



Kenya National Commission on Human Rights

MAPPING LAWS, POLICIES AND PROGRAMMES

ON ALBINISM AND EXISTING GAPS AND MAPPING
ORGANIZATIONS OF PERSONS WITH ALBINISM IN KENYA



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MAPPING

LAWS, POLICIES AND PROGRAMMES ON ALBINISM AND EXISTING GAPS
AND MAPPING ORGANIZATIONS OF PERSONS WITH ALBINISM IN KENYA

GLOSSARY OF TERMS

Albinism: Albinism is a rare, recessive, non-contagious, genetically inherited condition, which occurs worldwide regardless of ethnicity or gender. It most commonly results in the lack of melanin pigment in the hair, skin and eyes causing vulnerability to sun exposure that can cause skin cancer and low vision, which can be termed as legal blindness.¹

Persons with Albinism: Human beings who manifest the albinism characteristics. We put the person before the condition for dignity and to comply with the Convention on the Rights for Persons with Disabilities (CRPD) recommendations on the person-first language.

Lifelong needs: These are lifetime needs of Persons with Albinism also referred to as cradle to grave needs. For instance, eye & skin care needs which require continuous protection against harmful ultra-violet (UV) rays. In addition, the complexity and uniqueness of albinism means that their experiences significantly and simultaneously touch on several human rights issues including, but not limited to, discrimination based on color, discrimination based on disability, special needs in terms of access to education and enjoyment of the highest standards of health, harmful traditional practices, violence including killings and ritual attacks, trade and trafficking of body parts for witchcraft purposes, infanticide and abandonment of children.

Organizations for Persons with Albinism: Organizations that address the needs and welfare of Persons with Albinism. They may be led by Persons with Albinism or not. This includes State organizations such as the National Council for Persons with Disabilities (NCPWD), which runs the National Albinism Support Programme.

Organizations of Persons with Albinism: Organizations formed by, led by or directed by persons with albinism to advance their interests and advocacy. They include the Albinism Society of Kenya (ASK) and Positive Exposure Kenya.

1 UN (September, 2013) Persons with albinism. Report of the Office of the United Nations High Commissioner for Human Rights. Twenty-fourth session of the Human Rights Council

Derogatory terms used to refer to people with albinism

- Albino** English word that is used to refer to a person with albinism
- Litondo** Luhya word that means eye boogers or 'matongo' in Swahili
- Mzungu** Swahili word that denotes people of the Caucasian race.
- Millionaire** Used to infer the wealth one would make if they involved themselves in human trafficking of persons with albinism
- Nguchiro** Swahili word that is used to refer to a person with albinism
- Pesa** Swahili word for 'money' but used to refer to the wealth a person would make if they involved themselves in human trafficking of persons with albinism
- Zeruzeru** Swahili word often used to refer to persons with albinism

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LIST OF ABBREVIATIONS AND ACRONYMS

ACHPR	African Charter on Human and People Rights
ACRWC	African Convention on Rights and Welfare of the Child
AEN	Albinism Empowerment Network
AFEA	Albinism Foundation of East Africa
ASK	Albinism Society of Kenya
AU	African Union
AUDA	African Union Disability Architecture
CBOs	Community Based Organizations
CEDAW	Convention on Elimination of Discrimination Against Women
CIDPs	County Integrated Development Plans
COK	Constitution of Kenya (2010)
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organization
DEVAW	Declaration on the Elimination of Violence Against Women
ESCR	Economic and Social Cultural Rights
FGDs	Focus Group Discussions
FGM	Female Genital Mutilation
GANHRI	Global Alliance of National Human Rights Institutions
GASSPP	Golden Age Albinism Support and Protection Programme
GOK	Government of Kenya
HIV	Human Immunodeficiency Virus
HRBA	Human Rights-Based Approach
HRC	Human Rights Council
IAAD	International Albinism Awareness Day
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on Elimination of Racial Discrimination
ICESCR	International Covenant on Economic Social and Cultural Rights
KCB	Kenya Commercial Bank
KII	Key Informant Interview

KNBS	Kenya National Bureau of Statistics
KNCHR	Kenya National Commission on Human Rights
KNH	Kenyatta National Hospital
KPC	Kenya Pipeline Corporation
KRA	Kenya Revenue Authority
MCA	Member of County Assembly
MOH	Ministry of Health
MOU	Memorandum of Understanding
NASSP	National Albinism Sunscreen Support Programme
NEMIS	National Education Management Information System
NCPWD	National Council for Persons with Disabilities
NDFPWD	National Development Fund for Persons with Disabilities
NGAO	National Government Administration Officers
NGO	Non-Governmental Organization
OPDs	Organizations of Persons with Disabilities
OSIEA	Open Society Initiative for Eastern Africa
PE-Kenya	Positive Exposure-Kenya
PHC	Pastoral Heritage Concern
SN	Special Needs Education
SPF	Sun Protection Factor
SPSS	Statistical Package for the Social Sciences
UDHR	Universal Declaration on Human Rights
UN	United Nations
UV	Ultra-Violet
UPR	Universal Periodic Review
UTSS	Under The Same Sun
VSLAs	Village Savings and Lending Associations
WEF	Women Enterprise Fund
WHO	World Health Organization
YDF	Youth Development Fund

EXECUTIVE SUMMARY

Just like any other human being, persons with albinism are entitled to the enjoyment of their rights as expounded in the bill of rights in our Kenyan constitution of 2010. Despite this, they are exposed to various risks and factors that limit their enjoyment of these rights. The lack of understanding and limited awareness in the community about albinism makes them be treated with some level of mystery that at times is enshrined in superstitions that lead to harmful practices where they are branded derogatory names and are at risk of grievous bodily harm, human trafficking, and even death. Other risks that persons with albinism face as a result of their disability is the exclusion in various basic services such as education, health care, and active participation in the day-to-day development activities of their communities. This study seeks to map out and thus have a better understanding of laws, policies, programmes, and organizations that make it possible for persons with albinism to enjoy their human rights. It seeks to determine the gaps in the laws, policies, and programmes as well as what mitigations that need to be put in and make the necessary recommendations.

The study used a mixed method approach combining both qualitative and quantitative approaches. The design was highly qualitative. The methods of inquiry for collecting and, in particular, analyzing data were built on strong empirical foundations. The analysis provided a focused and abstract way that helped explain the situation of albinism in Kenya. To this effect, the study utilized different sources of data including secondary/desk review and direct primary data collections. It also undertook an analysis of available international, regional, and national policies and legal frameworks. Sampling involved selection of 3 main regions of western, central and coastal Kenya. 3 focus group discussions were sampled comprising 29 respondents. 10 organizations working for and with persons with albinism were also sampled out of which 4 were reached.

The study established that the government is the largest single institution that has the most listed interventions and programmes for persons with albinism. These interventions are provided through the National Council for Persons with Disabilities (NCPWD) in the Albinism support programme. Interventions here include but not limited to the National Albinism Sunscreen Support Programme (NASSP), skincare support, job placement, National Development Fund for Persons with Disabilities (NDFPWD), assistive devices where eye care is included, education assistance for basic education, tools of trade and processing of tax exemption. Non-state actors some of whom are organizations that work for and with persons with albinism also offered various interventions and programmes for persons with albinism.

A look at the legislations that apply within the boundaries of our country, persons with albinism are not explicitly mentioned within the various acts but are assumed to benefit just like any other Kenyan. However, there are a few Acts that target persons with albinism within the broad category of persons with disabilities. For instance, the Persons with Disabilities Act (revised 2012) which makes broad provisions for persons with disabilities.

The only policy document that purposefully mentions persons with albinism is the Sector Policy for Learners and Trainers with Disabilities, 2018 that recognizes albinism as a category of persons with disabilities. International and regional legal instruments that have been ratified by Kenya equally make broad provisions for persons with disabilities without necessarily mentioning persons with albinism.

The study makes the following recommendations to mention but a few; there is need to develop a coordination and peer review mechanism for all stakeholders working on albinism at community and national levels; a communication and advocacy strategy on albinism public education, awareness and training needs to be put in place; advocacy should focus on enforcement of laws against abuse of persons with albinism; need to actively engage persons with albinism in all programmes affecting them especially regarding investments, programming and policies that concern them; there is need to strengthen registration and vital statistics to ensure legal compliance to persons with disabilities; there is need to ensure participatory programming for ownership and sustainability and explore ways of integrating and harmonizing systems for data, monitoring and evaluation of persons with disabilities

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CHAPTER 1

KNCHR STUDY ON LAWS, POLICIES AND PROGRAMMES ON ALBINISM

1.1 Introduction

Background

Numerous reports across Africa have been made on attacks and extreme violations of human rights against persons with albinism. Such attacks range from mutilation, maiming and murder to kidnapping, human trafficking and the desecration of graves (to steal and traffic body parts from the corpses) of persons with albinism. A notable attack that lingers freshly in memory is the case of mutilation of a baby with albinism in Zambia, in May 2021² and another one in Tanzania in the same month³. It has been reported that there exists a black market for body parts of persons with albinism⁴. It is also reported that many cases of attacks and other violations go unreported because of the involvement of family members in many instances, the weak monitoring capacity from the State and civil society organizations (CSOs) alike and because of the secrecy that surrounds these practices, most of which are ritual attacks⁵.

Equally, the rights of persons with albinism are often trampled upon mainly due to limited awareness on the subject of albinism which is a genetic condition that leads to the lack of melanin, the coloring pigmentation of the skin, hair and the eyes. This means that albinism is therefore seen behind a veil of superstitions and shrouded in mystery. What aggravates the situation further is the reality that few countries have specific laws, policies and measures that specifically address the human rights of persons with albinism⁶.

The African Union (AU) in 2018, adopted a Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa. This was aimed at realizing the vision of the African Union Agenda 2063, and to accomplish the "*Africa We Want*" in our lifetime. However, this instrument is yet to be ratified. It will only come into effect once it has been ratified by 15 member states of the African Union. As of May 2021, only one country had ratified it with others still at various stages of its ratification⁷. The AU then went ahead and adopted the African Union Disability Strategic Framework, which replaced the extended Plan of Action on the African Decade of Persons with Disabilities (2010–2019). The two instruments are part of the pillars of the African Union Disability

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- 2 Toumi, M, Ero, I, Tawata, H (2021) Report on a regional action plan on ending attacks and human rights violations against persons with albinism in Africa. Action on Albinism. Retrieved from: https://www.ohchr.org/Documents/Issues/Albinism/RAP_Report_01-07_21_EN.pdf on 27th January 2022
 - 3 Press release by Under the Same Sun. Retrieved from https://www.underthesamesun.com/May2021_PressRelease, on 27th January 2022
 - 4 Matata, L (November 2015). Global Press Journal. Market for their body parts forces Africans with albinism to live amid constant danger of attack. Retrieved from <https://globalpressjournal.com/africa/kenya/market-for-their-body-parts-forces-africans-with-albinism-to-live-amid-constant-danger-of-attack/> on 9th September 2022
 - 5 Toumi, M, Ero, I, Tawata, H (2021) Report on a regional action plan on ending attacks and human rights violations against persons with albinism in Africa. Action on Albinism. Retrieved from: https://www.ohchr.org/Documents/Issues/Albinism/RAP_Report_01-07_21_EN.pdf on 27th January 2022
 - 6 United Nations (2019), Seventy-fourth session, Item 72 (b), Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms.
 - 7 Antwi-Atsu, G (2021). The African Disability Protocol: A call to leave no one behind. Disability Rights. Sightsavers Retrieved from <https://www.sightsavers.org/blogs/2021/08/the-importance-of-the-african-disability-protocol/> on 13th September 2022.

Architecture (AUDA), which is a framework guiding Member States on ensuring disability rights and inclusion in Africa. The AUDA comprises three pillars: Legal Pillar (Disability Protocol); the Programme Pillar (Disability Strategic Framework); and the Institute (AU Disability Institute). The timeline of 2031 as indicated for the Plan of Action is also based on available baseline information in 2019 for the Report on the Implementation of the Continental Plan of Action on the African Decade of Persons with Disabilities (2010–2019)⁸.

Context

Pervasive myths and misconceptions about albinism in many parts of the country continue to make persons with albinism suffer unnecessarily due to their condition. This misunderstanding and misconceived notion continues to relegate persons with albinism in a vicious cycle of poverty. However, Kenya has made a noticeable move to improve the rights and welfare of persons with albinism by, for instance, incorporating albinism into its policies on disability, incorporating an affirmative action program in the public service, inclusion of an indicium specifically on albinism in the 2019 Kenya Population and Housing Census (KPHC) and introduction of a program to provide and distribute sunscreen to persons with albinism. In spite of these deliberate decisions, it remains to be seen whether these steps will be followed-through and concretized so that benefits are clearly seen in the lives of persons with albinism⁹.

In May 2008, Kenya ratified the Convention on the Rights of Persons with Disabilities (CRPD). This placed an obligation on the State to adopt appropriate measures for the implementation of rights espoused in the Convention. The Committee on the Rights of Persons with Disabilities (CRPD Committee) reviewed Kenya in 2015 and issued concluding observations in this regard. Touching on persons with albinism, the Committee recommended to Kenya to promptly investigate all cases of violence against persons with albinism, ensuring that they are appropriately prosecuted and punished; create redress services for victims of attacks, including free legal aid; redouble efforts to raise awareness about the dignity and rights of persons with albinism; and ensure the involvement of organizations of persons with albinism in any campaigns aimed at eliminating stigmatization and myths that underpin violence against persons with albinism.¹⁰

Persons with albinism in the country continue to face stigma and discrimination, particularly in the education system where they are often mocked for their appearance and their low vision remains unaccommodated. The result causes a high dropout rate among persons with albinism. This in turn leaves most of them un-skilled and ill-equipped for jobs thereby relegating them to menial jobs, including jobs that expose them to the sun and subsequently to skin cancer which is the primary killer of persons with albinism

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

9 AFEA et al. (2014) The human rights of Persons with albinism in Kenya

10 UN Committee on the Rights of Persons with Disabilities 'Concluding Observations on the Initial Report of Kenya' CRPD/C/KEN/CO/1 (30 September 2021) <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/223/37/PDF/G1522337.pdf?OpenElement>> accessed 5 May 2022

in the region of Sub-Saharan Africa¹¹. On the extreme end of stigma and discrimination against persons with albinism are physical attacks and subsequent impunity leaving perpetrators undeterred¹².

There are several challenges that perpetuate the continued stigmatization and discrimination of persons with albinism. These challenges include the fact that representative organizations of persons with albinism (especially rights-based organizations) are mostly urban-based, and many rural-based organizations lack the capacity to advocate for the rights of persons with albinism from a rights-based perspective. In this regard, the civil society movement of persons with albinism is not strong and this has negatively impacted on progress in some critical areas.

For example, Kenya is yet to put in place a country specific action plan on albinism (based on the Regional Action Plan on Albinism in Africa 2017 - 2021 which has subsequently been adopted by the AU as the African Union Plan of Action on Ending Attacks and Discrimination against People with Albinism 2021- 2031). Furthermore, some key legislation touching on the rights of persons with albinism require updating, including the Witchcraft Act, the Counter Trafficking in Persons Act, 2010 and the Persons with Disabilities Act, 2003. There are progressive programmes on persons with albinism, but these are not well documented, and many people with albinism, especially those in remote areas lack knowledge regarding these programmes. In addition, some of the programmes are *ad hoc* and it is not clear what the country's long-term strategy on albinism is (in the absence of a country-specific action plan on albinism). Additionally, there has been inadequate investigation and prosecution of offenses against persons with albinism.

The 2030 Agenda for Sustainable Development embraces a human rights-based approach in referring to persons with disabilities under various goals, including in education, employment, reducing inequalities, inclusive cities, and disaggregation of data by disabilities. While it is commendable that Kenya is not only developing laws, policies and programmes to protect people with albinism but also participating in the formulation of an action plan to aid in the implementation of the African Union Action Plan on Albinism (2021-2031), it is important to ensure that such laws and policies are not in contravention of the CRPD, the Constitution of Kenya, 2010 and other relevant international, regional and national legal instruments.

Study objectives

The overall objective of this study was to support the project towards the enhanced enjoyment of rights with albinism in Kenya. Specific objectives included:

1. Establishing laws, policies and programmes (national and sub-national) related to persons with albinism in Kenya;

11 Preliminary findings of Country Visit to Kenya by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, September 2018

12 AFEA et al. (2014) The human rights of Persons with albinism in Kenya

2. Identifying the existing gaps in the laws, policies and programmes related to persons with albinism in Kenya to determine the level of (non)compliance with the regional and international human rights principles and standards as well as the Constitution of Kenya, 2010. This included a trend analysis on complaints received and processed by KNCHR relating to persons with albinism;
3. Carrying out an in-depth assessment to establish the effectiveness of laws, policies and programmes targeting persons with albinism from the perspective of persons with albinism themselves;
4. Mapping and documenting organizations of persons with albinism in Kenya (both at national and grassroots levels) together with official contact details and major areas of focus; and
5. Developing a publication documenting laws, policies and programmes relating to persons with albinism in Kenya, the existing gaps in law, policy and practice and making appropriate and specific recommendations on how best laws, policies and programmes can promote and protect the rights of persons with albinism in Kenya. The publication aimed at including a trend analysis on complaints received and processed by KNCHR relating to persons with albinism. The publication also comprises an up-to-date list of registered organizations of and for persons with albinism in Kenya.

KNCHR's work on rights of persons with disabilities with focus on albinism

The Kenya National Commission on Human Rights (KNCHR) is an independent National Human Rights Institution (NHRI) established under Article 59 of the Constitution and operationalized by the Kenya National Commission on Human Rights Act, 2011 (revised 2020). The Commission has a broad mandate to promote the respect and a culture of human rights in the Republic of Kenya. The Commission's mandate is implemented through various strategies including research, advocacy and lobbying, education and training, complaints and investigations, litigation, monitoring, partnership building and networking among others.

The Commission's functions are guided by the 1993 United Nations approved principles on the establishment and functioning of national human rights institutions (Paris Principles) and is accredited as an 'A' status institution for its compliance with the Paris Principles by the Global Alliance of National Human Rights Institutions (GANHRI). The Commission also enjoys Affiliate Status before the African Commission on Human and Peoples' Rights. The Commission is the designated national monitoring agency under Article 33(2) of the Convention on the Rights of Persons with Disabilities¹³.

KNCHR was first assigned the monitoring mandate on the CRPD by the Attorney General in February 2011 and later in 2017¹⁴. The re-designation of KNCHR as the monitoring

13 KNCHR website. Retrieved from <https://www.knchr.org/Our-Work/Research-and-Compliance/Disability>. on 27th January 2022

14 In 2014, the mandate had been retracted and assigned to the National Gender and Equality Commission.

agency under Article 33(2) of the Convention was made pursuant to the Concluding Observations of the Committee on the Rights of Persons with Disabilities upon Kenya's review on its implementation of the Convention in 2015 (UN Doc CRPD/C/KEN/CO/1 para 60)¹⁵.

In this regard, the Commission has carried out monitoring of the implementation of the Convention in 12 Counties (Bungoma, Busia, Elgeyo Marakwet, Kiambu, Kilifi, Kisii Machakos, Makueni, Migori, Mombasa, Nyeri, and Uasin Gish) for the period 2011-2013¹⁶. A number of reports have been published on the basis of the monitoring. Relating to persons with albinism, the 2014 monitoring report titled *From Norm to Practice* found that in Kisii General Hospital, which had a total of 550 employees then, only three had disabilities, and only one of the three was a person with albinism¹⁷. In addition to monitoring, the Commission has worked on rights issues relating to persons with albinism, across its broad mandate including receiving and processing complaints and acting as the principal organ of the State in ensuring compliance with obligations under treaties and conventions relating to human rights as discussed below.

Relating to the Commission's role in ensuring compliance with obligations under treaties and conventions relating to human rights, in June 2014, KNCHR in collaboration with organizations of persons with albinism in Kenya including the Albinism Foundation of East Africa (AFEA), Albinism Society of Kenya (ASK), and Under The Same Sun (UTSS) submitted a report on the human rights of persons with albinism in Kenya to the Human Rights Council (HRC) under the Universal Periodic Review (UPR). This report raised key human rights issues affecting persons with albinism.¹⁸

The UPR is a unique process which involves a periodic review of the human rights records of all 193 United Nations (UN) Member States. The UPR is a significant innovation of the Human Rights Council which is based on equal treatment for all countries. It provides an opportunity for all States to declare what actions they have taken to improve the human rights situations in their countries and to overcome challenges to the enjoyment of human rights. The UPR also includes a sharing of best human rights practices around the globe.¹⁹

In January 2020, Kenya was reviewed in the third cycle. It received 319 recommendations and it supported 263 recommendations. Supported recommendations related to legal and general framework of implementation; universal and cross-cutting issues; civil and political rights; economic, social, and cultural rights; women's rights; and rights of other vulnerable groups and persons.

