Abbay ‘An Evaluation of Disability Human Rights under the African Regional Human Rights System’ (2015) African Journal of International and Comparative Law Vol 23, issue 3 at 499 available at <https://www.eupublishing.com/doi/pdfplus/10.3366/ajicl.2015.0132> (accessed 12 August 2022)

intersectional discrimination and unwillingness of State to fulfil their human rights obligation.¹¹⁶ Therefore, it is critical that the approaches taken by government in developing National Action Plans have taken a human rights approach to eliminate any barrier to realization of their freedoms.

3.5 Legislation, security and Administration of justice

Malawi, signed the CRPD in 2007 and ratified it on the 27 August 2009. It has shown commitment to comply to the general principles and spirit of the CRPD as the primary instrument promoting and protecting the rights of persons with disabilities, including those with albinism. Article 1 of CRPD provide the definition of persons with disabilities as including

‘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.’¹¹⁷

In the Preamble it has recognised disability as evolving concept and diversity of persons with disabilities. The term ‘reasonable accommodation’ as defined in CRPD article 2 is to provide appropriate modification and adjustments to ensure persons with disabilities exercise their rights equally. Additionally, General Comment No 2 of the CRPD Committee, emphasises that individual choices, dignity and autonomy can be achieved by means of reasonable accommodation and that implementation of accessibility by the State is unconditional.¹¹⁸ Thus, for persons with albinism such choices have being grossly violated and denied by the attacks.

At national level the Malawi Constitution of Republic of Malawi 1994, provides the foundation upon which human rights of persons with disabilities are promoted and protected as it provides for respect for and observance of human rights. The Constitution is the supreme law and governs the interpretation of all laws. The Constitution in article 5 talks about constitutionality of legislation in that any law that is inconsistent with the Constitution, if not such law shall be invalid. Thus, article 10 on application states that the provisions of the Constitution are regarded as the supreme

¹¹⁶ United Nation ‘First statement from Ms. Muluka Anne Miti-Drummond, UN Independent Expert on Albinism’ available at [OHCHR | First statement from Ms. Muluka Anne Miti-Drummond, UN Independent Expert on Albinism](#) (accessed on 9 July 2022)

¹¹⁷ CRPD (n 13 above)

¹¹⁸ Committee on Rights of Persons with Disabilities “General Comment No 2 on Article 9 Accessibility” UN Doc CRPD /C/GC/2 (CRPD General Comment No 2) of 11 May 2014 at para 26 8

arbiter and as ultimate source of authority.¹¹⁹ The Constitution has also provision on how the international human rights instruments entered into force by Malawi shall form part of the national legislations. Under Section 211 international law, the Constitution provides for legal status of treaties that (1) any international agreement ratified by an Act of Parliament shall form part of the domestic law and (2) agreements entered into before the start of the Constitution and binding shall form part of the law unless the agreement otherwise lapses. In terms of Customary international law, the Constitution states that unless inconsistent with this it that law shall form part of the national legislation.¹²⁰ The Constitution in the Preamble has the motive of seeking to guarantee the welfare and development of all the people of Malawi, national harmony and peaceful international relations. In article 12 on the Constitution principles (d) on inherent dignity and worth of each human it calls upon the State and all persons to recognize and protect human rights of all individuals, groups and minorities, which includes persons with disabilities. Furthermore, (e) it provides for all persons have equal status before the law.¹²¹ Additionally, section 13(g) directs for progressive implementation of policies aimed at promoting welfare, quality of life, dignity and meaningful participation of persons with disabilities in all spheres of life in Malawi. Section 24 on rights of women, it emphasis the need for full and equal protection by the law for women in particular right not to be discriminated against on the basis of their gender, 1(a) accorded same rights as men, equal capacity and equal right in decision making.¹²² Section 41(1) on access to justice and legal remedies provide that every person shall have a right to recognition as a person before the law.¹²³ and 45(g) prohibits derogatory even in times of public emergency with regards to the right to equality and recognition before the law.¹²⁴

3.5.1 The Disability Act

The Disability Act of 2012 (Disability Act) was adopted by Malawi government as a means of domesticating the CRPD and implementation of its obligations in national legislation.¹²⁵ With regards to programme development, the government has developed the National Disability

