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ENHANCING EQUALITY AND COUNTERING DISCRIMINATION AGAINST PERSONS WITH ALBINISM IN UGANDA

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ACRONYMS

AAFU	African Albinism Foundation of Uganda
ACHPR	African Charter on Human and Peoples Rights
ASSA	Association of South Africa
AU	Albinism Umbrella
CBO	Community Based Organism
CCRPD	Committee on the Convention on the Rights of Persons with Disabilities
CEDAW	Convention on Elimination of Discrimination against Women
CESCR	Committee on Economic Social and Cultural Rights
ACHPR	African Commission on Human and Peoples Rights
CRC	Convention on the Rights of the Child.
CRPD	Convention on the Rights of Persons with Disabilities
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
NCD	National Council for Disabilities
NCDs	Non-Communicable Diseases
NDP	National Development Plan
NUDIPU	National Union of Disabled Persons of Uganda
OCA	Oculocutaneous Albinism
OHCHR	Office of the High Commissioner for Human Rights
SNUPA	Source of the Nile Union of Persons with Albinism
UBOS	Uganda Bureau of Statistics
UDHR	Universal Declaration of Human Rights
UHRC	Uganda Human Rights Commission
UV	Ultra Violet
WHO	World Health Organization

Chapter 1: Introduction.

1.1. Background

Uganda has ratified several international and regional human rights instruments that commit her to promote equality and combat discrimination. At the international level, the instruments include the following: the United Nations Charter, 1945; the International Covenant on Economic Social and Cultural Rights (ICESCR), 1966; the International Covenant on Civil and Political Rights (ICCPR), 1966; the Convention on the Elimination of Discrimination Against Women (CEDAW), 1979; the Convention on the Rights of the Child (CRC), 1989; the Convention on the Rights of People with Disabilities (CRPD), 2007; the International Covenant on the Elimination of Racial Discrimination (ICERD), 1965, among others. Based on the Universal Declaration of Human Rights, these instruments impose legal obligations on States to respect, promote and protect the right to equality and non-discrimination, including by taking steps towards elimination of discrimination.

At the regional level, Uganda is party to, among others, the following instruments: the African Charter on Human and Peoples Rights (ACHPR), 1981; the Protocol to the African Charter on Human and Peoples Rights on the Rights of Women in Africa, 2003; the African Charter on the Rights and Welfare of the Child, 1990; the Constitutive Act of the African Union, 2000.

At the national level, the 1995 Constitution of the Republic of Uganda specifically provides in articles 20 (2), 21(2), and 32(1) the legal framework for protecting and enhancing the right to equality for marginalized groups including persons with albinism.

In many countries around the world, witchcraft-related beliefs and practice, myths and superstitions have resulted in serious violations of human rights of persons with albinism. Because of these beliefs and superstitions, persons with albinism have been subjected to discrimination, banishment, cutting of body parts and amputation of limbs, torture and murder and the graves of those who are buried after death are robbed. Persons with albinism constitute a vulnerable group that face multiple and intersecting forms of discrimination just because of their color. According to the

Witchcraft and Human Rights Information Network¹, there is currently no explicit normative framework or formal mechanism to conceptualize, record, monitor or respond to violations against persons with albinism. While there is no normative framework specifically developed for persons with albinism, they are, however, protected by the international human rights framework. The rights that are clearly protected include the right to life, physical integrity, liberty, security, equality and non-discrimination, health, education and an adequate standard of living.

Violations of the human rights of persons with albinism are known to take place in Africa and the practice have been manifest within East Africa including Uganda. The exact number of victims of such abuse is unknown, and is widely believed to be underreported. To respond to these violations, the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, through consultations with representatives from the United Nations, the African Union, Governments, and organizations of persons with albinism and other civil society organizations proactively developed a 5 year action plan to address attacks and other human rights violations against persons with albinism in Sub Saharan Africa. The indicators emphasized in this plan are prevention, protection, accountability, equality and non-discrimination. The plan spells out 15 specific, concrete and time-bound measures in key areas, such as public education and awareness-raising, systematic data collection, research on the root causes of violence, the use of legal and policy frameworks to deter harmful practices related to witchcraft and trafficking in body parts, and measures to fight impunity and to ensure support for victims. The Africa Regional Action Plan was endorsed by the African Commission on Human and Peoples' Rights during its 60th Ordinary Session in May 2017.

It is from the above background that the Albinism Community in Uganda, the Parliament of Uganda, and the Equal Opportunities Commission, in partnership with, and with the support of the Office of the High Commissioner for Human Rights (OHCHR) in Uganda, found it necessary to commission a study to analyze the situation and state of persons with albinism in Uganda. The study objective is to

¹<http://www.whrin.org/>

identify credible data that will enable a better understanding and appreciation of albinism issues and provide a credible source of information regarding the status of persons with albinism in Uganda, and to inform policy, planning and design of effective strategies for addressing challenges that affect the albinism community in the country.

1.2. Scope of study.

The terms of reference of the study specifically called for:

- Assessment of the international, regional and domestic legal framework applicable to persons with albinism and the level of government's compliance with its duty to respect, protect, and fulfil for persons with albinism, as per its international, regional and national obligations.
- Assessment of awareness about the rights of the albinism community among policy makers, implementers and persons with albinism, their caretakers and service providers.
- Mapping out the existing providers of services, and the type of services provided to people living with albinism, in the regions to be identified with the assistance of the albinism community and the OHCHR.
- Review of literature and collection of data to generate necessary information concerning the rights of persons with albinism in Northern, Western, and Eastern, Southern and Central regions of Uganda;
- Identify gaps and give concrete recommendations to improve the lives of persons with albinism.
- Establish the number of persons with albinism in Uganda.
- Analysis and description of the extent to which persons with albinism enjoy their human rights and equal opportunities.