15 KNCHR website. Retrieved from <https://www.knchr.org/Our-Work/Research-and-Compliance/Disability>, on 27th January 2022

16 *ibid*

17 Kenya National Commission on Human Rights 'From Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya' (July 2014)

18 The human rights of persons with albinism in Kenya. Retrieved from <https://uprdoc.ohchr.org/uprweb/downloadfile.aspx?filename=1483&file=EnglishTranslation>

19 Basic facts about the UPR. Retrieved from at: <https://www.ohchr.org/EN/HRBodies/UPR/Pages/BasicFacts.aspx>, on 27th January 2022

On albinism, the State received the following recommendations: redouble efforts to promote and protect the rights of people with albinism by creating support centers dedicated to this cause; strengthen the actions and resources used to effectively combat discrimination, stigma and attacks against people with albinism; and to ensure the effective protection of people with albinism against violence, discrimination and stigma; and to adopt and implement the Regional Action Plan on Albinism in Africa (2017–2021).²⁰

Scope of the Study

The study was limited to the following areas of focus: to map out existing laws, policies, programmes and organizations of persons with albinism. This was done within the boundaries of Kenya with focus on laws and policies that touch on albinism that were developed and implemented within the devolved governments.

Laws, policies and programmes for Persons with Albinism

Major concerns for laws and policies that touch on Persons with Albinism revolve around the following five key areas. The first is **right to life**, as Persons with Albinism generally have a lower life expectancy owing to multiple factors. These include skin cancer; HIV/AIDS (due to the myth that sexual intercourse with persons with albinism can cure the disease); and harmful practices related to the manifestation of belief in witchcraft, including the idea that the body parts of persons with albinism can bring success and good luck²¹.

The second important area is **health** since skin cancer is the most prominent health issue, with a stream of deaths of persons with albinism of all age groups reported consistently to the United Nations Independent Expert on the enjoyment of human rights by persons with albinism and mentioned extensively in several submissions received²². It is important to point out that skin cancer is a highly preventable form of cancer that generally responds well to treatment upon early detection. Yet, persons with albinism in the region, especially those in rural areas, face challenges in accessing health-care²³.

The third important area is **education**. Poverty is a major barrier to education, given that children with albinism often cannot afford the necessary assistive devices, tuition and sun-protective clothing²⁴. In some cases, parents withhold their children from school or have them start at a later age because of fear of attacks, prejudice or concerns about their child's learning ability, as well as fear of wasted investment since the future of the child remains in question in the light of societal prejudices²⁵.

20 Universal Periodic Review Kenya. Available at: <https://www.ohchr.org/EN/HRBodies/UPR/Pages/KEindex.aspx>.

21 UN (2019) Report of the Independent Expert on the enjoyment of human rights by persons with albinism. A/74/190

22 *ibid*

23 *ibid*

24 *ibid*

25 *ibid*

Teachers are often unaware, unable or unwilling to provide for the needs of students with albinism or do not invest the time necessary to help with basic accommodations that cost little to nothing, such as allowing students to copy from their notes. Children with albinism in school also face bullying, teasing, discrimination and stigmatization from their peers and teachers alike. Other students may refuse to play with children with albinism, sometimes on the orders of their parents or fueled by pre-existing social prejudices²⁶.

The fourth important area is **economic empowerment** in relation to formal/informal employment and adequate standard of living. Access to employment is a challenge for persons with albinism in Kenya²⁷. Barriers to education often result in a lack of qualification for indoor jobs. Many persons with albinism work outdoors on farms or sell their wares in markets, where they expose themselves to the sun and increase their risk of skin cancer. Lack of reasonable accommodation at work can also be hazardous, for example, where there is no flexibility around night shifts, which increases vulnerability to attacks in some countries²⁸.

Moreover, employers or potential employers often discriminate against persons with albinism, stigmatizing them as inferior or incompetent or as persons whose physical presence may scare potential customers away. In other instances, particularly in private enterprises, employees with albinism of all sexes are vulnerable to sexual harassment and ritual rape by employers due to the belief that such acts bring wealth and good luck in business²⁹. Many persons with albinism therefore live in extreme poverty. Where critical socio-economic schemes or services exist, knowledge on how to access them is lacking among persons with albinism, including social security benefits on the basis of disability.

The fifth area of importance that aims to be addressed by sound laws and policies is **access to justice and legal remedy**. Barriers to access to justice include a culture of silence related to a manifestation of belief in witchcraft, financial barriers and a fear of reprisals from relatives and community members when an attack has been perpetrated by a family member or a respected member of the community³⁰. There are also barriers attributed to lack of legal literacy among persons with albinism, including lack of understanding of legal processes, and lack of access to information, education and training. Underreporting and low levels of monitoring and follow-up by both State and non-State actors are also significant challenges³¹.

At the regional level, the Executive Council of the African Union (AU) adopted a Plan of Action on Ending Attacks and Discrimination against Persons with Albinism, (2021-2031) making it a continent-wide strategy for all member states³². The AU also resolved that a Special Envoy on Albinism would be appointed to ensure the implementation of the

26 *ibid*

27 *ibid*

28 *ibid*

29 *ibid*

30 *ibid*

31 *ibid*

32 African Union (2021). Retrieved from https://actiononalbinism.org/uploaded_documents/16270537974156ddw0tvbef7.pdf on 18th January 2022

Plan of Action. The Plan has been endorsed by various stakeholders in the region and internationally³³. However, there is no documented progress made by Kenya in respect to this Plan³⁴.

Inter-sectionality has also been drawn from a rights and disability perspective. With regards to albinism as a right and a disability issue, Article 27 (4) of the Constitution of Kenya provides for non-discrimination on the basis of colour and disability. The Universal Declaration of Human Rights (UDHR), 1948 guarantees the extension of social security to all citizens and the CRPD reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms, including social protection. The CRPD articulates equal opportunities for Persons with Disabilities to participate.

Kenya has a glaring gap on albinism-specific legislation. The only policy that mentions Albinism is the Sector Policy for Learners and Trainees with Disability, 2018 that recognizes albinism as a category of disability. However, Kenya, as a member state of the AU has put in place a few legislative measures on disability which can be a basis for Albinism, and is in the process of amending its laws to give effect to the provisions of the CRPD³⁶. Generally, there is no specific law, legislation or policy framework that speaks directly to albinism³⁷. A lot of provisions are enshrined in the Persons with Disabilities Act, 2003³⁸ which is a national law but it does not mention albinism expressly, creating a big leeway for misrepresentation and hampering implementation.

The Ministry of Education developed the Sector Policy for Learners and Trainees with Disability in 2018 which recognizes albinism as a category of disability³⁹. To this date, it remains the only single framework that mentions albinism. However, its focus is only in relation to inclusive education and leaves out other needs of Persons with Albinism including health and employment among others⁴⁰.

Several gaps in the legal and policy frameworks are noted in relation to persons with albinism: the lack of legislation on albinism presents the first barrier to access to equal opportunities, in all spheres, by Persons with Albinism in Kenya. The Ministry of Public Service, Gender, Senior Citizens Affairs and Special Programmes, and the National Council for Persons with Disabilities (NCPWD) do not have a national policy on

33 Plan of Action 2021-2031 - https://actiononalbinism.org/uploaded_documents/16270537974156ddw0tvbef7.pdf
Retrieved on 18th January

34 A.U (2021). Implementation matrix of the plan of action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031). Retrieved from https://actiononalbinism.org/uploaded_documents/16270537974156ddw0tvbef7.pdf on 18th January 2022

35 Government of Kenya (2018). Ministry of Education Sector Policy for Learners and Trainees with Disabilities. Retrieved from <https://www.education.go.ke/index.php/downloads/file/510-sector-policy-for-learners-and-trainees-with-disabilities> on 18th January 2022

36 AFEA et al (2014). The human rights of persons with albinism in Kenya. AFEA, Nairobi

37 NCPWD website. Retrieved from <https://ncpwd.go.ke/downloads/persons-with-disabilities-act/> on 18th January 2022

38 *ibid*

39 Government of Kenya (2018). Ministry of Education Sector Policy for Learners and Trainees with Disabilities. Retrieved from <https://www.education.go.ke/index.php/downloads/file/510-sector-policy-for-learners-and-trainees-with-disabilities> on 18th January 2022

40 *ibid*

disability⁴¹; most legal and policy documents on disability in Kenya have not embraced the concept of 'albinism'⁴². This includes the National Plan of Action on Implementation of Recommendations made by the Committee on the Rights of Persons with Disabilities to be implemented from September 2015-June 2022⁴³. This poses a challenge for the advocacy agenda in support of Persons with Albinism and also leads to lack of recognition of albinism in disability laws and policies developed at the County level. Like the national level, nearly all the county laws and County Integrated Development Plans (CIDPs) (2018-2022) reviewed have programmes and activities focusing on disability broadly but no mention of Persons with Albinism.

Some of the major programmes for Persons with Albinism that have been implemented by the government through the NCPWD include provision of sunscreen lotions at designated government health facilities, provision of comprehensive eye care which goes beyond the provision of eyeglasses, provision of protective clothing to guard against exposure of sun rays and awareness raising to sensitize the public on albinism and to fight against harmful practices^{44,45}. These are, however, not long-term and can be terminated at any point as there is no policy or legislative framework in their support. Some programmes by the Government come in the form of budgetary allocation through the Ministry of Social Protection. However, this is not attached to any policy or framework, it is the will of the government of the day. There is no way to defend by law. The National Albinism Sunscreen Support Programme (NASSP) domiciled at NCPWD⁴⁶ as at 2021 had been able to reach to an approximately 4,000 Persons with Albinism which is less than 50% of the PWA population of 9,729 as per the 2019 Kenya National Bureau of Statistics (KNBS) population census⁴⁸.

There are gaps that need to be closed, efforts that need to be consolidated, and more steps to be taken, for Kenya to fully address the challenges encountered by persons with albinism in the country. This calls for an urgent need to have a holistic albinism-specific policy that supports existing laws and aligns to the AU plan of action on albinism capturing more specific holistic measures on equality & nondiscrimination, accountability, prevention and protection. This will improve and safeguard the situation of persons with albinism and their human rights.

Organizations of and for Persons with Albinism

Up until 2015, there were only five organizations of Persons with albinism in Kenya. This number has since grown with the devolution of government being many more county level organizations of persons with albinism.

41 ibid

42 ibid

43 ibid

44 Human Rights Council 'Report of the Independent Expert on the Enjoyment of Human Rights by Person with Albinism' A/HRC/40/62/Add.3 (2019) para 41

45 NCPWD website. Retrieved from <https://ncpwd.go.ke/albinism-support-program/> on 18th January 2022

46 ibid

47 ibid

48 Ibid

1.2 Methodology

1.2.1 Study design

The study on mapping laws, policies and programmes on albinism and existing gaps and mapping organizations of persons with albinism in Kenya, was designed as an *ex-post-facto*⁴⁹ country-level survey that adopted a holistic descriptive analytical approach collecting and analyzing data and information on the present situation of albinism in Kenya. It used a combination of quantitative and qualitative tools to collect and analyze data. This approach was deemed appropriate for exploring a range of issues, generating and consolidating the various forms of data required for a study to explore the policy-to-practice continuum on the situation of albinism.

The study employed methodological triangulation to ensure that multiple sources of evidence were utilized to enhance validity and reliability. This allowed a strategic application of grounded theory⁵⁰ thinking in examining and explaining the situation of albinism in Kenya. The design was highly qualitative and therefore the grounded theory provided a set of systematic inductive methods for conducting the research. The methods of inquiry for collecting and, in particular, analyzing data thus built on strong empirical foundations. The analysis provided focused and abstract way that helped explain the situation of albinism in Kenya⁵¹. To this effect, the study utilized different sources of data including secondary/desk review and direct primary data collections. It also undertook an analysis of available international, regional, national and local policies and legal frameworks relating to persons with disabilities generally and albinism in particular, assessing the provisions they make and the gaps therein thereby proposing reviews and amendments of the same.

1.2.2 Study scope and geographical coverage

The study covered the nation of Kenya. The focus of this study was on the state of laws, policies and programmes on albinism and existing gaps and mapping organizations of persons with albinism in Kenya. The timeframe of this study, therefore, limited itself to all the happenings prior to December 2021. A critical emphasis of the study was on the nexus between the existence and implementation of the policies/legislation and how they influence the situation of people with albinism in Kenya and how effectively the existing programmes address the concerns of PWAs. Key sources of data and information for the study were policies and policy players; social and cultural agents including government officers, non-state actors, intervention implementers at regional and community levels. Testimonies from PWAs and their guardians were documented.


49 Sharma, S. (2019) Experimental and ex-post-facto designs, Horizon University. Retrieved from https://www.researchgate.net/publication/333220493_Experimental_and_Ex_Post_Facto_Designs on 18th January 2022

50 Charmaz, K. (2009) "Grounded Theory." *The SAGE Encyclopedia of Social Science Research Methods*. Retrieved from <https://guides.temple.edu/c.php?g=77914&p=504699>. on 27th January 2022

51 Ibid

The scope is summarized as follows;

- (a) **Geographically:** The study covered the nation of Kenya. However, due to limited resources, 3 main zones were purposely selected for data collection and actual field visits. These three zones were, Western, Central and Coast within the counties of Kakamega, Nyeri and Kilifi respectively. The selection of the three zones ensured that both urban and rural areas are captured and that a wide geographical cover is obtained by covering at least two extreme counties of Kakamega and Kilifi and one within the central region. The table below shows how the zones were divided.



Zone	Areas covered
Western	Kakamega County
Central	Nyeri County
Coast	Kilifi County

- (b) **Thematically:** The study focused on policies, laws, programmes and interventions for persons with albinism within Kakamega, Nyeri and Kilifi counties. Emphasis was made on the (dis)connection between the existence and implementation of the laws and policies; and on existing interventions in the study sites.
- (c) **Target population:** The study adopted a multi-level analysis approach that ensured that issues that were related to laws, policies, programmes and organizations for persons with albinism were tackled from the individual, to the household level and community level. Such that all these segments of society provide a value for deeper understanding of our research variables. Thus, the population was policies and policy players; social and cultural agents including intervention implementers at the community level; community leaders and local institutions.

1.2.3 Data collection tools and methods

The study team implemented a two-pronged approach to collect the necessary data:

- (d) Desk review of policies and legislations internationally, regionally and in Kenya, trends analysis on complaints at KNCHR brought forward by persons with albinism and data references and survey data to assess policies, programmes and legislations on persons with albinism, existing gaps and mitigating factors; and,
- (e) Primary data collection through actual visits to the study sites and use of in-county experts. This approach made use of key informant interviews, Focus Group Discussions (FGDs), case studies, online survey and stakeholder consultations to collect primary data/information.

To collect information from the field, open-ended and structured questionnaires, as annexed, were developed, tested and employed for data extraction, including Key Informant Interviews (KIIs) and secondary data review across the selected study sites. The following data collection methods were employed for the study:

(a) Literature review/Desktop study: This involved a desk review of the relevant documents such as the legislative frameworks, policies, studies, policy briefs/papers, articles, essays, documentation of, interventions, analysis and research regarding albinism and disability. Specifically, the study took a special look into the following documents as listed in the table below:

Global instruments	Regional instruments	National legislation
Universal Declaration on Human Rights (UDHR)	African Rights Charter on Human and People	Constitution of Kenya, 2010
International Covenant on Economic Social and Cultural Rights (ICESCR)	Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with Disabilities in Africa	Persons with Disabilities Act, 2003
International Covenant on Civil and Political Rights (ICCPR)	African Convention on Rights and Welfare of the Child (ACRWC)	Basic Education Act, 2013
International Convention on Elimination of Racial Discrimination (ICERD)	AU Plan of Action on Albinism (2021-2031)	Social Assistance Act, 2013
Convention on The Rights of Persons with Disabilities (CRPD)	Pan African Parliament	Public Service Act (Values and Principles), 2015
Convention on Elimination of Discrimination Against Women (CEDAW)	Maputo Protocol (The Protocol To The African Charter on Human and Peoples' Rights on the Rights of Women in Africa)	Public Procurement And Disposal Act, 2015
		Employment Act, 2007
		Sector Policy for Learners and Trainers with Disabilities, 2018
		Witchcraft Act
		Children's Act, 2001
		Counter Trafficking Of Persons Act, 2010
		Sexual Offences Act, 2006

Other documents reviewed were;

- Relevant national policies;
- Guidelines for a Human Rights-Based Approach (HRBA) to Public Policy and Law Making at the National and County Levels, 2017 (KNCHR);
- Regional Action Plan on Albinism and other regional frameworks (AU level);
- Relevant reports by intergovernmental bodies; and other relevant material.

Key observations and recommendations from these international treaties and special mandates and any other policy briefs were noted down and included in the literature review.

- (b) **County demographic and vital statistics extraction:** Key demographic and vital information statistics were extracted from the relevant county level and regional databases and literature including respective County Integrated Development Plans (CIDPs) on disabilities and albinism. Specific templates were designed for extracting such data by the study team. The data and statistics were used to show the status of disabilities and albinism and other key demographic factors in the various counties. In addition, statistics from the 2019 KNBS census report was used to extract data of Persons with Albinism.
- (c) **Key informant interviews:** Key individuals were identified and selected based on their knowledge and experience of disability and albinism and related issues through KNCHR contacts and networks and from the consultants' own networks and knowledge. This targeted the county governments, National Government Administrative Officers (NGAOs), National Government ministries, state agencies, non-governmental actors and civil society organizations in the field of social development, disabilities and albinism. Through interviews, the key informants provided their perspectives regarding policy and legislation and the existing gaps in disability and albinism.
- (d) **Case studies:** Case studies as a research method were used to understand individual experiences and stories of significance of Persons with Albinism in relation to gaps in policies and legislation and gaps in reference. These provided an understanding of the underlying issues across the various regions in the country. Existing case studies were reviewed against the objectives of the study in addition to identifying and documenting specific case studies as they related to the study.
- (e) **Stakeholder consultation:** The study engaged key stakeholders working on disabilities and albinism to understand the challenges and opportunities that persons with albinism encounter in their day-to-day life in view of the policies, legislations, programmes and organizations working with and for persons with albinism. Guardians, parents, and persons with albinism were among those consulted to explore the various objectives of the study.
- (f) **Online survey:** The study utilized online survey techniques by constructing a digital survey monkey on Google platform that was circulated to 10 organizations involved in disabilities and albinism out of which 4 organizations responded positively.

This was done in line with protocols by the Ministry of Health (MOH) to reduce movement and contact for containing the spread of coronavirus and COVID-19 infection. The survey used a snowballing method to circulate the questionnaire as widely as possible starting with the key informant interviews and their networks. The survey was distributed to a target audience. Additionally, snowball sampling was used to identify the survivors and girls at risk. At all cost, the study fully adopted the “Do No Harm” principle which always emphasized respecting the respondents’ privacy and confidentiality, particularly, letting those being interviewed to know who would have access to their information and how it would be used. The respondents were provided the option of providing their information anonymously. In addition, the study also observed the “Leave No One Behind” principle which emphasized inclusion targeting all categories of respondents especially the marginalized children, the elderly, people living with disabilities and people living with HIV. The study worked with respective KNCHR county focal persons to select and organize the data collection points and sources as well as identify key respondents of all the proposed categories.

The table below summarizes the distribution of the specific data collection processes:

Activity	Target	Proposed number	Numbers reached
Focus Group Discussions (Interviews with Persons with Albinism and their guardians)	Nyeri, Kilifi, Kakamega	3 (24 participants- 8 per FGD)	3 (29 across the 3 areas)
Stakeholders’ consultation	OPDs, NCPWD, Ministry of Labor and Social Protection, Ministry of Health, Ministry of Education within Nyeri, Kilifi and Kakamega	3	1
Organizations of/For PWA through an online structured questionnaire	Positive Exposure- Kenya, Albinism Society of Kenya, Dr. Choksey Albinism Foundation, Albinism Foundation of East Africa, KASCU, GASSP County albinism forums.	10	4
Key informants’ interviews including community leaders and influencers	KNCHR Staff, Legislatures (at both National and County Assemblies)	5	12

1.2.4 Data analysis

The data analysis was undertaken in such a way that it addressed concerns emerging from the findings. Key findings were discussed with the field team and presented to stakeholders for feedback and contextual fleshing out of the key findings. Qualitative data including case studies analyzed using the grounded theory were used to triangulate and deepen the analysis by giving and comparing county specifics with actual human stories. Quantitative data from the structured questionnaires were analyzed using Statistical Packages for Social Sciences (SPSS) to test trends regarding policies and legal implementation of interventions for Persons with Albinism.