¹¹⁹ Constitution of Malawi art 5 & 10

¹²⁰ n 119 above, art 211

¹²¹ n 119 above, art 12 (d) & (e)

¹²² n 119 above, art 24(1)(a)

¹²³ n 119 above, art 41(1)

¹²⁴ n 119 above, art 45(g)

¹²⁵ Disability Act 2012

Mainstreaming Strategy and Implementation plan 2018-2023, as a tool of ensuring needs of persons with disabilities are included in sector plans.¹²⁶ The overall aim of the Disability Act provisions is to ensure equalization of opportunities for persons with disabilities by protecting and promoting their human rights. The Disability Act defines equalization of opportunities as a means through which various services, society, environment and information are made accessible and available to all persons with disabilities. In particular, it provides for penalties where the rights are violated.¹²⁷ In section 3, the Disability Act calls upon the State to adopt policies and legislation that promotes equalization of opportunities for persons with disabilities as a means of ensuring promotion and protection of their rights, but also to ensure their dignity and wellbeing in all aspect of life.¹²⁸ The Disability Act provisions guarantees persons with disabilities enjoyment of a wide range of rights such as rights to healthcare services, information and communication services, education and training, work and employment, social protection, freedom of association and representation, participation in political and public life, participation cultural, decent housing, economic empowerment, and research and information.¹²⁹

3.5.2 The National Policy on Equalisation of Opportunities of persons with disabilities.

In 2006, the National Policy on Equalisation of Opportunities for Persons with Disabilities (Disability Policy) was adopted which has incorporated the Constitutional and CRPD provisions and declarations on disability. The overall aim of the Disability Policy is to promote the rights of people with disabilities to enable them play a full and participatory role in society; and further to ensure that concrete steps are taken for people with disabilities to access the same fundamental rights and responsibilities as any other Malawian citizen. The policy describes numerous struggles faced by persons with disabilities for their survival in the mainstream society that limit their access to enjoyment of fundamental economic, social, cultural and political rights.¹³⁰ The policy framework adoptes a human rights and development orientation to disability that defines and

¹²⁶ National Disability Mainstreaming Strategy and Implementation plan 2018-2023 available at http://www.rodra.co.za/images/countries/malawi/policies/National%20Disability%20Mainstreaming%20Strategy_FINAL%20AND%20PRINTED-2.pdf (accessed 23 August 2022)

¹²⁷ n 125 above, part IV

¹²⁸ n 125 above, sec 3

¹²⁹ n 125 above, part IV

¹³⁰ Malawi Government (2006) National policy on equalisation of opportunities for persons with disabilities at 8

promotes disability as a social construct to achieve full equalization and participation of persons with disabilities

The Education Act of 2013 states that the Minister responsible for education to promote education without discrimination on various grounds including disability.¹³¹ The Employment Act of 2000 section 5 prohibits discrimination against any employee or prospective employee on various grounds including disability in respect of recruitment, training, promotion, terms and conditions of contract of employment and in all aspects of employment. It further, calls for special measure to achieve equality in employment;¹³² equal remuneration for equal work without discrimination;¹³³ and prohibits dismissal of any employee on the ground of disability.¹³⁴ The Child Care, Protection and Justice Act of 2010 the Act has provided for the need to recognise children with disabilities. Thus, Section 72 provides that local government authority shall keep a register of children with disabilities within its area of jurisdiction and give assistance to them whenever possible in order to enable those children grow up with dignity among other children and to develop their potential and self-reliance.¹³⁵ This is in line with CRPD article 7 on children with disabilities that calls for disability and age appropriate measures¹³⁶ by government and Disability Protocol article 7(f) which provide for right to hold legal document to enable the children to exercise their legal capacity.¹³⁷ Further, the Child Care, Protection and Justice Act provides that the proceedings of a child justice court shall be informal and in particular the presiding officer shall ensure that children with disabilities are accorded assistance to meet their special needs where necessary.¹³⁸

There is also steady progress in the realisation of human rights such as right to health, education and political participation among persons with albinism. The specific treaties like the Disability Protocol have also been useful in prohibiting discrimination and encouraging equal participation of persons with albinism in human rights instruments. Hence the research support the proposition