1.3. Methodology

In order to obtain the most robust and reliable information, the study employed a mixed-methods approach. A full range of sources including desk reviews, interviews with some persons with albinism, organizations of persons with albinism and other stakeholders, and individuals was applied. Use was made of the internet to review literature on regional and international human rights instruments applicable to persons with albinism.

The conditions of persons with albinism and the way they are treated by society touch on several human rights issues including: discrimination and exclusion based on colour and disability; special needs associated with the right to the highest standard of health; extrajudicial killings; infanticide and neglect of children with albinism; torture and ill-treatment; trade and trafficking of body parts etc.

Two events in which a number of persons with albinism were present were attended during the research period. One was the celebrations to mark the international day of persons with albinism that was held in Mbale on 13 June 2018, and attended by the Speaker of Parliament, Right Honourable Rebecca Kadaga. The other was a cancer and sight screening camp in Gulu, held on 28 July 2018 and organized by the Lions Club, attended by a number of persons with albinism from the greater northern region of Uganda.

Consultations, as a method, was used to interview persons with albinism and their organizations and some service providers. A tool consisting of questionnaires was also administered to persons with albinism and their organizations. Interviews were conducted face to face and over the phone with some persons with albinism and with some organizations.

1.4. Limitations

Among the scope of work for this study were: assessing the awareness about the rights of the albinism community among policy makers, implementers and persons with albinism, their caretakers and service providers; mapping out the existing providers of services and the type of services provided for people living with albinism; and establishing the number of persons with Albinism in Uganda. These tasks required formal interviews and contacts with persons with albinism and their organizations around the country and relevant government departments and agencies. Initially the agreed plan was to travel to the four geographical regions of the country together with some leaders of persons with albinism who would assist in mobilization and collection of data. Problems with resources made this impossible as the available funds did not cover travels. As a result the collection of information was done by the consultant approaching persons with disabilities during the two above referred functions organized for persons with disabilities in Mbale and Gulu. Interviews were also

conducted over the phone but this met with a lot of difficulties, one because many of the interviewees could not understand the English well and the phone connections were susceptible to interruptions. Further it proved a challenge to get people on phone or to carry out in-depth interviews.

Lack of funds for travels made it impossible to reach western Uganda and the West Nile region and therefore voices of persons with albinism from these regions have not been captured fully in this report. Indeed during validation of this report people from these regions pointed out this gap.

The lack of a comprehensive quantitative data on the numbers of persons with albinism in the country and their geographical distribution is evident in the report. It was not possible to come up with a comprehensive data without reaching all parts of the country and in particular at village level.

Chapter 2: Background information on albinism

2.1. Associated beliefs, myths and superstitions

According to the Independent Expert on the Rights of Persons with Albinism, a range of exogenous determinants greatly, and often negatively, affect the enjoyment of the right to health by persons with albinism, in addition to the socio-economic and environmental factors². Those factors include myths, discrimination and stigmatization, which are often conveyed and reinforced through popular culture, such as folklore, media and film, and exacerbated by a widespread lack of awareness about albinism, including among health professionals. The Independent expert has noted that in sub-Saharan Africa, it has been widely documented that myths and misbeliefs surrounding persons with albinism have led to witchcraft-related harmful practices, involving the use of their body parts obtained through brutal attacks and mutilations.

In sub-Sahara Africa, the psychological impact of stigmatization and fear of being attacked greatly affect the health of persons with albinism. For instance, in the United Republic of Tanzania, persons with albinism — victims or not — often exhibit a high level of anxiety, including hypervigilance scanning, which is often a response to a ubiquitous fear in all environments. The Independent Expert further noted reports that persons with albinism — particularly when there is a strong visible contrast between their appearance and that of the general population — are rejected, shunned and excluded from their community, owing to the myths surrounding the condition and related stigmatization.

The social and cultural understanding of albinism in Africa is therefore guided by cultural beliefs and myths that in certain communities are so strong that they lead to harmful practices against persons with albinism. These beliefs and superstitions are many and vary from place to place while others are common. They include the following: Persons with albinism always have red eyes³; Persons with albinism are

² See Report of the Independent Expert- IE report A/HRC/37/57-paragraphs 18 , 19 and 20

³ Salewi DH “The Killing of Persons with Albinism in Tanzania: A Social-Legal Inquiry” 2011 Dissertation submitted in partial fulfilment of the requirements of the Degree LLM (Human Rights and Democratization in Africa) at the Faculty of Law, Centre for Human Rights, University of Pretoria 1-47 at 8.

totally blind⁴; Children with albinism are gifts or possess magical powers that include powers to tell the future⁵; Children with albinism are a curse⁶.

Other myths and superstitions are: Persons with albinism are born as a result of the sins of their mothers or parents or family; Albinism is a result of the bewitchment of the parents of the child⁷; Body parts of persons with albinism, for example their genitals and hands are useful and can be used in rituals for good fortune⁸; Witch doctors administer potions made of body parts of persons with albinism as charms for obtaining riches⁹; Marrying a person with albinism brings good luck or fortune to the couple¹⁰; Persons with albinism eat human flesh¹¹.

In many folk tales, persons with albinism are often portrayed as evil cannibals¹². For example children are told that persons with albinism eat naughty or children who misbehave¹³. In some cultures, it is believed that children with albinism are a product of inbreeding in the family. Others believe that albinism is a result of a black woman mating with a white man¹⁴. There is also the belief that albinism is a contagious condition¹⁵ - that a person who shares a meal or drinks from the same vessel or sits or

⁴ Olagunju OS "Towards a Biblical Response to Myth and Discrimination against the Human Right of Albinos in Yorubaland" (2012) 1 *Journal of Studies in Social Sciences* 46-58 at 52. Also see Thuku M "Myths, Discrimination, and the Call for Special Rights for Persons with Albinism in Sub-Saharan Africa" at [Http://www.underthesamesun.com/sites/default/files/MYTHS.Final_.pdf](http://www.underthesamesun.com/sites/default/files/MYTHS.Final_.pdf).

⁵ Salewi 15 Ibid.