1.2.5 Study quality assurance, data management and reporting

Pre-testing the tools: Pre-testing of the tools was a vital component of the test development processes to ensure relevance and reliability of the tools. This was done by taking the survey tools through a pilot phase by interviewing different persons in an environment that varied from the ones sampled. The pilot survey was done within Nairobi area.

Training of research team: The research team underwent a one-day training on the expectations of the study and its ethical guidelines. The nature of the training had an effect on the quality of the literature review, data collection, and analysis.

Research authorization: The Regional offices of KNCHR were tasked with in-county facilitation of the study including identifying opportunities for data collection in addition to availing in-county sources of data. This also entailed the involvement of relevant government departments both at national and county levels for the validation of the study.

Data recheck: The researchers conducted data recheck of every respondent interviewed. The purpose was to monitor the nature and type of data captured by the enumerators. Data recheck presented an opportunity to check quality and learn and improve the processes of the study.

Data management: The data entry packages that were used had in-built entry and recheck mechanisms. Digital data gathering tools were created with a user-friendly front end to enable a smooth data entry process. Furthermore, the entry form was masked to minimize data entry errors, for instance, by ensuring that the data entry system had some mandatory fields such as unique identifiers to avoid the issue of duplicates, as well as minimum and maximum values.

Preparation of dummy tables and templates: Blank data tabulation templates containing the variables and information were prioritized for interpretation and preparation. These tables had the further advantage of checking that the data collection tools actually collected the data that was envisaged for the analysis. Each region prepared its specific tables which were compared at the national level. The study ensured the results and data were provided as per these dummy tables.

Analysis: The analysis was undertaken in such a way that it addressed concerns at regional and national levels. That data was compared as appropriate. The comparison presented a possibility for regions to gauge their own standing in relation to others. Key findings were discussed with the field teams to get their interpretation of the findings and to add further qualitative inputs to the study. Cross-country analysis and comparisons were undertaken to ensure a regional outlook of the study. Quantitative data was analyzed using the SPSS statistical tools.

Preparation of regional report and policy brief: The consultant prepared a draft report of the study summarizing key findings and recommendations for review and comment by the KNCHR Team and Policy Advisors including a validation meeting by all key stakeholders, NGOs, CBOs of Persons with disabilities/albinism who supported in data collection and study operationalization. All inputs from the validation exercise that was conducted in Mombasa on June 12th, 2022 as a part of the International Albinism Awareness Day (IAAD) celebrations were incorporated into the draft report to produce a final study report. The findings were published in formats accessible to the general public. The data was presented in simple tables, case studies and clear diagrams, and other innovative methods that made the publications eye-catching.

CHAPTER 2

ANALYSIS OF LEGAL FRAMEWORKS AND POLICIES ON ALBINISM

This section analyses the legal frameworks that either mention or touch on issues related to albinism or wholly make provisions for persons with albinism. This analysis is made at four levels starting with global human rights instruments, then looking at regional level instruments and frameworks, then moving lower to national level legislation then finally looking at county-level legislation.

2.1 Global human rights instruments

The main United Nations Conventions that were analyzed include the Universal Declaration of Human Rights hereinafter UDHR, the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), Convention on the Rights of the Child (CRC), and the International Convention on the Rights of Persons with Disabilities (ICRPD).

By analyzing the global instruments and frameworks on human rights, the aim was to determine if persons with albinism have specifically been mentioned or if there is any mention of key concerns that affect them such as human trafficking, dealing in witchcraft practices etc. With the understanding that human rights are entitled to all human beings, likewise, persons with albinism are equally included in all provisions. This analysis sought to explore rights of persons with albinism as per the UN major Conventions.

2.1.1 Universal Declaration on Human Rights (UDHR)

The UDHR (1948) is the first instrument to have been drafted providing for human rights to be universally protected and is said to have inspired and paved the way for the adoption of other human rights treaties both at global and regional level⁵². In the preamble, the UDHR recognizes the inherent dignity and of the equal and inalienable rights (meaning no one can take it away) of all members of the human family as the foundation of freedom, justice and peace in the world. Prominent provisions in the UDHR are as follows:

- Article 1 provides that all human beings are born free and equal in dignity and rights.
- Article 2 provides that everyone is entitled to all the rights and freedoms set forth in the UDHR, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
- Article 3 provides that everyone has the right to life, liberty, and security of the person.
- Article 5 adds that no one shall be subjected to torture or to cruel inhuman or degrading treatment or punishment.
- Article 7 provides that all we equal before the law and are entitled without discrimination to equal protection of the law.
- Article 23 states that everyone has the right to work, just and favorable working conditions and remuneration.
- Article 25 everyone has the right to a standard of living adequate for their health and wellbeing including food, clothing, housing and medical care and necessary social protection.
- Article 26 provides for the right to education including free elementary and fundamental stages.

52 Universal declaration of human rights. Retrieved from <https://www.un.org/en/about-us/universal-declaration-of-human-rights> on 18th January 2022

All the above rights cover all human beings and this includes persons with albinism. Unfortunately, this is not the reality with regards to the implementation of the UDHR for persons with albinism particularly on the right to education, right to medical care, right to life, right to an adequate standard of living.

2.1.2 International Covenant on Economic Social and Cultural rights (ICESCR)

The ICESCR (1966) provides for the rights to economic, social and cultural rights for all⁵³. This includes the rights to adequate food, housing, education, health, social security, to take part in cultural life, to water and sanitation and to work. Key provisions in this instrument are;

- Article 1 provides that everyone has a right to determine their political status and to freely pursue their economic, social and cultural development.
- Article 6 (1) provides for the right of everyone to the opportunity to gain his/her living by work which he/she freely chooses/accepts, and States will take appropriate steps to safeguard this right.
- Article 6(2) further provides steps for States to take to achieve rights to work including technical and vocational guidance, training programs, policies and techniques to realize steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.
- Article 7 provides for just and favorable working conditions including fair wages and equal remuneration.
- Article 10 (2) provides for special protection to mothers for a reasonable period before and after childbirth. During such a period, working mothers should be accorded paid leave or leave with adequate social security benefits.
- Article 10(3) provides for special measures of protection and assistance to be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. It adds that Children and young people should be protected from economic and social exploitation and that States should set age limits below which the paid employment of child labour should be prohibited and punishable by law.
- Article 12 provides for States to recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
- Article 16 provides that States undertake to submit reports on the measures which they have adopted and the progress made in achieving the observance of the rights recognized herein.

Despite all the progressive provisions, this convention provides to all groups of the population, it does not make mention of persons with albinism. All people are considered homogenous.

53 United Nations (1966) International Covenant on Economic, Social and Cultural Rights. Retrieved from <https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/cescr.pdf> on 18th January 2022

2.1.3 International Covenant on Civil and Political rights (ICCPR)

The ICCPR (1966)⁵⁴ makes the following outstanding provisions:

- Article 1 of the ICCPR is similar to Article 1 of the ICESCR that states that everyone has a right to determine their political status and to freely pursue their economic, social and cultural development.
- Article 6 provides that every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

This statute does not mention anything on persons with albinism.

2.1.4 International Convention on Elimination of Racial Discrimination (ICERD)

The ICERD⁵⁵ provides for rights and freedoms without distinction of any kind, as to race, color, or national origin. The Convention defines the term "racial discrimination" as any distinction, exclusion, restriction, or preference based on race, color, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life. Specific articles of importance are mentioned below:

- Article 2, 1 (c) Each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists;
- Article 2,1 (d) Each State Party shall prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization.
- Article 5 (b) highlights the right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution.

Persons with albinism are targeted and have faced numerous human rights violations because of their color. The convention does not make a specific reference to persons with albinism.

One of the factors at the origin or facilitating attacks against persons with albinism is their visibility, due to the color of their skin. The appearance of persons with albinism makes them stand out, particularly in environments where most of the population have darker pigmentation and the contrast between the two groups is stark, as is the case in all countries where attacks have been reported including Kenya.

Persons with albinism are therefore a visible minority group whose appearance and coloring has made them subjects of instantaneous discrimination. Their stigma, the

54 United Nations (1966) International Covenant on Civil and Political Rights Retrieved from <https://www.ohchr.org/sites/default/files/ccpr.pdf> on 18th January 2022

55 United Nations (1965) The International Convention On The Elimination Of All Forms Of Racial Discrimination Retrieved from https://legal.un.org/avl/pdf/ha/cerd/cerd_e.pdf on 18th January 2022

lifelong social exclusion and general discrimination they face, is a similar experience to that of vulnerable racial minorities because of their skin color. The Convention on the Elimination of All Forms of racial discrimination is therefore another ground for protection persons with albinism in addition to other frameworks.

2.1.5 Convention on the Rights of Persons with Disabilities (CRPD)

The purpose of the CRPD⁵⁶ is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. It is the international treaty that covers the rights of persons with disabilities as it was drafted by persons with disabilities. Specific articles that have been brought out read as follows:

- Article 1 defines persons with disabilities as 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.
- Article 2 defines “Discrimination on the basis of disability” as any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.
- Article 4 provides for States to ensure and promote the human rights and fundamental freedoms of all persons with disabilities without discrimination on basis of disability. Like all other conventions, States are obligated to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities, and to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs.
- Article 5 States that persons with disabilities are equal before the law prohibiting discrimination on the basis of disability.
- Article 6 provides for rights of women and girls with disabilities recognizing the multiple discrimination faced by women and girls with disabilities on the basis of gender and disability.
- Article 6 addresses the rights of children with disabilities including the right to enjoy all human rights and fundamental principles on an equal basis with other children. In all actions regarding children with disabilities, the best interest of the child is the primary concern.
- Article 8 provides for State to adopt immediate, effective and appropriate measures.
- Article 10 States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

56 United Nations (2006) Convention on rights of persons with disabilities Retrieved from <https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd> on 18th January 2022

- Article 13 provides for access to justice where States are obligated to ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages. This includes training in the field of administration of justice, including police and prison staff.
- Article 15 states that No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment and that States shall ensure measures in place to prevent persons with disabilities from being subjected to torture or cruel, inhuman or degrading treatment or punishment.
- Article 16 provides for States to put measures in place to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence, and abuse, including their gender-based aspects.
- Article 24 addresses the right to education for persons with disabilities on an equal basis with others. It provides that States recognize the right of persons with disabilities to education, with a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning.
- Article 25 provides for right to health where States recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination based on disability.
- Article 27 provides for the right of persons with disabilities to work on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive and accessible to persons with disabilities. Critical elements included in this Article is prohibition of discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions; rights of persons with disabilities, on an equal basis with others, to just and favorable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy, Ensure that reasonable accommodation is provided to persons with disabilities in the workplace.
- Article 33 provides for State to put in place a focal point to ensure the implementation of the CRPD at country level and consideration of establishment of a coordination mechanism within government to facilitate related actions in different sectors and different levels.
- Article 35 States are mandated to provide a periodic report on progress made in implementing the CRPD to the CRPD committee.

While the CRPD does not mention albinism per se all the provisions in there can be applied to safeguard the welfare of persons with albinism.

2.1.6 Convention on Elimination of Discrimination against Women (CEDAW)

CEDAW⁵⁷ requires States to eliminate discrimination against women and girls in all areas and promotes women's and girls' equal rights. Particular articles that are of interest are mentioned below:

- Article 1 provides definition of the term "discrimination against women" as any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.
- Article 2(b) provides for States to put in place appropriate measures including legislation prohibiting discrimination against women.
- Article 3 provides for States to take in political, social, economic and cultural fields, and ensure all appropriate measures in place, including legislation, to ensure the full development and advancement of women, for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men.
- Article 10 looks at States ending discrimination against women to ensure them equal rights to men in the field of education including access to studies, access to scholarships, reduction of female students drop out.
- Article 11 States to take measures to end discrimination against women in employment in order to ensure equality between men and women including right to work as an inalienable right, same employment, equal remuneration, right to social security and right to protection of health and safety at work including reproduction.
- Article 12 provides for States to put measures in place to end discrimination against women in the field of healthcare ensuring equality including in family planning.
- Article 13 States to put measures in place to end discrimination in economic and social life including right to family benefits, rights to bank loans, mortgages and other form of financial credit and right to participate in recreational activities, sports and cultural life.
- Article 14 States to take into account issues faced by rural women and their role in economic support including unpaid care work.
- Article 18 States are to provide reports to the CEDAW Committee on legislative, judicial, administrative, or other measures which they have adopted to give effect to CEDAW provisions.

Women with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination. They are isolated by stigma, myth, and cultural prejudice as a result they experience sexual violence, physical assault as a result of these persistent myths and stereotypes. CEDAW does not have any provisions addressing women and girls with disabilities.

57 United Nations (1979). Convention on the Elimination of All Forms of Discrimination against Women Retrieved from <https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/cedaw.pdf> on 18th January 2022

2.1.7 Declaration on the Elimination of Violence Against Women (DEVAW)

DEVAW came into place in 1993 to strengthen and compliment CEDAW in elimination of violence against women⁵⁸. This is also with recognition of the need to have in place a commitment in place by States on their role and responsibility in ending violence against women with clear statements on definition of VAW, rights to be applied to ensure elimination of violence against women.

- DEVAW provides for definition of the term “violence against women” as any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.
- Article 2 provides for what constitutes violence against women,
- Article 3 provides for rights of women including the right to life;
 - (a) The right to equality.
 - (b) The right to liberty and security of person.
 - (c) The right to equal protection under the law.
 - (d) The right to be free from all forms of discrimination.
 - (e) The right to the highest standard attainable of physical and mental health.
 - (f) The right to just and favorable conditions of work.
 - (g) The right not to be subjected to torture, or other cruel, inhuman, or degrading treatment or punishment.

In as much as this instrument makes provisions to protect all women against violence, it is silent on women with disabilities and especially so on women with albinism. Yet women with disabilities and those with albinism are highly susceptible to violence, they face double marginalization, i.e. being women and having a disability.

2.1.8 Convention on the Rights of the Child (CRC)

This is one very important instrument as it makes provisions to protect the rights of children that is all persons under the age of 18 years. Its importance is as a result of the many vulnerabilities that children face especially in the age of industrialization and modernization⁵⁹. Article 1 defines a child as every human being below the age of eighteen years unless under the law applicable to the child, the majority is attained earlier.

Article 2 provides that States shall respect and ensure the rights of all children within their jurisdiction without discrimination regardless of legal guardians' age, race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status. Children with albinism in Kenya often face discrimination and exclusion from their peers and society, causing some of them to skip school or drop out altogether, in addition to this they remain the most vulnerable when it comes to rights violations.

58 United Nations (1993) Declaration on the Elimination of Violence against Women Retrieved from <https://www.ohchr.org/en/instruments-mechanisms/instruments/declaration-elimination-violence-against-women> on 18th January 2022

59 United Nations (1989) Convention on the rights of the child Retrieved from <https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/crc.pdf> on January 18th 2022

The Kenyan Constitution Article 2(6) states that any treaty or convention ratified by Kenya shall form part of the law of Kenya under this Constitution. Therefore, for the above Conventions that have been ratified by Kenya form part of Kenyan law.

The preamble to the conventions is clear that human rights and fundamental freedoms are universal, indivisible, interdependent and interrelated and that the rights of every individual are recognized in the Conventions above. It is important to note that the UDHR makes no distinction between ICESCR and ICCPR is realized as you read both treaties as well. A good example to show how the two treaties are linked is that individuals who cannot read or write often have a harder time realizing their full potential than those who cannot find work or take part in political activity. When we look at hunger and malnutrition, they are less likely to occur where individuals can effectively exercise their right to vote and influence government priorities⁶⁰.

Similarly, for persons with albinism there are major issues faced by persons with albinism highlighted in this study including right to life, right to health, right to education, right to employment /economic empowerment, right to access justice among others.

For persons with albinism, Article 12 of the ICESCR is critical, especially the provision of free sunscreen as a basic need and further having it available in the smallest health unit as an essential medication to ensure prevention of skin cancer. ESCR are critical to ensure persons with albinism can have sustained livelihoods, basic needs including food, clothing and shelter. While clothing and shelter are a major priority, skin & eye health for persons with albinism are equally very essential and basic needs.

Looking at the progressive realization nature of ESCR and when Kenya ratified the ICESCR, there is a need to see positive steps in advancing ESCR. It is taking longer than it should for persons with albinism to access ESCR.

The three major treaties do provide for fundamental human rights for all but there is a need to ensure that this translates to how the Kenyan Government ensures the rights are realized in Kenya and more specifically for persons with albinism. The purpose of the global treaties is that States like Kenya implement them at the domestic level. There are therefore lots of relevant laws with minimal application at the country level.

Looking at the global level, there are applicable laws covering right to life, right to health, right to access justice, right to education, right to ESCR. More treaties have been adopted to address more vulnerable groups including rights of the child, women and girls' rights and rights of persons with disabilities.

There has been renewed attention to the importance of economic, social and cultural rights, particularly in the context of the 2030 Agenda for Sustainable Development and addressing and preventing conflict crises worldwide, including the COVID-19 pandemic.⁶¹

60 United Nations (1966). International covenant on economic social and cultural rights. Retrieved from <https://www.ohchr.org/en/human-rights/economic-social-cultural-rights> on 18th January 2022

61 *ibid*

2.2 Regional human rights instruments

The following regional human rights instruments were identified as suitable for this study.

2.2.1 African Charter on Human and Peoples' Rights

As the main regional Charter protecting human rights of Africans, The Banjul charter seeks to promote and protect human rights and basic freedoms in the African continent.⁶²

- Article 3 states that everyone is equal before the law and entitled to equal protection of the law.
- Article 4 provides those human beings are inviolable and entitled to respect for their life and integrity of the person therefore no one may arbitrarily deprive them of this right to life.
- Article 14 right to property is guaranteed.
- Article 15 provides for right to work under equitable and satisfactory conditions and receive equal pay for equal work.
- Article 16 right to best attainable state of physical and mental health.
- Article 17 provides for right to education.
- Article 18 (3) provides that the State shall ensure the elimination of every discrimination against women and ensure protection of rights of the women and child.
- Article 18(4) states that the aged and disabled shall also have the right to special measures of protection in keeping with their physical or moral needs.
- Article 22 right to economic, social and cultural development.
- Article 45 the Charter provides for a Commission whose function includes promoting human and people's rights including documentation, research studies on African problems in the field of human and people's rights and can give views or make recommendations to Governments.
- Article 66 States that Special protocols or agreements may, if necessary, supplement the provisions of the present Charter.

There are several Protocol to the Banjul Charter that have been adopted and this report highlights relevant protocols. However, no mention is made on persons with albinism.

2.2.2 Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with Disabilities in Africa

This is one of the most recently adopted protocols that was ratified by Kenya in September 2021⁶³. Article 2 states the purpose of the Protocol is to promote, protect and ensure the full and equal enjoyment of all human and people's rights by all persons with disabilities and to ensure respect for their inherent dignity.