¹³¹ Education Act 2013 Sec 4(1)

¹³² Employment Act 2000 Sec 5(2)

¹³³ n 132, Sec 6(1)

¹³⁴ n 132, Sec 57(a)

¹³⁵ Child Care, Protection and Justice Act 2010 sec 72

¹³⁶ CRPD (n 13 above) art 7

¹³⁷ Disability Protocol (n110 above) art 7(f)

¹³⁸ n 135 above, sec 145(d)

to call for urgent appointment of the AU albinism envoy who will contribute significantly to the coordination of National Action Plan and engagement with States Parties to demand accountability from the government on various human rights violations for the group. The domestic laws such as the Constitution and Disability Act have also domesticated and implemented the provisions of the CRPD as evidenced by the modification of laws, adoption of new legislation and ensuring implementation of effective measures to end the attacks through National Action Plan on albinism.

The research exposes high levels of cruel and inhumane treatment by the police in handling cases of persons with albinism that is contributing to poor investigation and delayed access to justice. According to a report of an investigation into the death of Mr. Buleya Lule in police custody who until his death was a key suspect in the criminal case of abduction of Goodson Fanizo a child with albinism who was abducted and killed. The Malawi Human rights Commission report showed that there was brutal, cruel and inhuman treatment by the police officer on the suspects and recommend for commencement of criminal proceedings of all police officers who were alleged to be involved in the circumstance that led to the death of the suspect in police custody. The victim was tortured to death whilst in Police custody arbitrarily deprived the victim right to life as guaranteed in international human rights instruments.¹³⁹ In another criminal case of murder of Ian Muhama young man with albinism, police investigators acted with gross negligence when examining the victim's body and gather evidence, there was unprofessional, mismanagement and unethical conduct on how they were dealing with remains of the victim.¹⁴⁰ These cases are not isolated events as they illustrates a bigger problem of institutionalized discrimination, biases and inadequacies among police officers. The Joint docket tracing exercise report for cases of persons with albinism in Malawi by the Malawi police service, the Malawi Human rights Commission Buleya Lule report and the report on a research study on the Markets and criminal networks for body parts of people with albinism by the European Union have conclusive evidence of names of police officers suspected to be involved directly or indirectly in the crimes against persons with albinism either through missing of files, police officers holding on investigation file and misplacing evidences.

¹³⁹ Malawi Human Rights Commission (2019) A Report of An Investigation Into The Death Of Mr. Buleya Lule in Police Custody, Hrc/05/03/234

¹⁴⁰ Malawi Police Service (2021) Inquiry Report into The Alleged Mishandling by Limbe Police Station of The Missing, Death and Burial of Ian Muhama, A Person with Albinism

This renews public concerns on law enforcement officer's response to the investigation of the attacks and undermines the confidence in the fairness of justice and ability of the criminal justice system in Malawi in dealing with these violations of human rights. It gives legitimate attention which have not been fully explored in this research relating to the possible links of the police officer's involvement in the cases or past cases as shown by a pattern of impunity when the victim is a person with albinism or cases relates to albinism. Similar, views were observed by the Human Rights Council Advisory Committee which noticed the increased tendency of delayed investigation and some law enforcement and judiciary authorities sharing the superstitious beliefs about persons with albinism.¹⁴¹ Therefore, unless there is an independent investigation on the police officers suspected to be involved in the criminal activities, persons with albinism will continue to face challenges in trusting the criminal justice system in Malawi. Such acts by the police officers would be in contravention with General Comment No 6 paragraph 14 on equality before the law, whereby the Committee prohibits discrimination against persons with disabilities by judiciary and law enforcement officers in the administration of justice.¹⁴²

In Malawi, despite the United Nations Independent expert on albinism call for accountability by State to ensure effective, speedy and impartial investigation, prosecution and appropriate remedies to victims of attacks.¹⁴³ The alleged involvement of the police officer as law enforcement agency, has sustained lack of speedy outcomes in the criminal investigation and prosecution of crimes against persons with albinism. Comparable observation were also made in General Comment No 36 of ICCPR article 6 right to life, where States Parties are urgently called to respond to adopt special measure to protect persons who are in vulnerable situation, placed at risk of any form of threat or pattern of violence.¹⁴⁴ The professed involvement of police officers and delayed investigation demonstrates government let-down to provide adequate and urgent protection to