⁶ Lund & Gaigher 370.

⁷ Phatoli R *et al* "Being Black in a White Skin: Beliefs and Stereotypes around Albinism at a South African University" (2015) 4 (1) *African Journal of Disability* 1-10 at 5. Also see the United Nations, General Assembly, *Report on Persons with Albinism*, A/HRC/24/57, 12 September 2013 at 5-9.

⁸ Phatoli *et al* 2. Ibid.

⁹ United Nations, General Assembly, *Report on Persons with Albinism*, A/HRC/24/57, 12 September 2013 at 5-9.

¹⁰ Ntinda RN *Customary Practices and Children with Albinism in Ruppel OC Childrens Rights in Namibia* (2009, Windhoek: McMillian Education Namibia) 244-245 at 244.

¹¹ Williamson R *Tavua the white Cannibal* (2007, Ludwighshafen: Verlag Angelika Hoernig) at 51. Also see Ntinda 244-245.

¹² Ntinda 244-245. Ibid

¹³ Ntinda 244-245.

¹⁴ Ntinda 244-245. Also see Mswela & Nothling-Slabbert 25.

¹⁵ Baker C *et al* "The Myths Surrounding People with Albinism in South Africa and Zimbabwe" (2010) 22 (2) *Journal of Cultural Studies* at 7: "As a consequence of the reluctance to accept genetic inheritance as the sole explanation for the birth of a child with albinism, other reasons for such a birth are sought. A young woman in northern South Africa describes how her mother explained the cause of her albinism to her as something she had 'caught' by touching a child with albinism. The mother attended a party while pregnant and saw a mother with a baby precariously strapped to her back in a blanket. Fearing the baby was about to fall she went forward to help tighten the blanket. She then saw to her fright that the baby had albinism. She believed that, as a direct result of this encounter, she had given birth to a child affected with the same condition."

sleeps next to, or has any form of physical contact with a person with albinism may be infected with albinism or smell like them¹⁶. Other extreme beliefs are that persons with albinism do not die, they disappear¹⁷ and that sex with an albino woman can cure a man of HIV¹⁸. It is also believed in some societies that people with albinism are sterile¹⁹ while others believe they do not live long²⁰. And some societies assert that albinism is a sign of failure or weakness or curse in the family that has a person with albinism²¹.

2.2. Stereotypes about albinism.

In social psychology, a stereotype is an over-generalized belief about a particular category of people which belief is taken as true because of its repeated assertion. Stereotypes are generalized because one assumes that it is true for each individual person in the category. The myths, beliefs and superstitions held by people about albinism are in many cases so strong that they lead to stereotypes about albinism. Consequently stereotypes have been used to negatively portray albinism in popular culture and in films and fiction²². The portrayal, referred to as the “evil albino bias”, reinforces or manipulates or is used to justify attitudes and opinions that result in societal intolerance, stereotypes and discrimination against persons with albinism²³. Such stereotypes help to strengthen the stigmatization and discrimination that persons with albinism suffer.

2.3. The “evil albino” stereotype

People with albinism have been subjected to misrepresentation and discrimination across the world. The degree of misrepresentation or discrimination varies from direct or subtle discrimination, bullying, and inaccurate representation in films. In the old Eastern Europe some cultures depicted death as a “pallid (pale) woman with light

¹⁶ Ntinda 244-245.Ibid

¹⁷ Lund & Gaigher 370.ibid

¹⁸ Ntinda 244-245.ibid

¹⁹ McElroy RJ Simple Man (2008, New York: SHS Publications) at 39. Also see Ntinda 244-245.

²⁰ Ntinda 244-245.

²¹ Ntinda 244-245.

²² Mswela MM “The Evil Albino Stereotype in Film: An Impediment to the Right to Equality” (2013) 32 (1) Medicine and Law 79-93 at 79-93.

²³ Dahl M “The Role of the Media in Promoting Images of Disability - Disability as Metaphor: The Evil Crip” (1993) 18 (1) Canadian Journal of Communication, at <http://www.cjc-online.ca/index.php/journal/article/view/718/624>. Also see Twohig & Kalitzkus 116.

hair”²⁴ and this kind of representation still persists in the modern film industry. The National Organisation for Albinism and Hypopigmentation, a non-profit advocacy group for people with albinism, has identified sixty-eight films which have been released since 1960, featuring negative portrayals of persons with albinism²⁵.

The Hollywood Films industry has many times created movie villains using the genetic condition albinism²⁶. Twelve films were released in 1980, twenty in the 1990’s and 24 after the year 2000 all depicting persons with albinism as evil beings. In general, Hollywood movie characters with albinism are portrayed as violent, scary and willing excellent killers or murderers. The films also portray them as suffering from grave health problems, give them silly nicknames and are always made to meet grisly ends²⁷.

In the 2002 science fiction “The Time Machine”, the actor Guy Pierce is an inventor who creates a device to carry him to the future. Scenes of futuristic locations are followed by scenes of threatening monsters. Finally, the villain of the future is revealed as a person with albinism- white haired, a monster with gleaming skin and nearly colourless eye pupils colorless. After terrorizing Pierce, the colourless scary monster grabs him as the Machine departs for another era. The albino monster’s arms are torn off, depicting a violent end which is typical of movie characters depicting persons with albinism²⁸.

In the film, *The Da Vinci Code*, the character Silas is a remarkable fictional depiction of a character as the “evil albino”. Silas, an albino monk in the service of the *Opus Dei* organisation, is portrayed as coming from a background of confusion, fear, and hatred. Silas eventually murders his father and indulges in a life of crime. By miracle he is freed from prison and goes into the Catholic Church where he is used by *Opus Dei* as an assassin, killing those against the historical facts preferred by the Church convinced

²⁴ Adcock B “Power Was Given unto Them: The ‘Evil Albino’ Stereotype in Horror Fiction” at <http://www.bloodsprayer.com/uncategorized/power-was-given-unto-them-the-evil-albinostereotype-in-horror-fiction>.