62 Organization of African Unity (1981) African charter on human and people's rights Retrieved from <https://www.achpr.org/legalinstruments/detail?id=49> on 18th January 2022

63 Antwi-Atsu, G (2021). The African Disability Protocol: A call to leave no one behind. Disability Rights. Sightsavers Retrieved from <https://www.sightsavers.org/blogs/2021/08/the-importance-of-the-african-disability-protocol/> on 13th September 2022

- The preamble states that human rights and fundamental freedoms are universal, indivisible, interdependent and interrelated and that the rights of every individual are recognized in international human rights instruments including the Universal declaration of Human rights of 1948, the International Covenant on Economic, Social and Cultural Rights of 1966 and the international Covenant on Civil and Political Rights of 1966.
- The preamble highlights members of the African Union are alarmed by the maiming or killing of persons with albinism in many parts of the Continent.
- Article 1 defines discrimination on the basis of disability similar to the CRPD “Discrimination on the basis of disability” as any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. Discrimination on the basis of disability shall include denial of reasonable accommodation;
- It also defines “ritual killings” as killing of persons motivated by cultural, religious or superstitious beliefs that the use of a body part has medicinal value, possesses supernatural powers and brings good luck, prosperity and protection to the killer.
- Article 4 provides for States to put measures in place including policy, legislative, administrative, institutional and budgetary steps, to ensure respect, promote, protect and fulfil the rights and dignity of persons with disabilities without discrimination on the basis of disability including modifying outlawing, criminalizing or campaigning against any harmful practice applied to persons with disabilities, budget allocation to ensure implementation of the Protocol, ensuring effective participation of persons with disabilities or their organization including women and girls with disabilities and children with disabilities in all decision making process including in development of legislation, policies and administrative process to the Protocol.
- Article 5 provides for non-discrimination and reiterates that person with disabilities are entitled to enjoy the rights and freedoms guaranteed under the Protocol without distinction of any kind on any ground including race, ethnic group, colour, sex, language, religion, political or any other opinion.
- Article 6 states that every person with disability is equal before the law and has equal protection and benefit of the law. Reinstating that equality includes the full and equal enjoyment of all human and people’s rights.
- Article 8 provides that every person with a disability has the inherent right to life and integrity.
- Article 10 provides for right of persons with disabilities to respect of their inherent dignity and to be free from torture or cruel, inhuman and degrading treatment, slavery, forced labour or unlawful punishment.
- Article 11 addresses harmful practices where States are to take appropriate measures and offer appropriate assistance to victims of harmful practices including legal sanctions, educational campaigns, advocacy to eliminate harmful practices perpetuated against persons with disabilities including witchcraft, abandonment, concealment, ritual killings

- Article 13 provides for the right to access justice calling on States to ensure that persons with disability have access to justice on an equal basis with others including through procedural, age and gender appropriate accommodations. It also calls for inclusive customary law processes, training for law enforcement and judicial personnel to ensure the rights of persons with disabilities are recognized and implemented without discrimination.
- Article 16 provides for the right to education on an equal basis with others calling on States to ensure inclusive quality education and skills training for persons with disabilities is realized including ensuring access to free, quality compulsory basic and secondary education, access to tertiary, vocational training, adult education and lifelong learning without discrimination with reasonable accommodation at all levels and equipped with relevant teaching resources and professionals.
- Article 17 provides for the right to health on an equal basis with others including providing health services needed by persons with disabilities specifically because of their disabilities, providing health care in the community, health campaigns include disability specific needs with stigmatization.
- Article 19 provides that every person with disability has the right to decent work, just and favorable working conditions, protection against unemployment, exploitation and forced or compulsory labor. States are to ensure measures in place for persons with disabilities to have their right to work on an equal basis to others and some of the measures include prohibiting discrimination on basis of disability with regards to all forms of employment and employment opportunities, promoting opportunities for the, to initiate self-employment, entrepreneurship and access to financial services, employing them in public sector including and enforcing minimum job quotas for employees with disabilities.
- Article 27 provides for the rights of women and girls with disabilities on an equal basis with others including participating in social, economic and political decision making and activities, removing barriers in society that hinder women with disabilities from participating, access to employment, access to income generating opportunities and credit facilities, protection from sexual and gender based violence(SGBV) and provision of rehabilitation and psychosocial support against SGBV, SRHR guaranteed and disability inclusive gender perspectives included in policies, legislation, programs, budgets and activities in areas that affect women with disabilities.
- In Article 28, states are to ensure children with disabilities enjoy human and people's rights on an equal basis with other children.

2.2.3 African Charter on Rights and Welfare of the Child (ACRWC)

The ACRWC is said to be a comprehensive instrument that sets out the rights and defines universal principles and norms for the status of the children⁶⁴. The ACRWC and CRC are said to be the only international and regional human rights treaties that cover the whole spectrum of civil, political, economic, social, and cultural rights.

⁶⁴ African Union (1990). African Charter on the Rights and Welfare of the child. Retrieved from <https://au.int/en/treaties/african-charter-rights-and-welfare-child> retrieved on 18th January 2022.

Article 2 defines a child as a human being below the age of 18 years. Article 38(1) of the African Charter on the Rights and Welfare of the Child (ACRWC/the African Children's Charter) and Rule 58 of its revised Rules of Procedure, which mandate the Committee to establish its own rules of procedures and establish special mechanisms, including working group.

The Working Group on Children with Disabilities of the African Committee of Experts on the Rights and Welfare of the Child (ACERWC/the Committee) during its second meeting held virtually on 14 March 2022, passed Resolution NO 19/2022 on the status of children with albinism⁶⁵. It acknowledged that children with albinism continue to experience violence and other violations of their rights within the jurisdiction of some States Parties of the African Children's Charter. It was aggrieved by the violent nature and continued prevalence of acts targeting children with albinism, such as ritual killing and maiming across the African region. It was concerned about the absence and/or insufficiency of measures to enhance the quality of life of children with albinism, including the lack of accessible and affordable medical care suited to their needs on an equal basis with other children in their respective communities, and the availability and accessibility of appropriate protective gear, including sunscreen, and hats.

It recognized the persistence of the ignorant and dangerous social, cultural and religious beliefs underlying the violence targeting children with albinism and further, it also recognized that stigma and discrimination against children with albinism leads to violations of their right to education, which in turn drives them into poverty or deepens their poverty making them more susceptible to attacks. It noted that measures taken by most States Parties in response to the COVID-19 Pandemic led to an increase in violence against children in general, including violence targeting children with albinism in particular.

While commending the measures taken by some States Parties to raise awareness on albinism and to counter the beliefs that propagate violence against children with albinism, it was concerned that despite the Committee's recommendations to States Parties to adopt measures to address the plight of children with albinism, they continue to experience discrimination and violence. The resolution on the status of children with albinism makes specific recommendations and provisions to safeguard children with albinism in a quest to mitigate the cyclic violations of their basic rights.

2.2.4 African Union (AU) Plan of Action

The executive Council of the AU adopted a plan of Action on Ending Attacks and Discrimination against People with Albinism making it a continent-wide strategy for all member states⁶⁶. The AU also resolved that a Special Envoy on Albinism would be appointed to ensure the implementation of the Plan of Action. The Plan has been endorsed

65 African Union (2022). Resolution No. 19/2022 of the ACERWC working group on children with disabilities on the situation of children with albinism in Africa. Retrieved from <https://www.acerwc.africa/wp-content/uploads/2022/04/Resolution-No-192022-on-the-Situation-of-Children-with-Albinism-in-Africa.pdf> on May 2022.

66 African Union Plan of Action 2021-2031- Retrieved from https://actiononalbinism.org/uploaded_documents/16270537974156ddw0tvbef7.pdf on 18th January 2022

by various stakeholders in the region and internationally. There is no documented progress made by Kenya in respect to the Regional Action Plan.

2.2.5 Maputo Protocol

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, better known as the Maputo Protocol, is an international human rights instrument established by the African Union in 2003 and that went into effect in 2005⁶⁷. Kenya ratified the instrument in 2010⁶⁸.

The preamble states that, State parties to the Protocol are concerned that despite the ratification of the African Charter on Human and Peoples' Rights and other international human rights instruments by the majority of States Parties, and their solemn commitment to eliminate all forms of discrimination and harmful practices against women, women in Africa still continue to be victims of discrimination and harmful practices; and that they are firmly convinced that any practice that hinders or endangers the normal growth and affects the physical and psychological development of women and girls should be condemned and eliminated; and determined to ensure that the rights of women are promoted, realized and protected in order to enable them to enjoy fully all their human rights.

Under the definition's sections, Maputo Protocol makes the following important terminologies. **"Discrimination against women"** as any distinction, exclusion or restriction or any differential treatment based on sex and whose objectives or effects compromise or destroy the recognition, enjoyment or the exercise by women, regardless of their marital status, of human rights and fundamental freedoms in all spheres of life. **"Harmful Practices"** as all behavior, attitudes and/or practices which negatively affect the fundamental rights of women and girls, such as their right to life, health, dignity, education and physical integrity. **"Violence against women"** as all acts perpetrated against women which cause or could cause them physical, sexual, psychological, and economic harm, including the threat to take such acts; or to undertake the imposition of arbitrary restrictions on or deprivation of fundamental freedoms in private or public life in peace time and during situations of armed conflicts or of war and finally, **"Women"** as persons of female gender, including girls.

The instrument makes the following selected and important provisions that are of importance to this study;

- (a) **Article III** provides for the Right to Dignity and States that every woman shall have the right to dignity inherent in a human being and to the recognition and protection of her human and legal rights. It provides that States Parties shall adopt

67 African Union (2003). Protocol to the African charter on human and peoples' rights on the rights of women in Africa Retrieved from <https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WG/ProtocolontheRightsofWomen.pdf> on 18th January 2022

68 Oxfam (2014). Implementing the Protocol on the Rights of Women in Africa: Analyzing the Compliance of Kenya's Legal Framework Retrieved from <https://oxfamlibrary.openrepository.com/bitstream/handle/10546/333065/ml-implementing-protocol-womens-rights-africa-010314-en.pdf;jsessionid=ED301BBEBC2CEACFD960A18DF5410062?sequence=1> on 13th September 2022

and implement appropriate measures to prohibit any exploitation or degradation of women and further provides that States Parties shall adopt and implement appropriate measures to ensure the protection of every woman's right to respect for her dignity and protection of women from all forms of violence, particularly sexual and verbal violence.

(b) **Article IV** provides for the Rights to Life, Integrity and Security of the person. It states that every woman shall be entitled to respect for her life and the integrity and security of her person and that all forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited. It provides for States Parties to do consider the following important measures:

- (i) Take appropriate and effective measures to enact and enforce laws to prohibit all forms of violence against women including unwanted or forced sex whether the violence takes place in private or public.
- (ii) Adopt such other legislative, administrative, social and economic measures as may be necessary to ensure the prevention, punishment and eradication of all forms of violence against women.
- (iii) Identify the causes and consequences of violence against women and take appropriate measures to prevent and eliminate such violence.
- (iv) Actively promote peace education through curricula and social communication in order to eradicate elements in traditional and cultural beliefs, practices and stereotypes which legitimise and exacerbate the persistence and tolerance of violence against women; Punish the perpetrators of violence against women and implement programs for the rehabilitation of women victims.
- (v) Establish mechanisms and accessible services for effective information, rehabilitation and reparation for victims of violence against women.
- (vi) Prevent and condemn trafficking in women, prosecute the perpetrators of such trafficking and protect those women most at risk.
- (vii) Provide adequate budgetary and other resources for the implementation and monitoring of actions aimed at preventing and eradicating violence against women.

• **Article V** provides for Elimination of Harmful Practices and calls for States Parties to prohibit and condemn all forms of harmful practices which negatively affect the human rights of women and which are contrary to recognized international standards. It also provides for States Parties take all necessary legislative and other measures to eliminate such practices, including:

- (i) Creation of public awareness in all sectors of society regarding harmful practices through information, formal and informal education and outreach programmes.
- (ii) Prohibition, through legislative measures backed by sanctions, of all forms of female genital mutilation, scarification, medicalization and para-medicalization of female genital mutilation and all other practices in order to eradicate them.

- (iii) Provision of necessary support to victims of harmful practices through basic services such as health services, legal and judicial support, emotional and psychological counselling as well as vocational training to make them self-supporting.
 - (iv) Protection of women who are at risk of being subjected to harmful practices or all other forms of violence, abuse and intolerance.
- **Article VIII** provides for Access to Justice and Equal Protection under the Law. It states that women and men are equal before the law and shall have the right to equal protection and benefit of the law and that States Parties shall take all appropriate measures to ensure:
 - (i) Effective access by women to judicial and legal services, including legal aid.
 - (ii) Support to local, national, regional and continental initiatives directed at providing women access to legal services, including legal aid.
 - (iii) The establishment of adequate educational and other appropriate structures with particular attention to women and to sensitize everyone to the rights of women.
 - (iv) That law enforcement organs at all levels are equipped to effectively interpret and enforce gender equality rights.
 - (v) That women are represented equally in the judiciary and law enforcement organs.
 - (vi) Reform of existing discriminatory laws and practices in order to promote and protect the rights of women.
 - **Article XXIII** provides for special protection of women with disabilities and calls on States to:
 - (i) Ensure the protection of women with disabilities and take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision-making.
 - (ii) Ensure the right of women with disabilities to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity.
 - **Article XXV** provides for remedies and its States that States Parties undertake to:
 - (i) Provide for appropriate remedies to any woman whose rights or freedoms, as herein recognized, have been violated;
 - (ii) Ensure that such remedies are determined by competent judicial, administrative, or legislative authorities, or by any other competent authority provided for by law.

Despite this protocol having provisions for the protection of African women from harmful practices, it does not explicitly mention women with albinism. It is important to note that

under Article V on **the elimination of harmful practices**, it focuses on FGM leaving out other harmful practices including sexual violence and attacks on women with albinism. **Article XXIII** provides for special protection of women with disabilities. Even though there is no specific mention of women with albinism, this article can be used to hold the Kenyan Government accountable and call on more to protect women with albinism who are at great risk of sexual violence, ritual killings, and other harmful practices.

2.2.6 Marrakesh Treaty

The Marrakesh VIP Treaty (formally the Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired or Otherwise Print Disabled), provides for the exchange of accessible-format books across international borders by organizations that serve people who are blind, visually impaired, and print disabled. This instrument was adopted in 2013 and entered into force in 2016⁶⁹.

The Treaty was principally conceived in line with principles of nondiscrimination, equal opportunity, accessibility, and full and effective participation and inclusion in society, proclaimed in the UDHR and the CRDP Convention. The Preamble is mindful of the fact that there is a plethora of challenges that prevent the complete development of persons with visual impairments or with print disabilities, limiting their freedom of expression including, the freedom to seek, receive and impart information and ideas of all kinds on an equal basis with others, through all forms of communication of their choice as well as their enjoyment of the right to education and the opportunity to conduct research.

The treaty was ratified by Kenya on the 2nd of June, 2017. While this treaty does not mention albinism it is important to note that the key characteristic of all types of albinism is lack of pigment in the eyes which leads to low vision and therefore this treaty is of huge benefit to persons with albinism in accessing information in all spheres of life.

Undeniably, the Kenya government has portrayed commitment in terms of ratification of international treaties and conventions. However, the implementation has been hampered by lack of a documented framework for implementation. Sessional paper No. 14 of 2012 cites that one of the challenges related to access and equity in the provision of education and training to children with special needs is the slow implementation of guidelines on special needs education (SNE) policy and inclusive education (GOK, 2012). Article 189(2) of the 2010 Constitution provides that national and county governments should cooperate in the performance of functions and exercise of powers. The national and county governments should work together on initiatives to enhance access to education for visually impaired students. Collaboration and establishment of linkages among stakeholders in the education sector with other service providers is important. It is hoped that this would ensure a conducive environment for learners with disabilities to participate in quality learning

Persons with albinism have low vision and implementation of this law should be reinforced especially for learners with albinism in accessing education materials. In most cases they

69 World Intellectual Property Organization website. The Marrakesh Treaty. Retrieved from https://www.wipo.int/marrakesh_treaty/en/ on 18th January 2022

have been forced to study in braille or regular print; the in-betweenness of the vision of persons with albinism has only been addressed in this treaty.

2.3 National laws on albinism

Kenya has a glaring gap on albinism-specific legislation. The only policy that mentions Albinism is the Sector Policy for Learners and Trainees with Disability of 2018 which recognizes albinism as a category of disability.

Kenya has put in place several legislative measures and programs on disability which can be a basis for Albinism rights. Further, Kenya is in the process of amending its laws to give effect to the provisions of the Convention on the Rights of Persons with Disabilities. Kenya has made progress in safeguarding and protecting the rights and welfare of persons with albinism through de facto interventions. There is no specific law, legislation or policy framework that directly safeguards persons with albinism, magnifying the gaps for advocacy as the legal provisions are non-existent.

For laws on disability that are currently being discussed in Parliament like the Persons with Disabilities (amendment) bill, 2020, which has been in discussions for years and to date it has not been passed into law. At the time of developing this report, the 12th Parliament had adjourned for the 2022 General Election without finalizing the amendment bill for the Persons with disabilities act. This continues to marginalize under-represented groups like persons with albinism when it comes to legal provisions that advocate and provide for their rights. This results in delays in judicial remedies and legal redress for persons with albinism. Key informants indicated that even the amendment of the Persons with Disabilities (amendment) bill, 2020 that is still pending in Parliament is still very silent on persons with albinism.

2.3.1 Constitution of Kenya 2010

The Constitution of Kenya is the Supreme Law in Kenya and any other law inconsistent with it is said to be void to the extent of the inconsistency. The Constitution of Kenya is said to be a progressive law with a well drafted Bill of Rights. The following are key articles with provisions that are of great importance to this study;

Article 2 asserts the supremacy of the Constitution and makes the following declarations:

- (i) The constitution is the overarching law of the land and all persons and state organs are bound by it.
- (ii) Any law, including customary law that is contrary to the constitution is null and void as far as it contradicts the constitution.
- (iii) If further provides that the general rule of international law shall form part of Kenyan law
- (iv) Any treaty or convention ratified by Kenya shall form part of the Law of Kenya under the Constitution⁷⁰.

70 Kenya Law website. Retrieved from <http://kenyalaw.org/lex/actview.xql?actid=Const2010> on 18th January 2022

Article 2(6) above is important especially when discussing insufficient/gaps in laws and policies on albinism in Kenya. Therefore, any treaty or convention at international and regional level signed and ratified by Kenya forms part of Kenyan Law and can be used to advance the rights of persons with albinism. This can be used strategically for advocacy, access to justice, localization of laws and policies.

There is no specific mention of albinism in the Constitution, though Article 54 references persons with disabilities providing for the right of persons with disabilities to be treated with dignity, respect, and being referred to in a manner that is not demeaning. It provides for the right to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person. The right to reasonable access to all places, public transport, and information, to use sign language, braille, or any other appropriate means of communication and to access materials and devices to overcome constraints arising from the persons with disabilities. Article 43 provides for economic and social rights for all including health, accessible housing, to be free from hunger, clean and safe water, social security, and education.

2.3.2 Persons with Disabilities Act, 2003 (Revised 2012)

Kenya has made progress in safeguarding and protecting the rights and welfare of persons with albinism. However, there is no specific law, legislation or policy framework that speaks directly to albinism; many provisions are enshrined in the Disability act 2003 which as the national law does not mention albinism expressively, creating a big leeway for misrepresentation and implementation. The Kenya Law Reform Commission in collaboration with NCPWD and Ministry of Public Service Gender Senior Citizens' Affairs and Special Programmes and other stakeholders are currently working on amending the PWD Act, 2003 and to this end has drafted The Persons with Disabilities (Amendment) Bill to ensure that the provisions of the act are harmonized with international instruments and with the CRPD and the constitution of Kenya 2010. The amendment efforts include the definition of disability to include persons with Albinism. This will formally classify persons with albinism as persons with disabilities and oblige reasonable accommodation and accessibility to essential services like health, education, employment and economic empowerment.

2.3.3 Basic Education Act, 2013

The preamble of the Act states that it is an Act of Parliament that gives effect to Article 53 of the Constitution and other enabling provisions; to promote and regulate free and compulsory basic education; to provide for accreditation, registration, governance, and management of institutions of basic education; to provide for the establishment of the National Education Board, the Education Standards and Quality Assurance Commission, and the County Education Board⁷².

71 NCPWD website. Retrieved from <https://ncpwd.go.ke/downloads/persons-with-disabilities-act/> on 18th January 2022

72 Government of Kenya, M.O.E website. Retrieved from <https://www.education.go.ke/index.php/downloads/file/96-basic-education-act-no-14-of-2013> on 18th January 2022

The Act defines “basic education” as the educational programmes offered and imparted to a person in an institution of basic education and includes adult basic education and education offered in pre-primary educational institutions and centers⁷³.

Section 4 provides for guiding principles of the Basic Education Act which among a number of provisions gives every child the right to free and compulsory basic education include; protects every child against discrimination in learning institutions; protects the right of every child in a public school to equal standards of education; promotes peace, integration, cohesion, tolerance, and inclusion as an objective in the provision of basic education. It also endeavors to eliminate hate speech and tribalism through instructions that promote the proper appreciation of ethnic diversity and culture in society; promote good governance, participation, and inclusiveness of parents, communities, private sector and other stakeholders in the development and management of basic education; promotes the respect for the right of the child’s opinion in matters that affect the child. In addition, it eliminates gender discrimination, corporal punishment or any form of cruel and inhuman treatment or torture; promotes the protection of the right of the child to protection, participation, development, and survival and non-discriminates, encourages and protects the marginalized, persons with disabilities and those with special needs.

Section 5 establishes and provides for the function of the National Education Board which includes: putting measures in place to ensure all children attend and remain in school to complete basic education requirements and putting measures to ensure, where applicable, transition to the next level of education, especially for the vulnerable and marginalized children.

Section 20 provides for the composition of the County Education Board which provides for a chairperson and 12 other members appointed by the Cabinet secretary (C S) through an open and competitive process. One of the 12 members should be a representative of persons with disabilities and there should also be a representative of a child rights organization.