¹⁴¹Human Rights Council, Report of the Human Rights Council Advisory Committee on the Study on the Situation of Human Rights of Persons Living with Albinism, U.N. Doc. A/HRC/28/75 at 30

¹⁴² Committee on Rights of Persons with Disabilities "General Comment No 6 on Equality and Non-Discrimination" UN Doc CRPD/C/GC/6 (CRPD General Comment No 6) of 26 April 2018 at paras 14 & 18

¹⁴³ United Nations General Assembly – Human Rights Council (2015) 'Independent Expert on the Enjoyment of Human Rights by Persons 'A/HRC/RES/28/L.10 paras 2 & 13

¹⁴⁴ United Nations Human Rights Committee 'General Comment No 36 on ICCPR article 6 right to life' (HRC General Comment No 36) of 3 September 2019 available at <https://www.refworld.org/publisher/HRC.html> (accessed 5 March 2022)

persons with albinism who experience pre-existing pattern of threats and attacks across Malawi. Thus, the government fails to comply with the obligations under article 6 of ICCPR to promptly, independently, thoroughly and transparently investigate human rights violation against persons with albinism.¹⁴⁵ Furthermore, CRPD article 10 reaffirms that every human being has the right to life and State should take measures to ensure enjoyment of such right on an equal basis with other. In addition, article 16(1) underpins the protection of persons with disabilities from all forms of violence (5) and end impunity by identifying, investigating and prosecuting any instance of abuse against persons with disabilities.¹⁴⁶ However, the study shows that the government is taking longer to investigate and prosecute cases, with cases taking an average of more than three years to be completed. Whereby other commentators have also argued that for the majority of people in Africa, the law is inaccessible due to failure by law enforcement agencies to investigate human rights violations and delays in courts.¹⁴⁷

3.6 Conclusion

The chapter examines the legal instruments conformity with various activities and focus areas of the National Action Plan. With specific attention paid to provisions that are framed to support human rights of persons with albinism and make them most visible. It strongly recommends the approach of focusing on legal reforms and budgetary investment by the Malawi government, as demonstration of its principal responsibility of ensuring it adopt protection and promotion measures of human rights for persons with albinism. The government should ensure that such legal reforms should address both the processes and outcomes of justice system. Particularly, consider issues of reasonable accommodation within the justice system to ensure that the system is capacitated with comprehensive judicial training programmes on investigation and prosecution of cases of attacks on persons with albinism and general disability rights. It is arguable that National Action Plan should not merely be an impressive political symbol aimed at bringing attention to the issue of attacks against persons with albinism locally and internationally. Thus, National Action Plan

¹⁴⁵ ICCPR (n 144 above) art 6

¹⁴⁶ CRPD (n 13) above arts 10, 16(1) & (5)

¹⁴⁷ A Sarat & TR Kearns 'An-na'im the legal protection of human rights in Africa How to do more with less' 2001 173 as cited in C Heyns & K Steffiszyn 'Human rights Peace and Justice in Africa: A Reader' 2006

should provide a service based framework for action and strategies to advance the human rights of people with albinism.

CHAPTER FOUR : ADDITIONAL MEASURES TO ENSURE THE EFFECTIVE PROTECTION OF PERSONS WITH ALBINISM IN MALAWI.