²⁵ Schiappa E Beyond Representational Correctness: Rethinking Criticism of Popular Media (2008, Illinois: Southern Illinois University) at 6.

²⁶ www.skinema.com

²⁷ <http://www.skinema.com/albinism/>

²⁸ <http://www.skinema.com/albinism/>

that the murders are for the good of the Church²⁹. In the film, a person with albinism comes out as a character or personality full of hatred and always willing to kill.

When characters with albinism are not portrayed as vicious and brutal, they are represented as threatening, menacing ghosts. "The Omega Man" (1971) stars a whole race of ghosts who are sensitive to light, wearing sunglasses indoors and at night. In the film persons with albinism are portrayed as ghosts. It doesn't seem enough to depict a person with albinism as having nasty, disagreeable and revolting character. To really let them be scary and stand out from the crowd, they are depicted as persons with serious health problems as well. In the movie "The Eiger Sanction" (1975), actor/director Clint Eastwood is given orders to kill by the albino character "Dragon." Dragon is a person who cannot leave a red lit room, because his skin would burn. He is very prone to infections and is obsessed with hygiene. He tells Eastwood he needs his blood "changed" twice a year and is actually shown having a prolonged blood transfusion³⁰.

The conclusion from these examples is that, in the eyes and perhaps the belief of movie makers, persons with albinism are not normal beings as they are associated with evil, unsavoury deeds and should be destroyed. These kind of representation of albinism may be influenced by beliefs and stereotypes in society and the movie representations can serve to reinforce these beliefs and stereotypes to the disadvantage of persons with albinism.

2.4. Epidemiology, health needs and prevalence rate of albinism

2.4.1. Epidemiology

According to the Independent Expert on the Rights of Persons with Albinism, "albinism is a relatively rare, non-contagious, genetically inherited condition that affects people regardless of race, ethnicity or gender"³¹. The same report explains that for a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance, in each pregnancy, that their child will be born with

²⁹ 94 Schiappa 6. Ibid

³⁰ <http://www.skinema.com/albinism/>

³¹ Report of the Independent Expert on the enjoyment of human rights by persons with albinism-A/73/181, paragraph 4.

albinism. The condition is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment in any part or all of the skin, hair and eyes.

Dr. Misaki Wayengera, a genetist,³² explains that albinism is passed on in a recessive manner. Both parents must carry the albino gene for it to be passed on to some of their children. If both parents carry the gene they can pass it to their children even when the parents themselves have no manifestations of albinism. Because it is a recessive gene it is always possible that a person with albinism may sire children without albinism. Carriers of the gene have a 50% chance of passing the gene to their children. If both parents are carriers, there is a 25% chance for each of their child to have albinism.

Dr. Wayengera further explains that albinism in humans is a congenital disorder characterized by the complete or partial absence of pigment in the skin, hair and eyes and that there are varying degrees of albinism. While an organism with complete absence of melanin is called an albino, an organism with only a diminished amount of melanin is described as leucistic or albinoid³³. Dr. Wayengera says the common type of albinism is oculocutaneous albinism or OCA (meaning the type that affects the eyes the skin and hair colour). According to him oculocutaneous albinism is classified into 4 types: Persons with type 1 often have milky white skins, white hair and blue eyes when they are born. Some of the persons with type 1 oculocutaneous albinism may at a later stage of childhood produce melanin and therefore some tanned pigmentation of the skin. Type 2, which mainly occurs in Afro-Americans and Native Americans, is indicated by hair which is yellow in colour, auburn, ginger or red, while the eyes are likely to be blue-gray or tan. If not protected from sun rays a person with type 2 OCA may develop skin cancers and dark spots on the skin.

Type 3 oculocutaneous albinism is also known as rufous or red albinism – while it is rare globally, it is common in Africa. Africans with this type may have red or reddish-

³² Co-chair, Genomics Education and Coordinated Training Working Group (ECTWG), H3Africa Consortium, Unit of Genetics and Genomics- Department of Pathology/Microbiology Immunology and Molecular Biology Makerere University School of Biomedical Sciences

³³ Available at http://www.rightdiagnosis.com/o/oculotaneous_albinism/intro.htm,

brown skin, ginger or reddish hair, and brown iris. Type 4 albinism is found mainly in people of East Asian descent and causes hypopigmentation of the skin, hair, and eyes.

Dr. Wayengera also described two other rare conditions, both very serious medical conditions that can afflict persons with albinism. One is known as Hamansky-Pudlak syndrome (HPS) which causes bleeding problems, bruising of the skin, lung and bowel cancers. He says the syndrome should be suspected and investigated if a person with albinism has unusual bruising or bleeding. The second condition is known as Chedak-Higashi syndrome which is also a rare disorder but affects multiple systems of the body. The symptoms are being prone to infections, anemia and enlargement of the liver³⁴.

The medical effects of albinism are mainly poor sight and skin problems that may include skin cancers. Persons with albinism can suffer from involuntary eye movements or “shaking” of the eye. A child with albinism often develops a preferred head position in order to reduce the involuntary eye movements in an attempt to improve or enhance the child’s vision. Albinism can result in misalignment of the eyes and sensitivity to bright light or glare. Many persons with albinism suffer from refractive errors manifested as nearsightedness or farsightedness. They have irises without pigment to screen out light coming into the eye. Persons with albinism can have challenges with vision that can range from normal for those minimally affected to legal blindness (vision that is less than 20/200) or worse for those with severe forms of albinism. Generally a person with albinism with the least eye pigment will have the poorest vision.

Dr. Wayengera adds that persons with albinism can leave a perfectly normal life. He explains that albinism is not contagious and is not anything to fear because it is one of the few genetic disorders that may not affect the quality of a person’s life. Persons with albinism are usually as healthy as the rest of the population, with growth and development occurring as normal, but they can be classified as persons with disabilities because of the associated visual and skin problems. A person with albinism therefore has to learn how to navigate the world in order to leave a normal life because of their visual impairments and risks of sunburns and skin cancers.