Section 28 (1) gives the Cabinet Secretary the mandate to implement the right of every child to free and compulsory basic education.

Section 28 (2) Provides that the CS in consultation with the National Education Board and the relevant County Education Board shall provide for the establishment of: pre-primary, primary and secondary schools, mobile schools, and adult and continuing education centers, within a reasonably accessible distance within a county. In addition, it tasks the CS for Education to appropriate boarding primary schools in arid and semi-arid areas, hard-to-reach, and vulnerable groups as appropriate; and academic centers, or relevant educational institutions to cater for gifted and talented learners in addition to **special and integrated schools for learners with disabilities**.

The Act does not mention learners with albinism specifically but mentions learners with disabilities. Also, the availability and accessibility of schools for learners with disabilities is in question. The reality however is different.

The Act gives the County government the role of providing funds for the development of the necessary infrastructure for institutions of basic education and training. Section 28, the Cabinet secretary is mandated to implement the right of every child to free compulsory education and in consultation with the National Education Board and relevant County Education Board provide for the establishment of special and integrated schools for learners with disability.

34. (1) A child shall be admitted in a school at the commencement of the academic year or within such extended period as may be prescribed. (2) A school or person responsible for admission shall not discriminate against any child seeking admission on any ground, including ethnicity, **gender**, sex, religion, race, colour or social origin, age, **disability**, language, or culture

Section 44 to section 48 of the Act provides for Special schools with the cabinet secretary having the role of establishing and maintaining public special schools, while the county education board in consultation with the relevant county government provides for education assessment and research centers including a special needs service in identified clinics in the county.

Section 44(3) defines Children with special needs as intellectually, mentally, physically, visually, emotionally challenged or hearing-impaired learners; pupils with multiple disabilities; and specially gifted and talented pupils.

In as much as the Act provides for the rights of every child to free and compulsory education; it does not specifically mention children with albinism.

Section 28 and Part IV of the Act provides for special needs education. This takes us back and does not create progress with regards to the rights of persons with albinism. Persons with albinism should be in mainstream schools with provision of reasonable accommodation.

2.3.4 Social Assistance Act, 2013

This Act came into place to give effect to Article 43(1)(e) of the Constitution; to establish the National Social Assistance Authority and to provide for the rendering of social assistance to persons in need⁷⁴. However, this act has never been entered into force more than 9 years later. In the year 2020, the Social Assistance (Repeal) Bill 2020 was established seeking to repeal the Social Assistance Act 2013 with the intention to operationalization of the Social Assistance Fund, under draft regulations through the Public Finance Management Act 2012⁷⁵. All the same, Section 17(1) of the Social Assistance Act of 2013 defines persons in need as orphans and vulnerable children, poor elderly persons, unemployed

73 Section 2 of the Basic Education Act

74 International Labour Organization website. Retrieved from https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=97356 on 18th January 2022

75 Mudora, H. (2020). Repeal of the Kenya Social Assistance Act 2013 is misguided Retrieved from <https://africaps.org/blog/repeal-of-the-kenya-social-assistance-act-2013-is-misguided/> on 14th September 2020

persons, persons disabled by acute chronic illness, widows and widowers, persons with disabilities and any other determined by Minister. It does not however include persons with albinism.

2.3.5 Public Service (Values and Principles) Act, 2015

This is an act of parliament that gives effect to the provisions of Article 232 of the Constitution regarding the values and principles of public service and for connected purposes⁷⁶. It makes general provisions for the public service for the management of human resource both at the national and county government level. Article 10. (2) d highlights the issue of fair competition and merit as the basis of appointments and promotions and further emphasizes that, the public service may appoint or promote public officers without undue reliance on fair competition or merit if— (d) persons with disabilities are not adequately represented in the public service or in a public institution. While this doesn't mention persons with albinism it provides a general provision for persons with disabilities to be included in the labor force as public servants. In Kenya currently the public service commission has rolled out an internship program targeting youths with disabilities which includes albinism to fast track their uptake into the public service positions.

2.3.6 Public Procurement and Disposal Act, 2015

This is an act of parliament that gives effect to Article 227 of the Constitution; it provides procedures for efficient public procurement and for assets disposal by public entities; and for connected purposes⁷⁷. The Act aims to promote competition and ensure that competitors are treated fairly; to promote the integrity and fairness of those procedures; to increase transparency and accountability in those procedures; and to increase public confidence in those procedures. The Act makes provisions for disadvantaged groups, women, youth, and persons with disabilities to access procurement opportunities. It provides general guidance and procedures to public procurement and disposal of public assets, it doesn't mention persons with albinism but mentions persons with disabilities.

2.3.7 Employment Act, 2007

The Act provides for the fundamental rights of employees, basic conditions of employment of employees and it regulates employment of children⁷⁸. Section 5(3) prohibits discrimination either directly or indirectly by employer against an employee on grounds of race, color, sex, language, religion, political or other opinion, nationality, ethnic or social origin, disability, pregnancy, marital status or HIV status. Even with Section 5 in place the reality is different as persons with albinism still face numerous challenges in gaining employment.

76 Government of Kenya (2015). Retrieved from <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/101064/121598/F-2001559592/KEN101064.pdf> on 18th January 2020

77 Government of Kenya (2015) Retrieved from <https://eacc.go.ke/default/wp-content/uploads/2018/06/PPDA.pdf> on 18th January 2022

78 Kenya Law website. Retrieved from <http://kenyalaw.org:8181/exist/kenyalex/actview.xql?actid=No.%2011%20of%202007> on 18th January 2022

2.3.8 Health Act, 2017

The purpose of the Act is to establish a unified health system, to coordinate the interrelationship between the national government and county government health systems, to provide for regulation of healthcare services and healthcare providers, health products and health technologies⁷⁹. Health is one of the major critical areas for persons with albinism but persons with albinism still face major challenges in accessing health services. This is one of the major laws that needs to consider the right of persons with albinism to access quality and affordable health care services.

Section 4 states that it is the fundamental duty of the State to observe, respect, protect and fulfill the right to the highest attainable standard of health including reproductive health care and emergency medical treatment. Section 5 further states that every person has the right to the highest attainable standard of health which shall include progressive access for provision of promotive, preventive, curative, palliative, and rehabilitative services. Section 15 states that the national government ministry responsible for health in consultation with county government, health stakeholders and the public shall develop health policies, laws, administrative procedures, and programs for progressive realization of the highest attainable standards of health.

The Act does not mention persons with albinism. It has provided for the right of all with Section 15 strategically allowing development of health policies, laws, programs to attain the highest standard of health. The government launched a free sunscreen program which aims to provide sunscreen to all persons with albinism in Kenya there is however no investment in skin cancer prevention measures and palliative care for those that have already been exposed to skin cancer which is prevalent to PWAs due to their lack of melanin. The question to ask is after being launched, how many persons with albinism can access sunscreen? How is information disseminated to ensure people know where to access and how accessible are the facilities where sunscreen is provided. Does it meet the demand?

Persons with albinism have many other health needs including lifelong eye care needs, mental and psychosocial related health needs and sexual and reproductive health rights as well and therefore the need to have specific policies to provide for the highest standard of health care for persons with albinism.

2.3.9 Sector Policy for Learners and Trainees with Disabilities, 2018

The Ministry of Education developed the Sector Policy for Learners and Trainees with Disability in 2018 that recognizes albinism as a category of disability⁸⁰. This to date remains the only single framework that mentions albinism. However, its focus is only in relation to inclusive education and leaves out other needs of persons with albinism including health and employment among others.

79 Government of Kenya (2017) Retrieved from <http://kenyalaw.org:8181/exist/rest/db/kenyalex/Kenya/Legislation/English/Acts%20and%20Regulations/H/Health%20Act%20-%20No.%2021%20of%202017/docs/HealthAct21of2017.pdf> on 18th January 2022

80 Government of Kenya. Ministry of Education website. Retrieved from <https://www.education.go.ke/index.php/downloads/file/510-sector-policy-for-learners-and-trainees-with-disabilities> on 18th January 2022

The purpose of the policy is to align education and training services for learners and trainees with disabilities with the relevant national policy frameworks; develop a clear policy framework for the provision of inclusive education and training; address the existing policy and implementation gaps in the provision of education and training for learners and trainees with disabilities; and develop guidelines for the implementation of the policy.

The policy covers assessment and early intervention, access to quality and relevant education and training, quality learning environment, health and safety, specialized learning resources, assistive devices and technology, capacity building and human resource development, public participation and engagement, advocacy and awareness creation, equity and gender mainstreaming, curriculum, financing and sustainability, partnership, collaboration and coordination, research, data management and innovation, inclusive disaster preparedness, response and reduction, mentorship, molding and nurturing of national values.

2.3.10 Children's Act, 2022

This is an Act that makes provision for parental responsibility, fostering, adoption, custody, maintenance, guardianship, care and protection of children⁸¹. It also makes provisions for the administration of children's institutions; to give effect to the principles of the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child.

It defines a "disabled child" as a child suffering from physical or mental handicap which necessitates special care for the child. The Act does not mention children with albinism and even with the definition of a disabled child clearly leaves out children with albinism.

Section 5 states that no child shall be discriminated on basis of origin, sex, religion, creed, custom, language, opinion, conscience, colour, birth, social, political, economic, or other status, race, disability, tribe, residence or local connection.

2.3.11 Counter-Trafficking in Persons Act, 2010

This Act seeks to implement Kenya's obligations under the United Nations Convention Against Transnational Organized Crime particularly its Protocol to prevent, suppress and punish trafficking in persons, especially women and children and to provide for the offences relating to trafficking in persons⁸².

Section 15(2) states that when developing the plans for support and protection of victims of trafficking, the Minister shall consider the age, gender, and the special needs of children and persons with disabilities and the personal circumstances of each victim of trafficking in persons. The Act has no provision on persons with albinism.

81 Kenya Law website. Retrieved from <http://kenyalaw.org:8181/exist/kenyalex/actview.xql?actid=No.%2029%20of%202022> on 15th September 2022

82 International Labour Organization website. Retrieved from <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/84999/115494/F-2071338712/KEN84999.pdf> on 18th January 2022

2.3.12 Sexual Offences Act, 2006

The SOA provides for what constitutes sexual offences, their definition, prevention, and protection of all persons from harm, from unlawful sexual acts. The Act defines a vulnerable person as a child, person with mental disabilities or an elderly person⁸³. Section 31 states that a vulnerable witness is a child, persons with mental disabilities or alleged victim. It does not specifically mention persons with albinism as vulnerable persons or witnesses. It is important to note that persons with albinism are targeted and subjected to attacks including sexual violence with a culture of silence.

Section 31(2) states that the Court can declare a witness vulnerable on other accounts including age, trauma, intellectual, psychological or physical impairment, cultural differences, possibility of intimidation, race, religion, language, relationship of witness to any part of proceedings, nature of subject matter.

The Sexual Offences Rules of Court, 2014 provides for reasonable accommodations in court for vulnerable witnesses. This can be used to request for reasonable accommodations in court for persons with albinism who are survivors of sexual violence and require accommodations.

2.3.13 Legal Aid Act, 2016

As described in Section 2 of the Legal Aid Act of 2016, legal aid is legal advice or legal representation or assistance in resolving disputes by alternative means of dispute resolution, drafting of relevant documents and effecting service incidental to any legal proceedings and reaching or giving effect to any out of court settlement⁸⁴. Legal aid is central to the concept of justice, human rights, equality, democracy, truth and freedom.

Justice in Kenya is administered by the court through litigation or alternative dispute resolution mechanisms which are usually costly both in terms of time and money. As a result, many Kenyans with lower financial capability and more so the marginalized are often disadvantaged in accessing justice.

Legal aid services are offered to all Kenyans irrespective of their status, religious affiliation or race, their disability status notwithstanding, as long as they meet the threshold, that is, that the person's income does not exceed thirty thousand shillings. The main aim of legal aid is to ensure that justice is served to all regardless of financial status. Section 5 of the Legal Aid Act, 2016 establishes the National Legal Aid Service with the mandate to inter alia provide legal aid services to indigent, marginalized, and vulnerable persons.

2.3.14 Persons with Disabilities Act (Income Tax Deductions and Exemptions) Order, 2010

The Order provides that a person with disability may apply to the Commissioner-General (of the Kenya Revenue Authority) through the National Council for Persons with Disabilities

83 Kenya Law website. Retrieved from http://kenyalaw.org/kl/fileadmin/pdfdownloads/LegalNotices/2014/LN101_2014.pdf on 18th January 2022

84 Nafula, S. (July, 2022) Understanding legal aid. Usawa na haki. NCPWD newsletter. NCPWD, Nairobi. Retrieved from <https://ncpwd.go.ke/wp-content/uploads/2022/08/Usawa-Na-Haki-July-2022-Issue-2.pdf> on 14th September 2022

for exemption from income tax of the first one hundred and fifty thousand shillings of their total income per month.⁸⁵ The tax exemption is required annually, meaning persons with disabilities have to get their disability approved every year, even though a majority of the disabilities are life long and irreversible.

2.4 County laws

Several counties, ten in number, through their county assemblies have created Persons with Disability Acts to safeguard and improve the wellbeing of persons with disabilities in their specific counties through the devolved units as at December 2021⁸⁶. These are county governments individual efforts in legislation or policy formulation on disability mainstreaming. The Counties which have legislated on disability mainstreaming include Turkana, Kisii, Machakos, Meru, Nakuru, Nairobi, Kisumu Makueni, Homabay & Kilifi. Where counties do not have relevant disability acts or people with disabilities are not mentioned in the County Integrated Development Plans, there has been found to be a lack of relevant policies addressing the inclusion of people with disabilities at the county level which further marginalizes persons with disabilities in the new dawn and spirit of devolution.

The focus of the county disability Acts is assistive devices, employment, and health to promote inclusive development at the county level. In all these Acts none mentions or cites persons with albinism even with the glaring and unique needs that persons with albinism experience.

2.5 Key Gaps

Several gaps in the legal and policy frameworks are noted in relation to persons with albinism:

1. Kenya has signed the African Disability Protocol and deposited the instruments of accession to the African Union⁸⁷. The Protocol makes provisions against ritual killings and harmful practices such as witchcraft which are concerns that strongly touch on persons with albinism. However, only 3 countries have signed the Protocol yet this instrument requires 15 member states to sign for it to be ratified. Further, Kenya received specific recommendations on albinism by the UN Independent expert on albinism and needs to have these implemented.
2. The lack of mention of albinism in the majority of the relevant laws presents the first barrier to access to equal opportunities, in all spheres, by persons with albinism in Kenya.

85 The Persons with Disabilities Act (Income Tax Deductions and Exemptions) Order 2010 s. 4 <http://kenyalaw.org/kl/index.php?id=740>

86 KNCHR (2022) Review of county legislation on the rights of persons with disabilities. Compliance with the UN Convention on the Rights of Persons with Disabilities and The Kenyan Constitution. Retrieved from <https://www.knchr.org/Portals/0/Disability%20Publications/Review%20of%20County%20Legislation%20on%20The%20Rights%20of%20PWDs.pdf?ver=2022-06-02-123434-927> on 14th September 2022

87 Extract from the Ministry of Foreign Affairs' website on depositing instruments of accession to the African Union <https://mfa.go.ke/kenya-deposits-three-instruments-with-au/>

3. Most legal and policy documents on disability in Kenya have not embraced the concept of 'albinism'. This includes the National Plan of Action on Implementation of Recommendations made by the Committee on the Rights of Persons with Disabilities to be implemented from September 2015-June 2022. This poses a challenge for specific advocacy agendas in support of persons with albinism.
4. Lack of recognition of albinism in disability laws and policies developed at the County level. Just like at the national level, all the county laws and CIDPs (2018-2022) reviewed have programs and activities focusing on disability broadly but fail to make mention of PWAs.
5. With albinism as a public health issue the programs that seek to address the health needs are ad hoc and not legislated; this makes it unsustainable and only dependent on good will and can easily be stopped at any time.
6. There lacks a well coordinated monitoring mechanism that first ensures a well-established data base of persons with albinism and intersectionality collaboration among the various government ministries and departments e.g. ministries of education, social services, health and with institutions like NCPWD among others.
7. The requirement by KRA for renewal of persons with disabilities certification for tax exemption was raised by respondents in FGDs on the basis of its justification. They reckoned as persons with a permanent form of disability, their situation is not subject to change whatsoever and therefore, this requirement is unrealistic to them and tedious to undertake every so often.
8. Non-responsiveness by police and institutions in authority when cases of abuse and incitement against persons with albinism are brought to them emerged as a key challenge. Abuses such as name calling or threats to bodily harm or threats to human trafficking deserve to be handled and treated with seriousness. It impacts negatively on the esteem and psyche of persons with albinism when no action is meted on perpetrators of such acts.
9. Many persons with albinism still face high risk of grievous bodily harm and being targeted for use of their body parts in harmful practices such as witchcraft and cultism. Their dignity is also interfered with since a majority of persons with albinism are often verbally abused and threatened that they may be sold out to human trafficking rings.

2.6 Recommendations

1. **International obligation and commitment:** On the backdrop that Kenya has received very specific recommendations on albinism first, by the UNCRPD committee in 2015 and secondly by the UN independent Expert on albinism during her Kenya country visit in 2018, there is need to accelerate the development of a National policy on albinism and further adopt a country specific action plan on albinism anchored on the continent wide AU strategy on albinism (2021-2031). This will provide mechanisms for practical and specific measure to end attacks, stigma, discrimination, and violations of rights of Persons with Albinism. The Independent Expert on Albinism Ms. Ikponwosa Ero in her report stated, "I also urge Kenya to

create a brief but comprehensive national action plan, in line with the Regional Action Plan, to end violence and violations against persons with albinism as recommended by the African Commission on Human and Peoples' Right”.

2. **Coordinated monitoring mechanism:** A task force on albinism consisting of members of various relevant Ministries; Special Programs, Education, Justice, Health among others needs to be established. This task force can help the government create a time-bound action plan and carry out its short-, medium- and long-term goals and assist in implementing other recommendations herein. The task force should have a budget and should consist of consultation with civil society including persons with albinism.
3. **Participation & representation:** There is a need to ensure meaningful, active participation and consultations with diverse persons with Albinism in all programs, laws and policies. Further, PWA need to be included in monitoring human rights frameworks and bring the intersectionality of issues in relation to albinism.
4. In light of the root causes of the gross human rights violations and attacks that are meted on persons with albinism, the state should review the anti-FGM act and capture harmful traditional and cultural practices so as to cover the specific attacks on PWA.
5. Kenya should act to end all forms of discrimination racial discrimination and institute policies to end harmful practices, particularly those centered on accusations of witchcraft and ritual attacks against persons with albinism.

CHAPTER 3

FINDINGS OF THE STUDY

This part provides an analysis of both primary data, secondary information and literature on the state of persons with albinism, programmes, policies and legislation across the three counties of Kakamega, Nyeri and Kilifi. The three counties represent the sample that were selected as a pilot phase of this study of mapping programmes, policies, legislations and organizations for persons with albinism.

3.1 Regional profiles

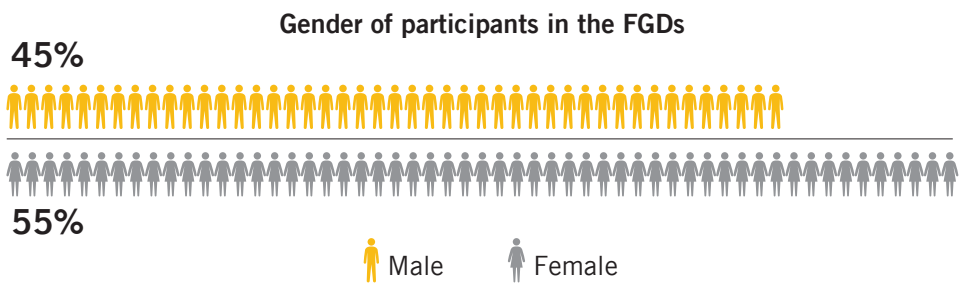
The table below shows a brief profile of the three regions sampled, their total population, percentage of population with disabilities, the actual number of persons with disabilities, those with albinism as per the 2019 national census and the estimated number of persons with albinism as provided by the respective NCPWD offices.