4.1 Introduction

General Comment No 5 calls on the State to ensure respectful and meaningful consultation of persons with disabilities in strategic planning and programming of support service such as the national action plan and albinism campaign programmes.¹⁴⁸ The CRPD prohibits discrimination on the basis of disability of any individual and affirm the need for the State to take specific measures to eliminate discrimination.¹⁴⁹ The chapter explores additional measures that the government of Malawi has taken and should take as a collective response to the attacks to ensure equality and non discrimination against persons with albinism. The chapter will conclude by providing recommendations

4.2 Access justice measures

Article 13 of CRPD, ensures effective access to justice by providing age-appropriate accommodation, facilitate the role of persons with disabilities as indirect participants in legal proceedings and investigation. It reinforces the need for training police investigators and prosecutors to ensure effective access to justice for persons with disabilities.¹⁵⁰ Access to justice is a fundamental right in the core human rights treaties, which provides that ‘all persons shall be equal before the courts and tribunals’.¹⁵¹ Similarly, the Committee on the rights of persons with disabilities in General Comment No 6 recognises the existence of laws and policies that approach disability from a medical model and that stereotypes, stigma and prejudices against persons with disabilities that remains a barrier to the enjoyment of their rights.¹⁵²

Malawi has adopted and modified some laws as its obligation to the protection and promotion of right of persons with albinism provided in international and national human rights legal frameworks. For instance, the Gender Equality Act of 2012, article 5, prohibits any forms of

¹⁴⁸ General Comment No 5 (n 93 above) para 42

¹⁴⁹ CRPD (n 13 above) art 5

¹⁵⁰ CRPD (n 13 above) art 13

¹⁵¹ United Nations Rule of Law, Informal Justice, available at: http://www.unrol.org/article.aspx?article_id=30 (accessed 20 July 2022)

¹⁵² General Comment No 6 (n 142 above) at para 21

harmful practices,¹⁵³ which include witchcraft related harmful practices. The Trafficking in Persons Act of 2015, article 16 (g) states the offence of removal of body parts or extracting tissues or organ as an aggravated form of trafficking.¹⁵⁴ This Act provides a solid legal framework for prevention, protection and prosecution against trafficking and abduction crimes of persons with albinism. The Act has stiffer penalties for trafficking in persons like 14 years and 21 years jail terms.

One of the specific steps taken by the Malawi government to ensure access to justice was to review and enact protective legislation specifically in line with crimes related to persons with albinism. In July 2016, the Malawi Parliament passed a private Members Bill 2 of 2016 to amend the Anatomy Act (Cap 34:03) to impose stiffer punishment on the offences of removal of body parts and unauthorized possession of human tissue. The Malawi Parliament also amended the Penal Code to provide specific protection and stiffer penalties for crimes relating to persons with albinism which included criminal offence in tampering with graveyard, possession of human tissue of persons with albinism and name calling.

Connected to the latter point, in 2016 a handbook for investigators, prosecutors and magistrate concerning offences against persons with albinism was developed. In particular part II of the handbook provides guidance for aspect of criminal law, evidence protection and procedures, guidance on how to frame relevant charges against accused person and trial process.¹⁵⁵ The handbook acts as a easy to read reference book with all the criminal charges of offence against persons with albinism for investigators, prosecutors and magistrates when handling cases of attacks.

Additionally, the chief justice issued a practice directive to ensure speedy handling of all cases against persons with albinism in Malawi. The practice directive only allowed senior magistrates to handle cases of attacks against persons with albinism. However, it is criticized that the directive did not significantly contribute to speedy prosecution of cases against persons with albinism. The senior magistrate were overloaded with increased number of reported cases against a few numbers

¹⁵³ Gender Equality Act 2012 art 5(1)

¹⁵⁴ Trafficking in Persons Act 2015 art 16(g)

¹⁵⁵ RE Kapindu Handbook for investigators, prosecutors and magistrate concerning offences against persons with albinism (2016) 16.

senior magistrates located across Malawi, hence causing further delays in the prosecution. Similarly, the delays were also due to inadequate funding to facilitate travel of the senior magistrates to hear case in the districts.¹⁵⁶ These challenges also led to avoidable adjustment of hearing of cases by the courts and suspect running away in hiding. Consequently, in the case of Maxwell Matchina Sosola et al v Republic of Malawi in 2019, the Judge observed that avoidable adjournment of the case due to non-compliance of defense lawyers delayed the process of justice delivery and completion of the case, and reassured the family members of the victim who was a persons with albinism to continue seeking justice.¹⁵⁷