³⁴ See also <https://aapos.org/terms/conditions/12>

2.4.2. Prevalence of albinism in the world.

According to the World Health Organization (WHO), the estimates about the number of persons with albinism across the world vary depending on the regions of the world. The World Health Organization estimates that the prevalence varies from 1 in 5,000 to 1 in 15,000 people in sub-Saharan Africa. In Europe and North America the estimate is 1 in 20,000 people. About 1 in 70 people in the world are estimated to be albinism carriers with one defective gene but no symptoms³⁵.

While there is no available up to date statistics regarding the prevalence of albinism in Uganda, there are estimates for some regions of Africa. In South Africa, the incidence of occurrence is about 1 in every 4,000 people. In Nigeria the occurrence of albinism is approximately one in 5,000. A 2006 review published in the journal *BMC Public Health*, gives the occurrence in Tanzania as 1 in 1,400. The occurrence in parts of Africa is therefore far higher than the worldwide average of 1 in 20,000.

2.4.3. Specific health needs of persons with albinism.

Albinism often results in two congenital and permanent health conditions: visual impairment to varying degrees and high vulnerability to skin damage from ultraviolet rays, in particular skin cancer. Skin cancer is a life-threatening condition for most persons with albinism and some reports from Africa indicate that most persons with albinism in Africa die from skin cancer between the ages of 30 and 40 years. According to the Report of the Independent Expert on the enjoyment of the human rights of persons with albinism, a recent study screened 77 persons with albinism from different parts of Africa for skin cancer and the result found that of the 77 persons sampled, 43 had skin cancer, 239 pre-cancerous lesions and 3 required immediate surgical attention.³⁶

The prevalence of skin cancer in persons with albinism has been attributed to factors that include limited or the lack of basic understanding of albinism by persons with

³⁵ See <https://healthresearchfinding.org/23-scary-statistics-albinism/8/3/2018>

³⁶ See the Report of the Independent Expert on the enjoyment of the human rights of persons with albinism-A/HRC/31/63 paragraph 37. See also Indicative sampling of 77 leaders and activists with albinism, Clinic Data Report, unpublished, "Standing Voice", Pan African Albinism Conference, held in Dar-es-Salaam, United Republic of Tanzania, 19-22 November 2015.

albinism and their families and how to live with the condition³⁷. For example, persons with albinism who expose themselves to the sun for hours are at high risk yet they may be doing so while ignorant of the danger of such exposure. Persons with albinism who mostly work outside in the sun without protection are exposed to a heightened risk of skin cancer. Such group of persons with albinism, particularly those in the rural settings, are often poor and have to work in the open fields under the hot sun without any protection. In addition they have limited means to address their health needs when they fall sick.

According to the Independent Expert on the enjoyment of the human rights of persons with albinism, “the general lack awareness of the link between albinism and skin cancer means that the prevalence of the condition has led to the belief that pre-cancerous and cancerous lesions on a person with albinism is a necessary part of albinism”³⁸. Yet, skin cancer in persons with albinism can be prevented or minimized with public education on albinism, access and use of sun-protective clothing, sun protection lotions and sunglasses. In addition, the risks could be reduced if there are programmes that monitor conditions of persons with albinism, remove barriers to accessing services relating to skin cancer prevention and treatment and to vision services.

³⁷ Ibid A/HRC/31/63 paragraph 38.

³⁸ Ibid A/HRC/31/63 paragraph 39

Chapter 3: International, Regional and National Legal Framework

3.1. International legal framework

3.1.1. Universal Declaration of Human Rights

Article 1 of the Universal Declaration of Human Rights (UDHR), 1948 provides “that all human beings are born free and equal in dignity and rights and are endowed with reason and conscience and should act towards one another in a spirit of brotherhood”. It is important to emphasize that under Article 2 of the UDHR, everyone is entitled to all the rights and freedoms in the Declaration without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no such distinction shall be made on the basis of the country or territory to which a person belongs or resides. Article 6 and 7 of the Declaration guarantees the right to equality of all persons including equality and equal protection before the law.

The UDHR is clearly very relevant for the protection of the rights of persons with albinism as it covers their unique circumstances such as the right not to be discriminated because of their skin colour, or for any other reason associated with their status as persons with albinism. The UDHR, together with other human rights instruments, provide important grounds to support advocacy for the protection of the rights of persons with albinism.

3.1.2. International Covenant on Civil and Political Rights

The International Covenant on Civil and Political Rights (ICCPR) is one of the instruments that guarantees fundamental rights and freedoms of all human beings. The State must ensure that all rights recognized under the Covenant are enjoyed by everyone within its territory without discrimination: “*Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, 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.*”³⁹ Additionally, Article 26 of the ICCPR provides for a general guarantee of

³⁹ ICCPR-Article 2.

equality before the law and provides that: *“All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”*

The United Nations Human Rights Committee has elaborated on the meaning of non-discrimination, equality before the law and equal protection of the law provided for in Article 26 of the ICCPR⁴⁰. The Committee explained that non-discrimination, together with equality before the law and equal protection of the law without any discrimination, are fundamental basic and general principle for protection of human rights. Each State party must respect and ensure that all persons within its territory enjoy the rights recognized under the ICCPR without discrimination of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

The Committee further explained that the prohibition on discrimination is of broad scope: *“any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.”*⁴¹

These provisions of the ICCPR are very important for the protection and advocacy for the realization of the rights of persons with albinism. They guarantee persons with disabilities equal rights and protection of the law. As human beings they should be treated as such and fairly and be entitled to enjoy all the civil and political rights that are recognized under the ICCPR. For example they should enjoy freedom of movement, freedom of speech, association, information etc. Any barriers that prevent them from enjoying these rights should be addressed by the state.