County	Total population ⁸⁸	% of population with disabilities ⁸⁹	Population of persons with Disabilities ⁸⁹	Population of persons with albinism ⁹⁰	Population of Persons with albinism registered and receiving support from NCPWD*
Kakamega	1,867,579	2.9	54,160	314	218
Nyeri	759,164	3.2	24,293	72	30
Kilifi	1,453,787	1.6	23,261	143	113

*Information sourced from Key informants

3.2 Respondents reached

A total of 29 participants were sampled and interviewed in the FGDs. Of these 13 were male and 16 were female. In Kakamega County, 10 respondents were reached (6 male, 4 female), while Nyeri county 9 were reached (3 males, 6 females) and in Kilifi County 10 were reached (4 male, 6 female). They comprised persons with albinism and parents/guardians of children with albinism. The pie chart below gives an illustration of the percentages of the respondents that were reached in the FGDs.



A total of 29 participants drawn from 3 Countries were sample and interviewed in the FGDs

88 Government of Kenya (2019) 2019 Kenya Population and Housing Census. volume I: *population by county and sub-county November 2019*

89 Development Initiatives (2020) Status of disability in Kenya. *Statistics from the 2019 census*. Background paper

90 Government of Kenya (2020). 2019 Kenya Population and Housing Census. Retrieved from. <https://open.africa/dataset/2019-kenya-population-and-housing-census/resource/6fcbd158-483e-405a-bce1-1cf8f62b48e9>. on 25th May 2022

3.3 Human rights violations faced by persons with albinism

The study identified numerous challenges that persons with albinism face in their day-to-day life. These challenges emerged as key concerns when persons with albinism who were interviewed were asked to mention what they regarded as key concerns that affect them. Other respondents, mainly key informants were also asked to identify key concerns that affect persons with albinism. These key concerns are categorized in the following subheadings.

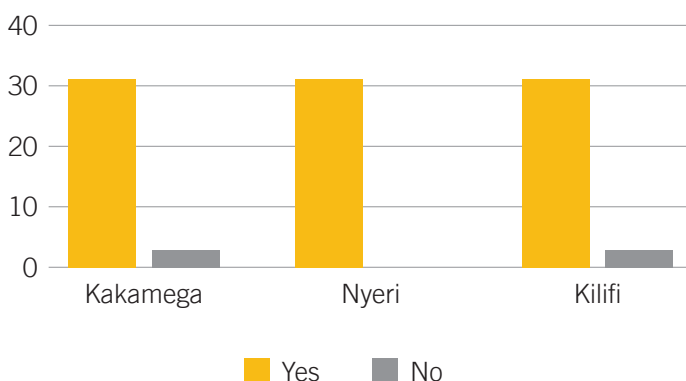
Stigma and discrimination

All the persons with albinism interviewed through the focus group discussions mentioned stigma as a key concern as a result of the name calling they received from the general public. This concern was corroborated by key informants who identified stigma as a key challenge that affects persons with albinism. They mentioned derogatory names that were used to refer to persons with albinism. The persons involved in this name calling showed no remorse or empathy using such demeaning terms. The table below illustrates how the respondents across the three areas experienced stigma by responding to 'yes' or 'no' on whether they had experienced stigma in their day-to-day interactions with their respective communities.

Stigma and discrimination

	Frequency			Percentage		
	Yes	No	Total	Yes	No	Total
Kakamega	9	1	10	31.03	3.45	34.48
Nyeri	9	0	9	31.03	-	31.03
Kilifi	9	1	10	31.03	3.45	34.48
Total	27	2	29	93.10	6.90	100

% Frequency of stigma and discrimination



Common derogatory names used as mentioned by the persons with albinism include; 'mzungu', which is Swahili word that signifies the Caucasian race, 'litondo' which is a Luhya word that means 'matongo' in Swahili or eye boogers in English. Another derogatory name is 'nguchiro' and 'zeruzeru' which even though in Swahili it is used to signify a person with albinism, it may take another turn to refer to things associated with witchcraft and occult practices.

Other non-pleasant ways that the community uses against persons with albinism is to assign them names of popular personalities of the Caucasian race for instance political figures and pop stars. For instance, a person with albinism in Kakamega mentioned how his peers have assigned him names of global political figures and wished that his friends would refer to him by his actual name that appear in his national identity card.

"... kama mimi marafiki wangu wamenibandika majina kama Vladimir Putin ama Fred de Klerk kwa sababu ya ngozi yangu... badala waniite kwa jina langu la nyumbani..."



Another derogatory term commonly used against persons with albinism is 'pesa' which is Swahili for money. This arises from the numerous incidences where persons with albinism have been physically attacked, maimed or killed for their body parts to be sold off to witch doctors for large sums of money. About 70% of persons with albinism that were interviewed mentioned how they have been called 'pesa' with 11% stating having been threatened or mocked to be sold off to Tanzania by persons known to them. The unfortunate thing is that when such matters were reported to the authorities, no action was taken or the issue was handled lightly without giving it the attention it deserved. This non-action by the police when such incidents are reported to them was mentioned by 21% of the respondents.

The biological condition that is albinism and the fact that it results in lack of melanin, the skin pigmentation, makes persons with albinism stand out from the rest of the community. This itself makes them easily recognizable in any social setting such as school, church and the communities they live in. They thus attract unwarranted attention whenever they go about their daily business which ultimately results to the name calling and sometimes getting different kind of treatment from the other members of the community and often discrimination.

"... unapata kwamba kwa sababu ya tofauti ya ngozi yetu, kila mahali tunapoenda tunatambulika kwa urahisi na unaona watu wanakuangalia tofauti..."



Limited awareness on self-care on albinism

The lack of or limited awareness of albinism among many community members and little understanding of the biological and genetic implications of albinism makes the situation harder in that this ignorance perpetuates the stigma towards persons with albinism. This ignorance is exhibited in the way the community handles and treats persons with albinism. There is a lack of understanding for instance that due to a lack of melanin, persons with albinism should not be exposed in the open sun, due to the heightened risk of skin cancer.

Access to government services

With limited awareness on the risks that persons with albinism face, accessing government services is a challenge especially when they happen to be long queues that wind up into the open sun. There is hardly any concern shown by concerned officers to prioritize attending to persons with albinism and have them not queue while exposed to the sun. About 15% of 29 respondents in the FGDs mentioned how they were turned away when they asked to be served before others in the queue after moments of exposure to the sun in the long queue.

Right to education

The study established that in schools where learners with albinism are integrated, there is still some level of ignorance on albinism among the teaching staff. Children with albinism have poor visibility and that means if they sit at the back of the class, they can hardly see the board. As a result, they struggle with catching up with the teacher as he/she writes on the board. Participants from the FGDs narrated their own experiences where their former teachers made no effort to assist them either by making them sit at the front of the class or helping them to catch up on the lessons. They also mentioned the wrong assumption that has been in place for a long time that all children with albinism need to be enrolled in special schools for the blind. Yet even in these special schools, some lack assistive devices specifically for persons with albinism thus making them learn using braille.

Noncompliance among persons with Albinism

Among persons with albinism, there was also a notable level of ignorance on the risks that they face as a result of lack of melanin. Even though the government provides support through the sunscreen programme, there were numerous reports from the County Pharmacists of Kakamega, Kilifi and Nyeri of persons with albinism defaulting on their monthly allocation of sunscreens. In Nyeri for instance, information from the County Pharmacist was that while the County referral hospital had an estimated 48 persons with albinism receiving sunscreen support, only about 30 (63%) were consistent with collecting their monthly allocation. That means 27% of persons with albinism fail to collect their sunscreens. One of the main reasons for the failure to collect the sunscreens was the long distances involved for some meaning that the cost for transport was higher and for those with limited financial capacity, raising the bus fare posed a challenge.

It was also reported that there was a lack of proper understanding of how the sunscreen is applied on the skin thus not making it effective. In addition, there were reports of persons with albinism who never adequately covered their bodies with protective clothing while staying exposed to the sun, thus putting them at risk of developing skin conditions that may lead to cancer of the skin.

Access to government facilities and services

Persons with albinism alluded to the fact that they have been left out in the employment sector. They felt that perhaps they are excluded because of their special needs and requirements such as not being exposed to the sun or perhaps prospective employers feared that they may be expensive to hire and yet they may be limited in a way to fully be effective on the job. They acknowledged that in recent times, many persons with albinism have accessed education up to higher levels while others are empowered with technical skills within various disciplines. Despite these achievements, they felt left out as many of them are still unemployed and have to seek ways of earning a living that may be detrimental to their health.

The government has put in place the 5% policy for reservation of employment of persons with disabilities as per section 13 of the Persons with disability Act (revised 2012). This 5% provision for employment is expected to cover all categories of persons with disabilities including persons with albinism. About 74% of persons with albinism interviewed felt that this allocation was not adequate and that they had to compete for scarce opportunities with other perhaps 'better placed' persons with disabilities thus leaving them out.

Tools of trade

Some of the persons with albinism above the age of 35 years stated that in addition to missing out on opportunities offered in the vocational and technical institutions, they also lack technical skills. What they are left to do to earn a living is doing menial jobs most of which end up exposing them to the sun and increasing their risks for skin cancer.

NCPWD provides tool kits to fresh graduates who are holders of certificates with technical skills. However, this intervention leaves out persons with albinism who are aged but who would still have benefited from that kind of support. Whereas some have taken to running small businesses, the lack of sufficient capital to lease premises that are secure and provide adequate shelter from the sun is a challenge. The allocation of market stalls by the County Social Services Departments has alleviated some of these challenges. However, as established in Nyeri, this is done on a needs basis. Once a person with disability approaches the department with this need, then can a stall be allocated to them.

Challenges in reading signs

The built environment poses a big challenge to persons with albinism mainly due to their visual challenge. Accessing government offices, business premises, markets where signs are erected to show direction or names of offices or shops poses a challenge as the signs are never legible or visible enough. This thus compels them to seek assistance to be directed accordingly. However, such humble requests are sometimes not well received or the person still insists that they read the erected signs to get to their destination.

Centralization of key services for persons with albinism

The study established that services such as the provision of sunscreen lotions are provided within centralized facilities. This means that a single distribution center serves about three or more sub-counties. Persons with albinism from far flung areas thus have to travel substantially long distances to access the lotion on a monthly basis. As reported by the Pharmacists in all the three counties, the provision of lotions is provided within certain hours within the set date for instance, issuance of lotions begins at 9 o'clock in the morning and ends at about 3 o'clock in the afternoon. Persons with albinism from the extreme corners of the catchment area thus have to be deliberate to get to their designated collection centers on time. However, transport challenges occasioned by rainy weather and poor roads on some occasions mean that they never get to the centers on time and thus miss out on their lotions. Sometimes, persons with albinism may have challenges getting money/bus fare to travel to the centers occasioned by low income levels and lack of employment.

It was also established that key services such as skin cancer management and care are provided at the Kenyatta National Hospital (KNH). This means that Persons with albinism from all over the country in need of this service have to travel to Nairobi for this treatment. Some of them reported that they have no relatives living in Nairobi making it complicated for them to access this treatment. They are compelled to look for money for accommodation which creates an additional burden on them. The final signature of the senior medical health officer that is required to acquire the disability identity card, is also done centrally in Nairobi. The waiting and turnaround time thus takes much longer for these cards to get back to the beneficiaries.

Erratic supply of commodities for persons with albinism

The provision by the government of sunscreen lotion and protective clothing has been of great benefit to persons with albinism. However, their supply at times has been erratic. At the time of conducting primary data collection in the three counties of Kakamega, Nyeri, and Kilifi, only Kilifi had received a recent supply of sunscreen lotions. The other two counties of Nyeri and Kilifi had been out of stock for more than one month. About 80% of persons with albinism interviewed mentioned that the supply of the lotions is never consistent in that there are times they travel long distances to their collection centers only to be informed that the lotions are out of stock. This, coupled with difficulties in raising the bus fare to town, contributes to numerous persons with albinism forfeiting to collect their allocations. From the three counties sampled, protective clothing for persons with albinism was issued only once about 3 years ago in 2019 and this intervention has never resumed ever since.

Tax exemption for PWAs

The study established that NCPWD facilitates tax exemption requests to the Kenya Revenue Authority (KRA) on behalf of persons with disabilities. Every five years, KRA requires that persons with disabilities renew their certification for tax exemption. However, a concern was raised by a respondent in the study regarding this requirement given that persons with albinism do not change their state of disability with time.

"... the question I am left to ask is, why ask a person with albinism to renew their status with KRA every 5 years?...does it mean that my pigmentation will have changed for the better after every five years?..."



The respondents from the FGDs stated that the renewal of the tax exemption certificate is such a tedious process yet their disability is permanent and will not change in any way.

Access to health

The study established that NCPWD supports persons with albinism with the treatment of cancer at the Kenyatta National Referral and Teaching Hospital. However, the respondents mentioned other costs like transport to Nairobi, and accommodation while undergoing therapy which may involve a number of days as a great challenge. And the situation is

harder if one has no known relatives in the city and therefore has to consider putting up in a hotel. One respondent from Kakamega narrated her experience while undergoing cancer treatment that was conducted at Kijabe Mission Hospital after being referred there from Kenyatta National Hospital.

"... after undergoing operation for my skin cancer and it was time to be discharged from hospital, I had no one to help me out. So I had to ask my friend who lives in Mombasa who finally came to help me out with the discharge process..."



Right to property

The study established that persons with albinism face the risk of being excluded from family inheritance. In Nyeri, one respondent who is a person with albinism narrated how her family had tried all means on numerous occasions to deny her from sharing her grandmother's inheritance, a piece of land, that she left behind for her. Yet the rest of the family members got their respective share of the land. Another respondent also mentioned how her neighbours had on two occasions tried to evict her from her property through acts of arson. In both these incidents, the relevant authorities were notified but no substantive action was taken against the perpetrators.

Low budgetary allocations to the Council

In all three counties that were visited, the study established from key informants that the annual allocation to NCPWD for the Albinism Support Programme had been reduced during the present financial year from Ksh.250 million to Ksh.100 million. This was a significant reduction of 60%. This meant therefore they could not adequately reach all the numbers of persons with albinism with services. This meant that every other intervention be it school bursary support or the sunscreen programme were all affected by the huge budget cuts.

Human resource constraints of the Council

Key informants from the three counties that were sampled indicated that NCPWD faces a big challenge in human resource. Officers in charge of the three respective areas each cover a huge geographical zone that covers more than one county with the officer from Kakamega covering the largest area that spans Vihiga, Kakamega, Nandi and Busia. The huge area makes brings with it challenges of effective coverage as the officer can only be in one place at the same time especially when she has to meet with the communities.

Case Study

Margarita's successful battle with skin cancer

*Margarita is a 22-year-old mother of one from Kisumu County and a person with albinism. She is the third born out of eleven siblings. She is the first to be born with albinism as she has 2 more siblings with albinism in her family. Margarita is a skin cancer survivor. The cancer started as a small wound while she was pregnant so nothing much could have been done by then. However, one year later, the cancer treatment commenced.

She first went to the county referral hospital in Kisumu for a biopsy test. She was instead referred to Kijabe Mission hospital where the biopsy was conducted. Traveling to Kijabe was difficult because she did not have money for transport. She approached the NCPWD Coordinator in Kisumu where she got help. They wrote a commitment letter to indicate that they will pay Ksh. 200,000 for her surgery. Usually, the NCPWD refers all skin cancer patients to Kenyatta National Hospital (KNH). But limited bed space challenges at KNH and difficulties in securing an appointment with a skin cancer specialist made her get referred to Kijabe. At Kijabe Mission Hospital, NCPWD made a deposit of Ksh. 80,000 to book her surgery and she was asked to go back later. A day or two to the booked date they postponed her surgery. The wound on her face was growing, it became itchy and was producing water. About three months later, in September, they contacted her and said the surgery was scheduled for 9th October 2017.

She went to Kijabe hospital and admitted herself. She stayed in the hospital for a long time. Her medical bill kept on increasing. Since NCPWD had made a deposit of Ksh.80,000 the hospital had advised her to take NHIF card. She underwent surgery and they did skin grafting. In total, she underwent three surgeries. The third surgery was done after two months. The whole time she was in the hospital, no one went to visit her and she was very lonely and would cry a lot. She juggled between the theater, Intensive Care Unit (ICU), and the High Dependency Unit (HDU). All this time her phone was switched off

and her sister got so worried. A friend of hers who also has albinism came from Mombasa to see her. By the time she reached the hospital, she was about to be discharged and they were following up with NCPWD. The lady friend would go to Nairobi to follow up on payment with NCPWD and return to the hospital; she managed to get the Council to write a letter committing that it will pay the bill and requested for the release of Elizabeth. It was difficult for the hospital to accept the letter since nobody from the council came to confirm. A man from the records office in the hospital talked to the hospital to give her the discharge papers.

Despite the few challenges, she is glad NCPWD came through for her. At first, she was never aware of this support by NCPWD as she only learnt about it from another person. However, she said she would be glad if skin cancer specialists would be made available at the county level instead of having to travel to see them in Nairobi or Kijabe. She used to sleep on hospital benches at Kijabe when she traveled to see the specialist as she could not travel back the same day due to the long distances involved.

There are also challenges with village elders and chiefs. During the Covid-19 period, there was a cash transfer program by the government to vulnerable families. There was door-to-door registration going on in her village, but the elder did not get to her. She met with another village elder and asked why her village elder did not go to her. This other elder called her village elder on the phone and put him on loudspeaker and asked why she was left out. Her village elder was heard asking what type of disability Margarita had because he could not see any. She recommends awareness of disabilities to everyone. Within her community, there are no structures to create awareness. She also says she will not be voting since people with disabilities are not recognized and they will not help.

CHAPTER 4

POLICIES AND PROGRAMMES FOR PERSONS WITH ALBINISM

This chapter spells out findings that were related to policies and programmes that target persons with albinism. Most of these are provided for by the government of Kenya through the NCPWD. Set up in November 2004, NCPWD is a state corporation established by an Act of parliament; the Persons with Disabilities Act No. 14 of 2003. Its mission is to promote and protect equalization of opportunities and realization of human rights for persons with disabilities to live decent livelihoods. This is perhaps the single most significant government institution that has put in place programmes and interventions for persons with disabilities in general with some interventions specifically targeted for persons with albinism, i.e. the Albinism support programme⁹¹.

91 NCPWD website. Retrieved from <https://ncpwd.go.ke/albinism-support-program/#:~:text=This%20program%20is%20designed%20to,then%20dispense%20them%20to%20PWAs> on 18th January 2022

4.1 Interventions directly targeting persons with albinism

4.1.1 National albinism sunscreen programme

Under the Albinism support programme, there is the National Albinism Sunscreen Support Programme (NASSP) that is targeting ALL persons with albinism in the country by providing sunscreen lotions. Currently, the program has registered a total of 3,738 out of which 1,772 are female while 1,967 are males. This is only 38.4% of the total number of 9,729 persons with albinism in Kenya reached through the sunscreen programme⁹². The programme offers three varieties of skin care products that are issued to persons with albinism namely; Sunscreen, lip balm and aftersun. The sunscreen is offered in the brand of Nivea SPF 50 for children and SPF 50 for adults. These commodities are issued out at centralized pharmacy departments within government owned health facilities on a periodic basis. All the three counties that were visited during this study were offering this intervention. The sun screen is aimed at protecting the non-melanated skin of persons with disabilities and shielding them from harmful UV light of the sun.

4.1.2 Skincare support

Linked to the sun screen programme is the skin care support with reference to skin cancer. The Council supports persons with albinism by sponsoring periodic skin clinics where skin specialist/dermatologists attend to persons with albinism and conduct assessments/screening for cancer. Three such clinics were reported in Kakamega, Nyeri and Kilifi. Cases that need immediate attention are identified and appropriate referrals are made to manage the skin cancer. The Council supports all the medical costs for the treatment and management of skin cancer for persons with albinism. For example, in the last cancer screening in Kakamega County, the key informants in that area reported that 5 persons with albinism were identified with skin cancer and were referred for treatment and management to Kenyatta National Hospital. Two of the five were already deceased at the time of data collection for this study since they had advanced skin cancer. As reported by a key informant from Kakamega, cryotherapy services were also provided by NCPWD as part of the initial intervention against skin cancer. A cryogun and liquid nitrogen canister was procured for Kakamega County Referral Hospital to support skin care management to persons with albinism. For clients to access this support, one is required to fill a skin cancer support application form.

4.1.3 Provision of protective gear

The study established from respondents in the FGDs that NCPWD provided them with protective gear (wide-brim hats and long-sleeved shirts). A number of the respondents in the three sampled areas were spotted wearing these protective clothing branded with the NCPWD logo and the coat of arms. However, the respondents indicated that this support was only provided once some years back.