Despite remarkable effort to ensure that there is access to justice, the reasercher views the delays in criminal justice system as government catastrophe of its duty to investigate the human right violation and bring the perpetrators to justice as provided in international human rights law. The criminal justice system has not effectivelly provided support services to deal with the circumstance of fear, torture and trauma experienced by persons with albinism. This upholds the interpretation in General Comment **No 1** on recognition before the law which calls the State to safeguard the exercise of legal capacity of persons with disabilities (with albinism) and prohibits support persons undue influence on the victim as a result of a sign of fear, threats or aggression.¹⁵⁸ The Committee on CRPD in the communication of Mr X v United Republic of Tanzania in 2017, also observed that there was discrimination and torture against MR X (as a person with albinism) which made him suffer pain and inhuman treatment. Similarly, the CRPD Committee observed lack of effective investigation and prosecution of the suspects, thus depriving the victim access to justice.¹⁵⁹ In a similar judicial decision by the High Court of Malawi in a case of Kenneth Moses et al v Republic of Malawi in 2018, the Court observed that the investigation was insufficiently exhaustive and reminded the State investigation and prosecution agency of their legal mandate and obligation.¹⁶⁰ The researher impression is that only if government provide specific support to persons with albinism to facilitate them make an informed decision, their direct participation during the legal

¹⁵⁶ Amnesty International (2021) 'Promoting and Protection the rights of persons with albinism' A manual for National Human Rights Institutions.

¹⁵⁷ Maxwell Matchina Sosola et al v Republic of Malawi (10 May 2019) Homicide 13 of 2018, The High Court of Malawi

¹⁵⁸ General Comment No 1 (n 94 above) para 22

¹⁵⁹ n 94, paras 8, 7 & 9

¹⁶⁰ Kenneth Moses V Republic of Malawi (19 April 2021) 55 Criminal Cause 14 of 2018, The High Court of Malawi

proceedings as victims or witnesses will not be meaningful. Thus, the State should ensure fulfilment of its obligation to equal and effective legal protection and prohibit direct discrimination that may have led to persons with albinism being treated less favourably in the criminal justice system.

However, as per the discussions above persons with albinism still face threat to their life, with last case of murder reported on 13 August 2021 of Ian Muhama, a 20-year-old person with albinism with both arms and legs severed in Blantyre District.¹⁶¹ These attacks perpetrated against persons with albinism leads to violation of rights as guaranteed in the Constitution of Malawi and the Disability Act such as section 16 right to life, right to human dignity, section 20(1) equality and non-discrimination, right to liberty and security. The State need to take all measures to ensure that every human being has the inherent right to life as enshrined in article 10 of the Constitution. It is the researchers view point that what it means is that majority of persons with albinism are not enjoying their rights and freedoms enshrined in the Constitution and measures put in place through National Action Plan. For instance Section 39 on right of freedom of movement and residence within borders of Malawi, it is urged that the attacks and abductions have caused fear, internal displacement and restriction in movement of persons with albinism and family members, which affect their participation in community life.

4.3 Non-discrimination and equality measures

The government of Malawi made public appointments of persons with albinism in decision making position such as appointment of a commissioner in the Malawi Human Rights Commission 2019,¹⁶² Presidential Advisor on disability and albinism and the first member of Parliament with albinism in Malawi was elected in 2021.¹⁶³ These appointments contribute to challenging

¹⁶¹ Standing Voice Statement on Murder of Ian Muhamba a Persons with Albinism, Lilongwe, Malawi, 17 August 2021 available at <https://www.standingvoice.org/> (accessed 22 February 2022)

¹⁶²A Nzangaya ‘APM appoints Malawi Human Rights Commission members’ Malawi24 3 April 2019 at 1 available at <https://malawi24.com/2019/04/03/apm-appoints-malawi-human-rights-commission-members/> (accessed 5 August 2022)

¹⁶³T Sanusi ‘Malawi MP Makes History as First Elected with Albinism’ Global Citizen 15 November 2021 available at <https://www.globalcitizen.org/en/content/malawi-mp-albinism-first-elected/> (accessed 5 August 2022)

discrimination and society negative assumptions about the abilities of persons with albinism and negative perceptions in society.