⁴⁰ See General Comment No 18: Non-discrimination (10 November 1989), the UN Human Rights Committee

⁴¹ Ibid

3.1.3. International Covenant on Economic, Social and Cultural Rights

Like the ICCPR, the International Covenant on Economic, Social and Cultural Rights (CESCR), 1966 provides for a general obligation on states to ensure enjoyment of the rights under the Covenant without discrimination⁴². Moreover, article 2 (2) of the Covenant requires that the economic, social and cultural rights provided under the Covenant are to be enjoyed by all persons without discrimination of any kind including disability⁴³.

The United Nations Committee on Economic Social and Cultural Rights has expressly explained that the rights under the Covenant are applicable to all persons with disabilities. The Committee explained that although the Covenant does not refer explicitly to persons with disabilities, the UDHR recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant. In addition, States parties are required to take appropriate measures, to enable such persons to seek to overcome any disadvantages flowing from their disability. Persons with albinism are entitled to the same rights and standards enjoyed by persons with disabilities because the lack of sufficient melanin in their eyes and skin is a disability that results in sensitivity to bright light, visual impairment and susceptibility to skin cancer). However, also note that an approach based exclusively on the disability framework fails to encompass the complex and intersecting discrimination faced by persons with albinism based on colour. However, it should be noted that an approach based exclusively on the disability framework does not fully encompass the complex and intersecting discrimination that are faced by persons with albinism based on colour.

The Committee stressed the obligation of member states to eliminate discrimination in the enjoyment of economic, social and cultural rights on the ground of disability and went on to define disability-based discrimination “*as...including any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the*

⁴² ICESCR Article 2.

⁴³ See: General Comment No 5: Persons with Disabilities (9 December 1994) E/1995/22, at [5]

effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.” It further observed that: “through neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation, persons with disabilities have very often been prevented from exercising their economic, social or cultural rights on an equal basis with persons without disabilities. The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.” In General Comment Number 20, the Committee further elaborates that the principles of non-discrimination and equality are recognized throughout the Covenant and points out that “non-discrimination is an immediate and cross-cutting obligation in the Covenant” and that “Article 2(2) requires States parties to guarantee non-discrimination in the exercise of each of the economic, social and cultural rights enshrined in the Covenant and can only be applied in conjunction with these rights”.

It is clear from these CESCR elaborations that persons with disabilities are entitled to the full enjoyment of economic, social and cultural rights. The CESCR has for example pointed out that each state should act to ensure that persons with disabilities enjoy the right to education to a level equal to their peers without disabilities in an integrated setting. This calls for the provision of reasonable assistance and removal of barriers that affect their access to education. In the case of persons with albinism it would involve measures to remove discrimination, bullying, address their vision impairments and deal with the risks they face from exposure to the sun as well as protection from possible physical danger.

[3.1.4. Convention on the Rights of Persons with Disabilities](#)

The Convention on the Rights of Persons with Disabilities (CRDP) marks a ‘paradigm shift’ in attitudes and approaches to persons with disabilities. On account of the Convention, persons with disabilities are not to be viewed as “objects” of charity, medical treatment and social protection; rather as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. The Convention provides for universal recognition to the dignity of persons with disabilities.

The CRPD does not explicitly define disability. The Preamble of the Convention states: *“Disability is an evolving concept, and disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others”*. Article 1 of the Convention further states: *‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’*. The question was if the Convention applies to persons with albinism.

The Preamble of the CRDP, read together with Article 1 of the Convention, provides a broad understanding of disability that covers all disabilities that hinder the full and effective participation in society. Persons with albinism are entitled to the same rights and standards enjoyed by persons with disabilities owing to the lack of sufficient melanin in their eyes and skin, which results in sensitivity to bright light, visual impairment, susceptibility to skin cancer and various associated barriers in society.

The Independent Expert on the Rights of Persons with albinism clearly indicated in several reports that persons with albinism are a constituency of persons with disabilities and have a right to the protection framework of the CRDP. This protection is granted due to all the social disadvantages that they encounter beyond the handicaps they face due to their visual impairment and skin problems.

Article 4 of the CRPD re-echoes provisions of the UDHR and requires States Parties to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. This obligation calls for states to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the Convention. These measures should include: modification or abolition of existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities; integrating the protection and promotion of the human rights of persons with disabilities in all policies and programs; ensuring that public authorities and institutions act in conformity with the Convention; and taking appropriate

measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise.

State Parties have the duty to raise awareness in society and at the family level in order to: foster respect for the rights and dignity of persons with disabilities; combat stereotypes, prejudices and harmful practices and to promote awareness of the capabilities and contributions of persons with disabilities to society⁴⁴. The State should: initiate and maintain effective public awareness campaigns designed to promote recognition and acceptance of the rights of persons with disabilities; promote recognition of skills, merits and abilities that persons with disabilities may have including their contributions to the workplace and the labour market; foster at all levels of the education system, an attitude of respect for the rights of persons with disabilities among others.

General Comment Number 2 on Article 9 of the CRPD stresses the importance of persons with disabilities being empowered to live independently and to participate fully in all aspects of life. States Parties must take appropriate measures to “*ensure that persons with disabilities can have access, on an equal basis with others, to the physical environment, to transportation, information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas*”. All goods and services, whether public or private should be accessible to all persons with disability.

The decision of the UN Committee on the Rights of Persons with Disabilities (CCRPD) in *Communication No. 22/2014 Mr. X versus Tanzania* is an authoritative interpretation confirming that persons with albinism are covered within the definition of persons with disability and their rights are guaranteed and protected under the CRPD. In that case the Committee’s decision was that Tanzania’s failure to protect an individual with albinism from violence and discrimination constituted a violation of the country’s obligations under the CRDP⁴⁵. The case concerned a man who was attacked and had his limb dismembered by men who targeted him due to his albinism.

⁴⁴ Article 8 1(a-c) CRDP

⁴⁵ Views of 31 August 2017 (UN Doc. CRPD/C/18/D/22/2014, paras. 8.1-8.7.)