92 Government of Kenya (2019) 2019 Kenya population and housing census. Distribution of population socio-economic characteristics. Vol. IV. Government printers. Retrieved from. <https://housingfinanceafrica.org/app/uploads/VOLUME-IV-KPHC-2019.pdf>

4.1.4 Eye care

Other areas of programming are in health where they try to address the gaps in government programmes. One such gap is in eye care management for persons with albinism. Support from the government has not been consistent and forthcoming as indicated by the respondents in the field. Quite a number of the non-state actors support their beneficiaries in accessing specialized eye care and enable them to acquire spectacles to improve and enhance their vision. With the advice from the UN expert on Albinism, the Council has been providing monocular devices to persons with albinism to further improve their ability to see.

4.1.5 Psychosocial support

Psychosocial support is another important area that is covered by non-state actors where they provide their beneficiaries with counseling sessions and make necessary referrals in order to improve on the welfare and well-being of persons with albinism that they work with. The study did not establish the existence of any state or non-state actors that focuses on sexual and reproductive health rights of persons with albinism which is a key component to holistic health. Additionally, there are no public health interventions to raise awareness on albinism being a recessive genetic condition even at prenatal clinics and programs or any campaigns to educate masses on skin cancer which is prevalent to persons with albinism.

4.1.6 Awareness and advocacy on albinism

NCPWD allocates part of the funds under albinism support to fund organizations working for and with persons with albinism to conduct awareness raising across the counties. The organizations for persons for and with albinism make an application to the council and upon a vetting process; successful organizations are funded to raise awareness on albinism. Several local and grassroots organizations implementing interventions on albinism have benefited from these funds. On its own, the council also conducts albinism awareness for instance during global annual calendar events such as the IAAD by organizing events such as beauty pageants for persons with albinism.

4.2 Interventions for all persons with disabilities as well as persons with albinism

NCPWD offers numerous other programmes that are not limited to persons with albinism but which they still receive as they are categorized as persons with disabilities.

4.2.1 Cash transfer

Cash transfer for persons with disabilities which is provided to persons with severe disabilities i.e. those who need permanent care including feeding, toiletry, protection from danger by other persons, and full time support has to be offered by a caregiver to ensure their needs are attended to. Persons with albinism who were interviewed in the three counties expressed concern that they were left out in this intervention, more for those among them that have developed skin cancer. They could not identify any person with albinism who has ever benefited from this particular intervention.

4.2.2 Job placement

Job placement is another intervention by NCPWD where prospective job markets are analyzed with market information trends in order to disseminate market intelligence to the persons with disabilities. The study identified innovative approaches that are used in this intervention. For instance, an online job placement system known as Fuzu.com was in use in Kakamega where persons with disabilities including those with albinism created their profiles online and when opportunities that matched their skills arose, they were notified to apply for those positions. This was to ensure the 5% job placement/employment legislation by the government is achieved.

4.2.3 Economic empowerment

Economic Empowerment is another government programme implemented through NCPWD. As mentioned by key informants, this is a fund that is set aside that is given as a grant of Ksh. 100,000 as was indicated by key informants. This is unlike other similar funds by the government outside NCPWD, like the Youth Development Fund (YDF), Women Enterprise Fund (WEF) which are given out as loans. These funds are only issued out to organized and registered groups of persons with disabilities. Key informants and persons with albinism from the three counties indicated that only one group of persons with albinism in each county benefited from this programme. However, numerous groups of persons with albinism have registered themselves and applied for this fund. NCPWD reported that in the 2019/2020 financial year, Ksh. 14,268,865 was disbursed to various groups of persons with disabilities. Of these, Ksh. 700,000 was disbursed to specifically groups of persons with albinism.

4.2.4 Assistive devices

Other essential programmes offered by NCPWD to all categories of persons with disabilities include provision of assistive devices. Key informants indicated that this is determined by a specialized doctor who ascertains whether a person with albinism requires this. Items such as wheel chairs or devices to aid in mobility are provided under this programme. In the financial year 2019/2020, 3,544 devices were provided to persons with various disabilities.

4.2.5 Education assistance

Education assistance at primary, high school and mid-level colleges is also offered. Key informants indicated that support given is in the form of bursaries. Scholarships are also provided where NCPWD partners and collaborates with key stakeholders in the corporate sector such as Kenya Commercial Bank (KCB), Equity bank and Kenya Pipeline Corporation (KPC) among others. In the 2019/2020 financial year, 4,032 persons received this support with 51 of them being persons with albinism.

4.2.6 Tools of trade

Tools of trade is another programme offered under NCPWD to persons with disabilities who are graduates of artisan and craftsmanship courses such as beauty and hair dressing, welding and metal work, carpentry etc. Persons with albinism are included

in this programme as well. Upon successful completion and graduation from an artisan course, the graduates are provided with a tool kit relevant to the specific artisanship and this tool kit acts as a startup boost for the graduate to go out into the market and look for contracts and opportunities for excelling in their skills. Respondents from the focus group discussions mentioned that this programme leaves out many older persons with albinism who may have acquired their artisanship certificates before this programme started. They identified quite a number of persons with albinism they know who could benefit from this programme but they are left out due to age. In the 2019/2020 financial year, 254 persons with disabilities were supported with tools of trade out of whom 9 were persons with albinism.

4.2.7 Support to special schools

As indicated by key informants, NCPWD provides infrastructure support to special schools through building class rooms and equipping these facilities. From NCPWD reports, the Council spent Ksh. 17,500,00 in providing infrastructure and equipment support to various institutions which served children with various forms of disabilities.

4.2.8 Processing of tax exemption

Processing of tax exemption for persons with disabilities as provided for in the Persons with Disabilities Act of 2003, is another programme provided for by NCPWD. For this intervention, a valid registration card for persons with disabilities is required. Respondents mentioned that every 5 years, they are required to register afresh with the Kenya Revenue Authority (KRA).

4.2.9 Business exemption letters

Other programmes that were identified that target persons with disability including persons with albinism include; business exemption letters for small traders and business that waives certain county level rates and licenses thus making it easy for persons with disabilities to set up micro-enterprises. Three Persons with albinism during the interviews reported to have benefited from this programme.

4.2.10 LPO financing

Local Purchase Order (LPO) financing is provided to persons with disabilities who have competitively won government tenders to provide either goods or services and they do not have immediate financial resources to provide the goods or services. They thus approach NCPWD who will demand confirmation through the necessary documentation that the tender indeed belongs to the applicant. The council has an undertaking with the Kenya Commercial Bank (KCB) who provide the complete financing for the tender. The beneficiary is contracted to refund the amount financed once they receive payment from the government. In the financial year 2019/2020, 23 persons with disabilities received this support. One challenge that was mentioned was low repayment rates by those who have been financed thus making it difficult to extend the services to other persons with disabilities anticipating to receive this service.

4.2.11 Legal support

Legal and complaints support is another programme offered by NCPWD together with another state actor, the Kenya National Commission on Human Rights (KNCHR). The study established that one case in Nyeri County was referred to the NCPWD legal unit that involved assault on a family that has three children with albinism. The family's home was set ablaze by arsonists on two separate occasions. The family strongly believed that the arson was instigated by the fact they had children with albinism and they were thus allegedly targeted as part of ritual. The KNCHR on its part has received two different cases that involved abuse of persons with albinism and the cases were handled in accordance with the organization's legal support protocols.

4.3 Programmes by non-state actors

Programmes for persons with albinism and persons with disabilities at large are not only limited to government and its related institutions. Non-state actors, mainly non-governmental organizations and Community-based organizations (CBOs) offer a wider variety of interventions. Though they receive funding mainly from donor organizations from overseas, there are a few who have been successful in raising their funds locally. However, they cannot match the government in terms of resource capacity. However small these organizations may be, they are bold and innovative in the way they work with persons with albinism. The study established that a number of these non-state organizations work and address different interventions depending on their strategic objectives and mission.

4.3.1 Economic empowerment and livelihood enhancement

Key areas of interventions are in economic empowerment and livelihood enhancement through the support of small and micro-enterprises such as soap making, artisanship through hairdressing, and cloth making among other trades. Most of these skills are taught through apprenticeships or local experts who journey with the target groups over a period of time. Economic empowerment is also achieved through Village Lending and Savings Associations (VSLAs) where they adopt the merry-go-round method of savings and lending amongst group members. This is popularly known as table banking.

4.3.2 Health

Other areas of programming are in health where the non-state actors try to address the gaps in the government-initiated programmes. One such gap is in eye care management for persons with albinism. Support from the government has not been consistent and forthcoming as indicated from the respondents in the field. Quite a number of the non-state actors support their beneficiaries in accessing specialized eye care and enable them to acquire spectacles to improve and enhance their vision.

4.3.3 Psychosocial support

Psychosocial support is another important area that is covered by non-state actors where they provide their beneficiaries with counseling sessions and make necessary referrals

in order to improve on the welfare and wellbeing of persons with albinism that they work with. The study did not establish the existence of any state or non-state actors that focuses on sexual and reproductive health rights of persons with albinism which is a key component to holistic health. Additionally, there are no public health interventions to raise awareness on albinism being a recessive genetic condition even at prenatal clinics and programs or any campaigns to educate masses on skin cancer which is prevalent to persons with albinism.

4.3.4 Awareness and advocacy on albinism

Awareness and advocacy on albinism is another area of intervention that the non-state actors implement in their programmes. This is normally done through community dialogue events, and outreaches in learning institutions. Advocacy campaigns to highlight the concerns for persons with albinism are also conducted for instance during annual global events like the International Albinism Awareness Day (IAAD) marked every 13th of June. In such events, awareness campaigns are conducted in collaboration with government institutions in order to increase community awareness on albinism and hopefully address the stigma that affects persons with albinism. The study established that some organizations that work for and with persons with albinism receive financial support from NCPWD to conduct awareness activities on albinism.

4.4 Gaps in policies and programmes

This section explores the challenges that were identified in the study with regard to the smooth implementation of policies and programmes for persons with albinism.

(a) Lack of adequate coordination among stakeholders and government

Among the numerous stakeholders working in initiatives and programmes that support persons with albinism, there are hardly any forums that bring them together to share ideas and learn from one another. There exist many similarities in the interventions that they run for instance economic empowerment through micro-enterprises and awareness creation on albinism.

(b) Limited awareness and advocacy on albinism

The study established a big gap among members of the community in the understanding of albinism and what it entails. Respondents mentioned the numerous incidents that they encountered high levels of ignorance on albinism among community members some of whom occupied high status in society. This ignorance on albinism within the community is what perpetuates stigma towards people with albinism.

(c) Lack of psychosocial support associated with stigma of albinism

The challenges of stigma towards people with albinism as a result of the name calling and threats towards bodily harm and human trafficking exerts emotional and psychological pressure on them. The risks of skin cancer with some of them acquiring and struggling with skin cancer equally bears immense mental pressure on them. They are thus in great need of psychosocial support which they hardly access.

(d) Limited access to employment opportunities

Access to employment opportunities for persons with albinism is never guaranteed even with the provision in the Persons with Disabilities Act of 2003 for 5% allocation of all job openings as was established in the study. This observation was equally made by an earlier study by KNCHR in 2014 titled *'From Norm to Practice'* which established that in Kisii General Hospital, which had a total of 550 employees then, only three had disabilities, and only one of the three was a person with albinism⁹³.

(e) Limited access to economic empowerment opportunities

Economic empowerment programmes provided by the government through NCPWD and other non-state agencies do not adequately meet the needs of persons with Albinism. From the study, it was established that in the three counties that were sampled only one group of persons with albinism in each county had benefited from the programme by NCPWD. Several other groups are still pending on the waiting list not sure when their turn would come despite them meeting all the necessary requirements. Other funding mechanisms by the government for example the Women Enterprise Fund, the Youth Development Fund among others have not benefited groups associated with persons with albinism in the sampled counties. The non-state actors, though providing similar programmes, are limited in terms of their resource capacity and scope and can only support a handful of groups for persons with albinism.

(f) Persons with albinism felt left out and left behind in interventions that involve them

The study established that in as much as numerous programmes were in place targeting persons with albinism and persons with disabilities at large, the form of relationship that existed between the agencies and the target population was that of provider and beneficiary; with each group on either side of the divide. The respondents felt somehow left out in actively participating in the design and actual roll out of the programmes. They mentioned that no person with albinism sat on the implementation desk directing the process and leading the way as they felt such persons would relate way better with their concerns.

(g) Data for persons with albinism not well integrated and harmonized

Some differences were observed in the data for persons with albinism when comparing data from the KNBS housing and population census of 2019 and data held by NCPWD with respect to the actual numbers that have been registered by the county offices and the numbers that receive sunscreen lotions at the health facilities that were visited. It should be noted that there are sets of data held by different ministries notably the Ministry of Education through its newly introduced National Education Management Information System (NEMIS) which captures all data of children in the education system in Kenya.

93 Kenya National Commission on Human Rights *'From Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya'* (July 2014) www.knchr.org/Portals/0/EcosocReports/From%20Norm%20to%20Practice_Status%20Report%20on%20the%20Implementation%20of%20the%20Rights%20of%20PWDs%20in%20Kenya.pdf?ver=2018-06-06-182335-003

(h) **Unrealistic requirements for registration and vital statistics for persons with disabilities**

The study gathered that for such services, persons with disabilities need to renew their registration every five years. The question they asked was whether a person's condition of albinism, for instance, would change to anything different from that. Yet the process involved in renewing the registration can be long, tedious and frustrating. In addition, persons with albinism noted that whereas the card for persons with disabilities captured certain other types of disabilities, it leaves out albinism.

(i) **Lack of integration of albinism into key health programs**

Albinism is a public health issue that should focus on holistic health both skin and eye care and all other health needs. These concerns need to be integrated into the health system yet this is not the case. Outside of NCPWD interventions, these services would hardly be provided.

(j) **Inadequate or non-existent legal support mechanisms**

Persons with albinism face a higher risk of abuse and grievous bodily harm as a result of the superstitions that surrounds the lack of awareness on albinism. The existence of harmful practices such as witchcraft and cultism only serve to increase this risk. The study established from the respondents in the FGDs that they had ever received threats or people making fun of them that they would sell them off to ritualists. There lacks channels and systems through which persons with albinism can follow through to get support. Reporting to the authorities on numerous occasions ends up with no punitive measures taken on persons who make such deadly utterances.

CHAPTER 5

STRATEGIC RECOMMENDATIONS AND CONCLUSION

This chapter gives the strategic recommendations and which are arranged according to the target ministry that can work on them. The following are the major recommendations that were established through the study.

5.1 Recommendations

5.1.1 Recommendations to the Ministry of Health

(a) **Psycho-social services and safety spaces/structures**

Programmes to minimize and cope with psychological consequences such as mental health risks, trauma of skin cancer, name-calling, threats to physical bodily harm and death, loss of voice and decision making; and dealing with gender-based violence should be initiated or scaled up at local levels. The programmes could include counseling services; and group activities with peers.

(b) **Integrate key health programmes into Albinism**

Albinism being a public health issue, there should be a focus on holistic health both skin and eye care and all other health needs and the same to be embedded in existing health systems.

Essential support like sunscreen should be listed as an essential drug to ensure its availability in the smallest health unit.

Eye care services (glasses and optical low vision devices) to be availed more frequently and sustainably as these are lifelong needs for persons with albinism. Further a quest for holistic public health interventions to raise awareness on albinism being a recessive genetic condition even at prenatal clinics and programs or any campaigns to educate masses on skin cancer which is prevalent to persons with albinism

5.1.2 Recommendations to the Ministry of Education

(a) **Communication and advocacy strategy on albinism public education, awareness and training**

The study established that stigma towards persons with albinism is as a result of little understanding of what albinism is about. There is thus a need for a purposeful communication and advocacy strategy on albinism at national level to increase the levels of awareness and appreciation of albinism and thus eliminate stigma towards persons with albinism. It is essential to undertake an intense and widespread sensitization campaign across the country in order to increase awareness and understanding of albinism. There was a widespread mention by persons with albinism that many people saw them as not fully impaired and they end up missing key opportunities and benefits from programs meant for persons with disabilities.

5.1.3 Recommendations to the Legislature

(a) **Enforcement of laws against abuse of persons with albinism**

Increasing investments on policy and programmes and strengthening accountability mechanisms at community, county and national levels is important.

5.1.4 Recommendations for Ministry of Public Service, Gender, Senior Citizens' Affair and Special Programmes

(a) Develop a coordination and peer review mechanism for all stakeholders working on albinism at community and national levels

The study shows that different agencies implementing programmes on albinism at community, county and national levels duplicate efforts and in certain cases do not synergize with government efforts. There is a need for a coordination mechanism for all stakeholders working on albinism and disabilities at all levels. Agencies need to work together with the government in order for the interventions to have effect whereas working in silos only leads to negative results. This will promote cohesiveness and provide great learning opportunities among different agencies. A common mechanism would also inform a coordinated national research and information management agenda. Such an agenda should be designed to incorporate emerging lessons and innovations into albinism and disability interventions, policy and investment options.

(b) Economic empowerment and social protection policies

Programmes that economically empower persons with disabilities including persons with albinism should be upheld and enhanced. The programme should be adequately resourced to include more groups of persons with albinism.

There needs to be better integration of efforts by government, civil society, and private sector (micro-finance institutions) so that linkages can be enhanced and more persons with albinism are enabled to access affordable credit to start and grow their business ventures. Efforts by the civil society working the persons with albinism to economically empower their beneficiaries should be promoted and supported through improved resourcing.

(c) Conduct effective public participation with persons with albinism

Actively engage persons with albinism in all programmes affecting them especially regarding investments, programming and policies that concern them

(d) Strengthen registration and vital statistics to ensure legal compliance to persons with disabilities

The registration and issuance of disability cards should be expanded to include albinism as one of the categories of disability and the card should be permanent as opposed to the requirement of renewal every 5 years.

(e) Integrate and harmonize systems for data, monitoring and evaluation of persons with disabilities

The National Council for Persons with Disabilities, the Ministry of Education, the Kenya National Bureau of Statistics and the Ministry of Health should harmonize their data. The synchronized data will inform better planning and resource mobilization for persons with albinism.

(f) Make provision for legal support mechanisms

There is an urgent need to have in place laws and policies on Albinism and with continued attacks, threats and stigma there is need to establish effective complaints mechanisms, referrals to ensure better access to justice.

Additionally, in light of the root causes of the gross human rights violations and attacks that are meted on persons with albinism, Parliament should review the Anti-FGM Act, 2011 and capture harmful traditional and cultural practices so as to cover the specific attacks on PWA.

(g) Participatory programming for ownership and sustainability

There is a need to ensure meaningful, active participation and consultations with diverse persons with Albinism in all programs, laws and policies.

Furthermore, they also need to be included in monitoring human rights frameworks and bring the intersectionality of issues in relation to albinism.

Additionally, explore ways for inclusion of persons with albinism in the cash transfer programmes through better understanding and definition of persons with severe disabilities. This is with the understanding that albinism is equally a permanent form of disability with heightened risk for loss of livelihoods associated with the risk of exposure to ultra violet rays.

(h) Plan for an exclusive albinism-specific survey

This will help to obtain factual data for persons with albinism, disaggregated into the type of albinism i.e. ocular albinism and oculocutaneous albinism. This will help in proper planning and budgeting and maximization of resources.

(i) Increase staff allocation to NCPWD

This will help NCPWD to adequately meet its mandate and work more efficiently with persons with disabilities and persons with albinism.

5.1.5 Recommendation to the National Treasury

(a) Increase budget allocation to NCPWD

Budget cuts to NCPWD have limited the reach of the council in reaching its target population and it also reduces the resources available to effectively reach persons with disabilities including persons with albinism. Already all interventions have been affected by the budget cuts and the council is left to do so much for very little at the risk of leaving many behind.

5.1.6 Recommendation to the Department of Justice and Office of the Attorney General

(a) Implement recommendations by the UN independent expert on albinism.

The Ministry of Foreign Affairs should accelerate the mainstreaming of albinism into policy and legislation and further adopt a country-specific action plan on albinism anchored on the continent-wide AU strategy on albinism (2021-2031).

(b) Coordinated monitoring mechanism

The National Council for Persons with Disabilities in partnership with the Ministry of Labour and Social Protection should establish a task force on albinism consisting of members of various relevant Ministries; Special Programmes, Education, Justice, Health among other agencies. This task force can help the government create a time bound action plan

and carry out its short, medium and long term goals and assist in implementing other recommendations herein. The task force should have a budget and should consist of consultation with civil society including people with albinism.

5.2 Conclusion

Persons with albinism are entitled to all the provisions that are provided for in the Bill of Rights as per the Kenyan constitution. The Persons with Disabilities Act of 2003 that is currently under review also stresses the significance of the entitlements for Persons with albinism just like other persons with disabilities. This is irrespective of the fact that they are not explicitly mentioned in the Act. The marginalization of persons with albinism in many spheres of their life including education, health, employment, access to justice etc. is a clear pointer as to the reason for increased emphasis that their rights need to be protected.