4.4 Conclusion and recommendations

The challenges faced by persons with albinism to enjoy their human rights are deeply intertwined in various factors mainly; inaccessibility, discrimination, negative attitudes and prejudices among stakeholders in our society. The legal instruments and national action plans explored above do resonate particularly strong to human rights standard relating to the right of persons with albinism within the context of other disability. Equal, effective and safe access to processes of developing national action plans requires ensuring that persons with albinism fully participate.

A human rights based approach (HRBA) to programming national action plan is essential to ensure that persons with albinism enjoy their rights and capitalize on their interconnections across Africa. A HRBA is a conceptual framework that is normative based on empowering rights holders by giving them greater opportunities to participate and claim their rights. The approach ensures that both the international human rights standards and the principles are operationally directed into policy making to fulfil the promotion and protection of human rights. This approach means placing emphasis not only on avoiding human rights violations against persons with albinism but making sure human rights principles are at the centre of development of national action plans targeting ending discriminatory practices and inequalities. In pursuing HRBA, programming national action plans should be designed explicitly to improve the enjoyment all human rights for persons with albinism. This means giving persons with albinism greater opportunities to participate in shaping the decisions that impact on their human rights and increasing the ability of government responsibility for fulfilling human rights through national action plans. In particular for persons with albinism it also means focusing on the following main principles;

Participation means persons with albinism actively, freely and meaningfully participate in decisions and support services in developing the plans which affect their human rights, including give attention to issues of accessibility and reasonable accommodation.

Accountability means persons with albinism through individually or collectively through their associations activities have the capacity to hold accountability duty bearers on various human rights violation through appropriate laws, policies and administrative procedures in order to secure their human rights.

Non-discrimination and equality means that national action plans should prioritize activities that prohibits, prevent and eliminate all forms of discrimination in the realization of human rights for persons with albinism and create an opportunity to express their voice.

Empowerment of persons with albinism as rights holders means that persons with albinism, their families and communities provides a conducive environment that fully support their participation in development of national action plans and community services. Persons with albinism should have adequate advocacy support to be able understand their rights and claim the rights.

Legality of rights means persons with albinism rights as championed by the national action plans should be in consistence with national and international human rights instruments so that they are legally enforceable entitlements¹⁶⁴

The position of this research is that programming of national action plan and legislative reforms should adopt a human rights approach that increases the involvement and participation of persons with albinism. Other promising practices such as the active involvement of the albinism associations, increased visibility of persons with albinism in significant position of power as a way of amplifying their voices and human rights based legal or policy reforms in promoting living conditions of persons with albinism should continue, as there has been the gaps acknowledged in the implementation of the 2018-2022 National Action Plan. However, government should give consideration on making the whole process of developing such policy documents accessible, available and affordable to persons with albinism especially in a context of Malawi where there is still uncertainty and fear among the group.

¹⁶⁴ European Network of National Human Rights Institutions (2017) 'Respect my rights an ENNHRI Toolkit on Applying a Human Right Based Approach to Long term care for older persons 14 available at https://ennhri.org/wp-content/uploads/2019/10/ennhri_17_005_toolkit_for_care_providers-03a-page.pdf (accessed 12 August 2022)

While acknowledging the willingness of government in developing of National Action Plan, the process cannot guarantee full protection of human rights of persons with albinism in a context characterized by the aforementioned challenges. The government campaigns in ending the attacks should be motivated by the human rights obligation and interest of protecting the right to life, equality, security, liberty and independent living of persons with albinism. “No one is safe until everyone is safe” even as a minority group in the community the population cannot necessarily be safe until the larger proportion of persons with albinism and their family members feel secure. Consequently, government through National Action Plan should adopt effective measures that will ensure that all relevant stakeholders, including persons with albinism themselves, their parents and relatives voice is heard to achieve a safe environment for all. As a result, strong recommendation is on ensuring regional and district level engagement be prioritised to advance the specific human rights issues of persons with albinism across Malawi.