Although the victim claimed to know the identity of the perpetrators, Tanzanian authorities failed to fully investigate his case and prosecutors dropped the case. The CRPD Committee held that failing to investigate and prosecute an attack that physically dismembered Mr. X because of his albinism constituted discrimination based on a disability in violation of the CRPD.

Under Article 5 of the CRPD, States must ensure that all persons with disabilities are treated equally under the law and that all are provided equal protection of the law without discrimination. The CRPD Committee found that Tanzania's failure to adopt any measures to prevent this common form of violence against persons with albinism placed "[the victim] and other persons with albinism in a situation of particular vulnerability." The Committee also noted that Tanzania had failed to take any measures to provide support for the victim. And because Tanzania neglected to take steps to address these issues, both in the victim's case and more broadly in the country, the Committee found that Tanzania had violated the victim's right to non-discrimination protected under Article 5 of the CRPD.

The Committee also held that Tanzania violated Mr. X's right to freedom from torture, cruel, inhuman and degrading treatment or punishment and to personal integrity protected under Articles 15 and 17 of the CRPD respectively. The violence against Mr. X was committed by non-State actors i.e. by private individuals and not agents of the state. The Committee nonetheless found that Tanzania violated its obligations to prevent torture and cruel, inhuman, or degrading treatment against X as required of her under Article 15 of the CRPD. The Article requires State parties to prevent individuals from being subjected to torture or cruel, inhuman, or degrading treatment or punishment. By failing to effectively investigate the violence against X, Tanzania had violated her obligation to prevent and punish torture and cruelty against X.

In the same case the CRPD Committee found that the violence suffered by the victim due to his albinism affected his physical and mental integrity, and thus clearly falls within the scope of Article 17 of the CRPD which states that, "every person with disabilities has the right to respect for his or her physical and mental integrity on an equal basis with others." The Committee read Article 17 together with Article 4 of the CRPD which places obligation

on State parties to take all necessary measures to ensure and promote the full realization of human rights for persons with disabilities, including the right to integrity. Because Tanzania failed to take any measures to prevent and punish these acts of violence, and because Tanzania did not take steps to support X to again live independently, the Committee concluded that Tanzania violated its obligations under Article 17 read together with Article 4 to ensure X's right to personal integrity.

The views of the CRPD Committee underscores the fact that persons with albinism are persons with disability and that their rights are protected under the elaborate provisions of the CRPD. The rights under CRPD are comprehensive and cover both civil and political rights as well as economic social and cultural rights. The general principles governing the Convention provided under Article 3 is very instrumental in guiding the protection of the rights of persons with disability and persons with albinism. The principles guaranty persons with disability among others respect for their inherent dignity, their right to equality and non-discrimination and the right to equality of opportunity, full and effective participation and inclusion in society. Others include equality between men and women and respect for the rights of children with disabilities and their evolving capacities.

One other principle which is important for the empowerment and inclusion of persons with albinism in society is the principle of accessibility.

Accessibility is both a general principle under Article 3 and a standalone right under Article 9 of the CRDP. Persons with albinism must be ensured access to:

- Justice (article 13)
- The means to live independently and inclusion in the community (article 19)
- Information and communication services (article 21)
- Education (article 24)
- Health (article 25)
- Habilitation and rehabilitation (article 26)
- Work and employment (article 27)
- Adequate standard of living and social protection (article 28)

- Participation in political and social life (article 29)
- Participation in cultural life, recreation, leisure and sport (article 30)

3.1.5. Convention on the Elimination of All Forms of Racial Discrimination

Discrimination based on the pale skin colour associated with albinism is covered by the Convention on the Elimination of All Forms of Racial Discrimination, (CERD), 1965. Under the Convention, State parties undertake to pursue all measures to eliminate all forms of racial discrimination⁴⁶. The CERD defines racial discrimination as “any distinction, exclusion, restriction, or preference based on race, colour, descent, 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”⁴⁷.

The Durban Declaration and Programme of Action on Racism and Xenophobia considers “colourism” as “racism and related intolerance.” The *Declaration* also speaks to “xenophobia and related intolerance” which covers discrimination faced by people with albinism⁴⁸. At the 2014 *Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward*, Patrick Thornberry, former member of the Committee on ICERD, underscored the relationship between albinism and ICERD. In his opinion, while bringing discrimination against persons with albinism within the concept of racial discrimination might appear a broad interpretation because albinism is not confined to particular ‘races’ or ethnic groups, the governing concept of ICERD was not ‘race’ but ‘racial discrimination’, which may be based on any of five “grounds”: race, colour, descent, national origin and ethnic origin”.⁴⁹

The Committee on ICERD has made it clear that the provisions of the ICERD is applicable to persons with albinism. In its concluding observations on the combined

⁴⁶ Article 2 CERD.

⁴⁷ Article 1 CERD.

⁴⁸ Durban Declaration and Programme of Action, Durban, South Africa: September 2001

http://www.un.org/en/durbanreview2009/pdf/DDPA_full_text.pdf

⁴⁹ See OHCHR and International Organization of la Francophonie, “Expert meeting on persons with albinism: violence, discrimination and way forward”, outcome report, 24 September 2014, para. 33 quoted in the Report of the Independent Expert on the enjoyment of human rights by persons with albinism-A/HRC/31/63 paragraph 33

fourth to eighth periodic reports of South Africa⁵⁰, the Committee made recommendations on the situation of persons with albinism: “*The Committee is concerned about the discrimination and stigmatization faced by persons with albinism, on the basis of colour. It is also alarmed by reports of cases of abduction, killing and dismembering of persons with albinism, including women and children, as their body parts are allegedly used for witchcraft purposes*” (para 20). “*The Committee recommends that the State party take effective measures to protect persons with albinism from violence, abductions, discrimination and stigmatization, including through the action plans and other measures taken to implement the Durban Declaration and Programme of Action.*”- (para 21)⁵¹.