The Government of Kenya has provided commendable interventions in terms and policies and programmes for persons with albinism but as established from the study, there are a few gaps that need to be sealed even as these interventions need to be strengthened and made more effective for the target population. While there is still much that is needed in terms of implementation of recommendations made by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism, the stakeholders in this sector need to determine the benefits of having certain provisions to explicitly provide for persons with albinism.

The area of legal support and redress for abuses against persons with albinism needs to be strengthened. Many offenses against persons with albinism remain unmentioned and not litigated since for those that have been brought out, nothing much has been seen to be done. For instance, a case that made national news headlines where a member of the National Assembly made hateful utterances towards his peer who is a person with albinism, has not been seen to be actively redressed and the matter has gone silent. This only makes it worse for many persons with albinism who do not have the strength economically and mentally to follow up on such legal cases.

Key stakeholders in the sphere of albinism and disability at large need proper coordination and support to fully push and advocate for strengthening its legal and policy provisions. Several areas still remained unmentioned for instance, in health, while it is largely agreed that sexual reproductive health is of great importance, little is mentioned about it and how it relates to persons with albinism and persons with disabilities at large. In pursuant to this data management, monitoring and coordination of programmes targeting persons with albinism is of paramount importance. Data on albinism needs to be properly disaggregated and the numbers according to the type of albinism determined. Data on who accesses what service and where and whether they are in line with the needs and expectations need to be well determined in order to adequately inform on policy and any legislative matters.

CHAPTER 6

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CHAPTER 7

ANNEXURES

Annex 1: Organizations of persons with albinism in Kenya

S/ No	Organization	Contact Details	Areas of Operation
1.	Positive Exposure Kenya	contact@positiveexposure-kenya.org +254736087683	NGO- International
2.	Albinism Empowerment Network	martinpepela@gmail.com/ timothyaseka@gmail.com +254724844963	County Level CBO-Bungoma, Kakamega
3.	Golden Age Albinism Support & Protection Program (GASSPP)	ongulobaro@yahoo.com	Kakamega / Bungoma, Tranzoia, Busia, Siaya, Homabay
4.	Nyandarua Albinism Forum	Margaret Kariuki +254718812773 Shirumargaret9@gmail.com	Nyandarua county
5.	Northern Nomadic Disabled Persons Organization (NONDO)	info@nondokenya.org +254706 579474.	Nomadic counties
6.	Dr. Choksey Albinism Foundation	vchoksey@yahoo.com	Nairobi
7.	Kwale Albinism Group	+254722111148	Kwale
8.	Mombasa Albinism Group	Josphat Musungu +254 728 861687	Mombasa
9.	Muranga Albinism Group	nancigita@gmail.com +254711304874	Muranga
10.	PHYALBI Network	Jeriter Mutinda Mutisya jeritermutinda2015@gmail.com	CBO Machakos County
11.	Emurwa Dikirr Albinism Association	Charles Koros +254725794688 kipronokoroscharls@gmail.com	Narok

S/ No	Organization	Contact Details	Areas of Operation
12.	Upendo Albinism Self-Help Group	Elizabeth Gweya elizabethgweya01@gmail.com atienoelizabeth45@yahoo.com +254719265680	Kisumu
13.	Malindi Albinism Network.	Omar Abdalla +254722171788 omarabdalla661@gmail.com	Kilifi county Malindi sub county
14.	Taita -Taveta County persons with Albinism Self Help Group	Pauline Mwake +254728002200	Taita Taveta
15.	Kajiado Albinism Association	Zipporah Ntinine +254728169194	Kajiado
16.	Nyeri Pamoja Self-help group	Naomi Orandi +254745397237	Nyeri
17.	Narok Albinism Association	Reuben Mpatiany +254728855087	Narok
18.	Albinism Foundation of East Africa	Wambui Kairi info.afea@gmail.com	Kiambu
19.	Othaya Albinism Support group	Regina +254714824084	Othaya
20.	KASCU	Mary.kiptoo@gmail.com	Eldoret
21.	Albinism Empowerment Network Community Based Organization	+254724243713	
22.	Muongano Albinism Parents Group	+25472211148	
23.	Albinism Care Foundation	+254726676558	
24.	Albinism Support Network	+254722987848	
25.	Mwingi Persons with Albinism Self Help Group	+254700063146	
26.	Albinism Society of Kenya	+254710841183	

S/ No	Organization	Contact Details	Areas of Operation
27.	Empowered Albinism Self Help Group	+254724374724	
28.	Kiaso Albinism Self Help Group	+254726034910	
29.	Nakuru Albinism Self Help Group	+254703627309	
30.	Township Albinism Self Help Group	+254721161721	
31.	Molo Albinism Self Help Group	+254711109980	
32.	Samburu Albinism Disabled Self Help Group	+254725034990	
33.	Namunyak Persons with Albinism Self-Help Group	+254706119798	
34.	Albinism Care Foundation C.B.O	+254728861687	
35.	Albinism Welfare Group of Tana River County	+254791567894	
36.	Black Albinism Community Based Organization	+254799339372	
37.	Vihiga Parents of Children with Albinism	+254724262541	Emuhaya

Annex 2: Data collection tools

Tool 1: Structured Questionnaire for Organizations working with and for Persons with Albinism

Q1. What is your Sex?

- a) Male b) Female c) Intersex

Q2. Age

- a) 20-24 b) 25-29 c) 30-34 d) 35-39
e) 40-49 f) 50-54 g) 55-59 h) 60-64

Q3. County of Residence.....

Q4. What is the name of your organization?.....

Q5. What does your organization concern itself with?

1. Awareness & Advocacy 2. Education 3. Health
4. Economic Empowerment 5. All
6. Other (State).....

Q6. Are you aware of any existing laws that protect Persons with Albinism?

1. Yes 2. No

Q7. If Yes, mention the ones you can remember

.....

Q8. Are you aware of any Programmes by the National/County government that give interventions for Persons with Albinism?

1. Yes 2. No

Q9. If yes, mention the ones you can remember and what they do.

.....

Q9. Are you aware of any policies whether county/national that protect Persons with Albinism?

1. Yes 2. No

Q10. If aware of the policies, please name them.

.....

Q11. What gaps can you identify in the laws for Persons with Albinism?

.....

Q12. What gaps can you identify in the programmes for Persons with Albinism?

.....

Q13. What gaps can you identify in the policies for Persons with Albinism?

.....

Q14. Please rate the how the following statements are true in context of your

Organization using a scale of 1 to 5 – where (1) = strongly disagree; (2) = disagree; (3) = neutral; (4) = agree; and (5) = strongly agree

Statement describing your community	1	2	3	4	5
a) There are sufficient laws that address the concerns of Persons with Albinism					
b) There are sufficient policies that address the concerns of Persons with Albinism					
c) There are sufficient programmes by the National/County government that target Persons with Albinism					
d) The laws, programmes and policies that relate for Persons with Albinism are well known by institutions and stakeholders					
e) The laws, programmes and policies that relate to Persons with Albinism are well known by the Persons with Albinism themselves					
f) Government institutions fully implement policies, programmes and laws that concern Persons with Albinism					
g) Other stakeholders (NGOs, INGOs, Churches etc.) fully implement policies, programmes and laws that concern Persons with Albinism					
h) Lack of knowledge of policies, programmes and laws concerning Persons with Albinism leads to the abuse and discrimination of Persons with Albinism					
i) Offenses against Persons with Albinism are well prosecuted using the prevailing laws and policies					
j) Government policy on provision of sunscreens is well implemented					
k) Persons with Albinism have better access to education and healthcare as a result of the policies, programmes and legislations that have been put in place					

Statement describing your community	1	2	3	4	5
l) Persons with Albinism are well represented in the County assemblies					
m) Persons with Albinism are well represented in the Senate and National Assembly					
n) Access to employment opportunities is well ensured and upheld by both government and private sector for Persons with Albinism					

Q15. The following statements describe various interventions towards Persons with Albinism. On a scale of 1-5, indicate how effective they are in your Organization- where (1) = does not exist; (2) = hardly working; (3) = being implemented with mixed results (4) = It is working (5) = Has worked with evident results

Statement describing local interventions	1	2	3	4	5
a) Cases on violations of Persons with Albinism are sufficiently handled to completion					
b) Community leaders, politicians and religious leaders publicly campaign against abuse of Persons with Albinism					
c) Parents/Guardians are educated and sensitized successfully to advocate for the rights of children who are Persons with Albinism					
d) Centers/schools where children with disabilities and systems where Persons with Albinism receive support are accommodative and friendly to their needs					
e) Government allocates budgets to schools and centers where children who are Persons with Albinism are					
f) Household economic and livelihood strengthening interventions exist for poor families with Persons with Albinism					
g) Cultural and traditional leaders and structures are involved in condemning harming of Persons with Albinism for witchcraft and trading in their body parts					

Q16. Please add any comment you would like to make regarding Persons with Albinism in your community

Comments:

.....

.....

.....

.....

.....

Tool 2: KII Guide for Stakeholders for PWAs

Introduction

- Introduce yourself
- Explain the purpose of this interview - We are carrying out a **Mapping of laws, programmes and legislation and mapping organizations of people with albinism** and the implications this has had on Persons with Albinism. We would appreciate your honest opinions during the discussion. Your responses will be treated with utmost confidentiality and will immensely contribute to this study.
- Record the discussion [with permission from the respondent]
- Take notes of the discussion

Ice Breaking Exercise

- Familiarize with the roles and responsibilities of the Respondent
- General discussion on forms and extent of Persons with albinism in the community

Bio data

1. Name of respondent (Optional):.....
2. Sex a) Male b) Female
3. Age a) 20-24 b) 25-29 c) 30-34 d) 35-39
 e) 40-49 f) 50-54 g) 55-59 h) 60-64
4. Designation:.....
5. Location/area/scope of operation:.....
6. Expertise/work:.....

Concerns of Persons with Albinism in the community

1. What are the various concerns of Persons with albinism in the community?
2. What is the most reported case/concern of Persons with albinism?
3. How do you deal with the cases reported? (Probe on linkages with local administration, police, NGOs)
4. Do you think the National and/or County Government system is providing adequate support for Persons with albinism? (Probe for awareness and knowledge for government policies etc.).

Addressing concerns for PWAs in the community

5. What needs to be done to address/increase awareness of concerns for Persons with albinism in your community?
6. Have you improved/increased any community mechanisms to provide support to Persons with albinism who are survivors of abuse / or initiatives undertaken to create awareness/reduce abuse on Persons with albinism (Probe on the role of community policing)

Policies and legislations

7. What are the main policies or legislations (national or county level) in place at the moment that address the concerns of Persons with albinism in your area?
8. How effective are these policies or legislations in meeting the concerns of Persons with albinism?
9. What programmes are in place that you are aware of that support Persons with albinism?
10. What propositions would you make to address these gaps?

Conclusion

11. Do you have any other comments/observations that you would like to share regarding this discussion? Please feel free to share your observations and suggestions.

Tool 3: KIIs KNCHR Staff

1. Name of respondent (Optional):.....
2. Sex a) Male b) Female
3. Age a) 20-24 b) 25-29 c) 30-34 d) 35-39
 e) 40-49 f) 50-54 g) 55-59 h) 60-64
4. Designation:.....
5. Location/area/scope of operation:.....
6. Expertise/work:.....

Situation and actions on Persons with Albinism

7. What is the state of Persons with Albinism in the country?
8. Which are the most rampant forms of abuse of rights of Persons with Albinism in the country that get reported to your office?
9. How were they resolved?
10. What interventions on Persons with Albinism are implemented by KNCHR?
11. What are the existing policies, laws and regulations addressing Persons with Albinism?
12. How effective are the existing policies and laws in protecting the welfare and rights of Persons with Albinism in the country?

Experiences and perceptions

13. What are your experiences in working in the community towards awareness and rights of Persons with Albinism?
14. How does the community view efforts towards ensuring rights and welfare of Persons with Albinism?

Challenges and Barriers

15. What are the barriers facing in addressing complaints raised by Persons with Albinism?

Improving Information accessibility and addressing Albinism issues

16. What are the main sources of information on concerns for Persons with Albinism?
17. Are there programs targeting protection of rights and welfare of Persons with Albinism? Who are the main supporters?
18. What is the level of familiarity/knowledge of the laws, policies and programs for Persons with Albinism in the country?

19. How can knowledge and information on rights and welfare of Persons with Albinism be disseminated more effectively?
20. What role can: school, family, society, judges, health centers, and clergy play in protecting the rights and welfare of Persons with albinism?

Conclusion

21. What government efforts are needed to improve the rights and welfare of Persons with Albinism in the country?

Tool 4: FGD Guide for beneficiaries (PWAs and their Guardians)

Introduction

- Introduce yourself
- Explain the purpose of this interview - We are carrying out a **Mapping of laws and legislation and mapping organizations of people with albinism** and the implications this has had on your life. We would appreciate your honest opinions during the discussion. Your responses will be treated with utmost confidentiality.
- Explain the Group Discussion Process: interactive, participative. Participants to be honest about their opinions and beliefs
- Explain the rules of discussion: one person at a time, no domination and side conversation, opportunity for all to participate
- Ask for permission to record the discussion
- Remember to take notes on the discussion
- Reiterate the confidentiality of responses

Type of albinism and knowledge of self

1. How did you learn that the condition you were born with or your child was born with is albinism?
2. What was your perception of yourself or your child upon realization that you/she/he had albinism?

Causes and factors of abuse on rights of PWAs

3. Have you ever had a situation where you felt your right and welfare or that of your child was deprived of you/them?
4. If yes, what was the situation or right that was denied of you/them?
5. How often do these situations of deprivation of your rights or your welfare occur?
6. Where and how do you seek redress for the deprivation on your rights or welfare?
7. How are you received when you seek redress in the places you have mentioned?

Knowledge, attitudes and practices

8. Do you know any government laws, policies or regulations that protect the rights and welfare of PWAs? Please explain
9. Have you (or your child) faced any stigma with albinism? If yes, please specify.
10. What are the dominant traditional views towards PWAs?

Effects and experiences of violations on the rights and welfare of PWA?

11. What advice would you give to people in the community about the rights and welfare of PWAs?

Tool 5: Case study documentation guide (PWAs)

Explain Purpose of the interview and study to the respondent.	
Bio Data Establishing Rapport	<ul style="list-style-type: none"> • Tell us about yourself <ul style="list-style-type: none"> - (Age, place of birth, school background, length of stay in ..., occupation, family information, no. of members in household, marital status, place of stay, religion,)
Nature of incident/ concern involving a PWA	<ul style="list-style-type: none"> • Could you share with us what happened to you? (Probe for: Who was involved, where, time period, by whom)
Response to the concern/incident	<ul style="list-style-type: none"> • Did you seek any help/ what did you do after the incident? <ul style="list-style-type: none"> - (Probe for: pattern of getting assistance. Who did you first approach? e.g. Family, Women's group, police, lawyer, chief, time that elapsed between incident and reporting, general reactions) If you did not seek help, why? • How did you cope? (Probe for: Support –who reached out, inner resilience) • How has/did the incident affect you? (Probe for: Effects on self, societal perceptions) • Since then, have you experienced any other forms of abuse on your rights?
System's attitude towards albinism	<ul style="list-style-type: none"> • Police: If you reported the incident to the police: (which) <ul style="list-style-type: none"> - How would you describe your experience? What was their attitude to you? - What assistance was provided? • Provincial Administration (Chief/AP/DCO): <ul style="list-style-type: none"> - Probe for: General experience, assistance accorded, evidence collection • Family Members <ul style="list-style-type: none"> - Probe for: reactions, support provided • Did you receive adequate assistance? Could more have been done?
Awareness levels on Concerns for PWAs	<ul style="list-style-type: none"> • At the time of the incident, what kind of information did you have of what to do? (Probe for: Legal, Medical, psycho-social, shelter, Support Services in the community (Women's groups/ NGO Forums) <ul style="list-style-type: none"> - What kind of information would have helped you deal with the incident better?

Support required	<ul style="list-style-type: none">• What support services are available in your community for the needs/concerns of PWAs?<ul style="list-style-type: none">- (Shelter, legal, livelihood support/strengthening, medical, support groups, counseling,)• What needs to be done to strengthen the support provided to PWAs?
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Tool 6: Individual Consent forms

Welcome and thank you for volunteering to take part in this KII/FGD/Case Study. You have been asked to participate as your point of view is important. We realize you are busy and I appreciate your time.

Introduction: I / We am / areand.....and I/we am/are here on behalf of Kenya National Commission for Human Rights conducting a study on Mapping of National laws, policies, programmes and organizations of Persons with Albinism. This interview is designed to assess your current thoughts and opinions on laws, policies, programmes and organizations of Persons with Albinism. The findings of this study will help KNCHR in advocating and pushing for better laws, policies and programmes for Persons with Albinism in Kenya.

This KII/FGD/Case Study will take no more than 1 hour, and I will be taking notes on what we are discussing.

Anonymity: Despite the discussion being noted down, I would like to assure you that the discussion will be anonymous. The notes will contain no information that would allow individual subjects to be linked to specific statements. Please answer as accurately and truthfully as possible. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Ground rules

- The most important rule is that only one person speaks at a time in an FGD. There may be a temptation to jump in when someone is talking but please wait until they have finished.
- There are no right or wrong answers.
- You do not have to speak in any particular order.
- When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you
- You do not have to agree with the views of other people in the group.

Does anyone have any questions? (Answers). If none or questions raised have been satisfactorily been answered, kindly have the respondent sign below.

On Photography

In consideration of my right to participate in the study for mapping of national laws, policies, programmes and organizations of Persons with Albinism, until I otherwise object:

- a) I consent to the use of photographs and/or video recordings of me during the study or at any other activity associated with the study
- b) I understand and agree that the KNCHR owns all intellectual property rights in and relating to the Images from the date of creation and may use, publish, amend, modify, delete, adapt, synchronize, screen and/or broadcast rework and/or reproduce (collectively, the “Use”) the Images in internal and external KNCHR publications,

including on the KNCHR’s websites and social media channels, either wholly or in part, in any medium and/or through any channel of distribution, in conjunction with any work for the purposes as intended by and/or for the benefit of the Bank, free of any encumbrances, anywhere;

- c) I hereby assign all rights that I may have in or relating to the Images to KNCHR, effective from the time of creation of each of the Images. I agree that KNCHR may assign or sub-license the rights in the Images to any third party at any time without notice to me;
- d) I waive any rights to select, inspect or approve the Images in their current or finished form, the context and purposes for which they are used, the medium in which they are reproduced, and/or the channel through which they are distributed, broadcasted or otherwise disseminated. I further waive all rights to be identified as the subject of the Images (which I hereby permit KNCHR to publish at its sole discretion) in any media in which the Images are reproduced;
- e) I understand that I will not receive any compensation, royalties or any other payment whatsoever for the Use of the Images and waive any rights to any compensation, royalties or any other payment associated with the Images;
- f) I understand that KNCHR may store my contact details on its database in connection with the Images and these details may be stored on a database outside my home territory. My details will not be used for any other purpose other than in connection with the Images; and
- g) I will not in any way, whether directly or indirectly, interfere with KNCHR’s Use of the said Images, make any claims or seek any injunction or bring any proceedings against KNCHR to prevent or alter the way in which KNCHR decides to use the Images.

I confirm that I have the capacity at law to enter into and perform any obligations under this form and that I am not prohibited (whether by contract or otherwise) from doing so.

I have read the foregoing and fully understand and agree to the contents thereof.

Signature of Participant.....

Date.....

If the participant is below the age of 18 years, a parent or guardian must also sign.

Signature of Parent / Guardian.....

Name of Parent/Guardian.....

Date.....

Annex 3: List of participating organizations/ institutions

Nairobi & Machakos Counties

1. National Gender and Equality Commission
2. National Council for Persons with Disabilities
3. Ministry of Education (Directorate of Special Education)
4. Albinism Foundation of East Africa
5. Action Network for the Disabled
6. Albinism Society of Kenya
7. PHYALBI Network
8. Positive Exposure Kenya

Nyeri County

9. Nyeri County Referral Hospital
10. Othaya Albinism Support Group
11. Pamoja Nyeri Albinism

Kajiado & Narok Counties

12. Kajiado County Albinism Association
13. Narok Albinism Association
14. Kilifi County Hospital

Kisumu & Kakamega Counties

15. Upendo Albinism Self- Help Group
16. Golden Aged Albinism Support and Protection Programme
17. Kakamega County Disability Leadership Caucus
18. Kakamega County Hospital

Kilifi County

19. Kilifi County Persons with Albinism Network
20. Kilifi County Hospital

END

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