Although there is a direct relationship between the advocacy or lobby capacities of albinism associations as civil society groups on their voices and the extent of knowledge on the implementation of National Action Plan. Persons with albinism representation was mainly at national level with limited involvement of the whole albinism movement in district level, such capacity gap and exclusion may weaken their ability to hold duty bearers accountable, track budgets and to influence National Action Plan activities as stipulated by the government NAP funds implementation guidelines in the districts. As shown from Tanzania, Uganda, Nigeria and Malawi, the need to invest in the capacity of organisations of persons with albinism is urgent as they have directly influenced and positively provides leadership in working with governments in the programming of National Action Plan. Person with albinism, as individuals or collectively through their association have shown resilience in their activism and holding governments accountable to adopt national action plans. There is sustained positive energy by associations to cope with change and increased networking even under crisis including attacks, wars, flooding and COVID-19 pandemic. Through their national association, persons with albinism in Malawi have been a useful source of information and advices on measures to end the attacks and recovery better. However, such participation and self-representation have not yet yielded into transformative steps in ending atrocities against people with albinism and dealing with institutional stigma among

policy makers. Such effort need to be backed up with adequate legal and policy frameworks that is enforceable within law and inform inclusive response programmes on the attacks.

The National Action Plan should provide opportunities for addressing particular experiences of persons with albinism that are overlooked in other legal and policy frameworks including strengthening legal literacy and human rights education among persons with albinism so that they can seek remedies for injustices and knowledgeable about their legal capacity under the law. Additionally, as seen in Tanzania and South Africa, State political will and gesture toward National Action Plan is subjective to several risk factors that delays its adoption, implementation and compliance to international human rights obligation. Hence, there is need to strengthen the legal systems to be at the center of protection and promotion of human rights of persons with albinism, as well as evaluating impact of National Action Plan on such vulnerable groups of people. This may help to constantly track States Parties obligations in fulfilling, respecting and protecting human rights of every Malawian.

Although the several commentators have recommended the need for training of officers in the criminal justice system in Malawi. The observation the research has made is that police officers involvement in the crimes against persons with albinism assume to be responsible for the poor quality of investigation and delays in finalising such cases. First, it is from this understanding that has led to a strong belief that law enforcement officers are the drivers and influencers of attacks against persons with albinism in Malawi. Second, factor is the deep rooted traditional belief in witchcraft in society, although the Witchcraft Act criminalise any act of accusing someone to be a witch or claiming to practice witchcraft and administer charms.¹⁶⁵ The existence of witchdoctors or traditional healers across Malawian communities is highly visible and remain major masterminders to harmful practices against persons with albinism as also confirmed in the case of *Matchina et al v Republic of Malawi* in 2022, where the judge sentenced a witchdoctor to 30 years imprisonment for transacting in human tissues and use of black magic to prevent the perpetrators in a case involving the killing of a persons with albinism.¹⁶⁶ The researcher did not find any clear

¹⁶⁵ Malawi Law Commission (2009) Witchcraft Act Review Programme- Issues Paper. 2-21

¹⁶⁶ *Innocent Wallasi et al V Republic of Malawi* (27 June 2022) 55 Criminal Case209 of 2022, The High Court of Malawi

difference between the witchdoctors and the herbalists in terms of their practices as a starting point to challenge the negative beliefs and harmful practices against person with albinism. What the research proves is that witchdoctors medicinal or supernatural practices have mounted to a series of threats to life and attacks for superstition belief on the body part of persons with albinism. Therefore, National Action Plan activities on human right education and albinism awarness should delibelately target the networks of witchdoctors or traditional healers. The witchdoctors practices, underpins the idea on the connection between disability and witchcraft accusation due to prejudice and beliefs, that has led to banishment, killings and physical violence against persons with disabilities.¹⁶⁷

In conclusion government's response to the killings, attacks, and discrimination against persons with albinism through National Action Plans is not adequate to end the attacks. There is an urgent need for a combination of approaches including the legislative reforms and stengtherning of implementing institution that are involved in the delivery of the various activities under the plans. It is apparent that there is prolonged common pattern of demand for body party of persons with albinism that is widespread across Malawi, Zambia, Tanzania and Mozambique. Hence the need for cross border collaboration in the investigations and prosecution of cases among the countires, as the attacks have created fear, exclusion and displacement among this marginalized group. The lack of effective protection mechanism, investigation and prosecution by the governments leds to further marginalization and victimization of persons with albinism acrosss the Southern African region.

¹⁶⁷ Groce (n 46 above)

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