Ikponwosa Ero, the *Independent Expert on the Enjoyment of Human Rights by Persons with Albinism*, agrees with the position of the Committee on ICERD that ICERD can be applied to protect persons with albinism from discrimination on the basis of their skin colour. In her 2016 report to the United Nations Human Rights Council she pointed out that discrimination, stigma and bullying of persons with albinism owing to their appearance have been reported in all regions of the world, to varying degrees. She then noted that discrimination based on skin tone or shade or colour, including within the same ethnic group, is an everyday reality for most persons with albinism. In her view “*there is potential to address albinism under the International Convention on the Elimination of All Forms of Racial Discrimination, as the governing concept is not “race” but “racial discrimination”, which may be based on any of five “grounds”: race, colour, descent, national origin and ethnic origin*”⁵².

3.1. 6. [The Convention on the Elimination of All Forms of Discrimination against Women](#)

The Convention on the Elimination of All Forms of Discrimination against Women, 1979, often described as an international bill of rights for women, defines discrimination against women and sets an agenda for national action to end such discrimination. Since its entry into force, the Convention has achieved near-universal

⁵⁰Committee on the Elimination of Racial Discrimination. “Concluding observations on the combined fourth to eighth periodic reports of South Africa.” CERD/C/ZAF/CO/4-8; October 5,

⁵¹ Committee on the Elimination of Racial Discrimination. “Concluding observations on the combined fourth to eighth periodic reports of South Africa.” CERD/C/ZAF/CO/4-8; October 5,

⁵² See Report of the Independent Expert on the enjoyment of the human rights of persons with albinism- A/HRC/31/63 paragraph 33.

acceptance, with 189 States parties. The Convention defines 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 field⁵³".

By accepting the Convention, States parties commit themselves to undertake a series of measures to end discrimination against women in all forms, including: incorporating the principle of equality of men and women in their legal system; abolishing all discriminatory laws and adopting appropriate ones prohibiting discrimination against women; establishing public institutions to ensure the effective protection of women against discrimination; and ensuring the elimination of all acts of discrimination against women by persons, organizations or enterprises.

3.2. Regional Legal Framework

3.2.1. The African Charter on Human and Peoples' Rights.

The African Charter on Human and People's Rights (ACHPR), 1981 (the Banjul Charter) is the premier African document akin to the UDHR concerning basic human rights. Article 2 of the Charter guarantees citizens of member states the enjoyment of the rights and freedoms recognized and guaranteed in the Charter without distinction of any kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. Article 3(1) and (2) like the UDHR guarantees every individual equality before the law as well as equal protection of the law.

On disability, Article 18(4) of the Charter explicitly provides, inter alia, that persons with disabilities shall be entitled to special measures of protection taking into account their physical and moral needs. On health rights, which is so critical for persons with albinism, the Charter, in Article 16 on health rights, provides for the enjoyment of the best attainable state of physical and mental health by everyone. State parties to the Charter are obliged to take the necessary measures to protect the health of their people

⁵³ See Article 1 of the Convention

and to ensure that they receive medical attention when they are sick.” Besides the right to health, the Charter also guarantees the right to education⁵⁴ and the right to work⁵⁵. These are key rights for persons with albinism given that they are often discriminated in the enjoyment of the right to health, education and work.

The African Commission on Human and Peoples’ Rights (ACHPR), which monitors the implementation of and compliance with the Banjul Charter, has pronounced itself on the situation of persons with albinism in Africa. In its 54th Ordinary Session held from 22 October to 5 November 2013 in Banjul, the Gambia, the Commission noted the wide spread discrimination, stigma, social exclusion and systematic attacks on persons with albinism in Africa and called upon states to take all necessary measures to ensure effective protection of persons with albinism⁵⁶. The Commission then urged African States to implement measures towards elimination of all forms of discrimination including measures towards the acceleration of education and activities for public awareness about albinism and the rights of persons with albinism. These calls were made on the basis of the Banjul Charter that guarantee the enjoyment of the rights in the Charter without discrimination, that require the state to take special measures to protect persons with disability and that require state parties to submit reports on legislative and other measures they have taken to guarantee the enjoyment of all rights recognized under the Charter.

3.2.2. The African Charter on the Rights and Welfare of the Child

Article 3 of the African Charter on the Rights and Welfare of the Child, 1980 provides that every child should enjoy the rights and freedoms in the Charter, regardless of his or her race, ethnic group, color, sex, language, religion, political or other opinion, national and social origin, fortune, birth or other status. And under Article 13, every child who is mentally or physically disabled has the right to special protection to ensure his or her dignity, self-reliance and active participation in the community. These provisions are equally important for children with albinism and like the provisions of

⁵⁴ ACHPR Article 17

⁵⁵ Ibid Article 15.

⁵⁶ Resolution ACHPR/Res.263 (LIV) 2013 on the prevention of attacks and discrimination against Persons with Albinism;

the international treaties, give the legal basis for the promotion, advocacy, advancement and protection of the rights of children with albinism.

3.2.3. The East African Policy on Persons with Disabilities

Under the Provisions of Article 120 (c) of the Treaty for the Establishment of the East African Community, the Partner States undertake to closely co-operate amongst themselves in the field of social welfare with respect to, among others, the development and adoption of a common approach towards disadvantaged and marginalized groups, including children, the youth, the elderly and persons with disabilities through rehabilitation and provision of, among others, foster homes, healthcare, education and training. Article 39 of the Common Market Protocol signed in November 2009 also provides for the harmonization of social policies by Partner States in areas that include promotion of equal opportunities and gender equality and promotion and protection of the rights of marginalized and vulnerable groups. Applying these provisions, the East African Community developed, for implementation by the partner states, the East African Policy on Persons with Disabilities.

The East African Community policy objective is to promote equalization of opportunities for persons with disabilities and generally to guide member states on the best approach to promote and protect the rights of persons with disabilities. The member states agreed to use the policy as a yardstick to inform other policies, programmes and sectoral plans of Partner States to ensure integration of disability rights in all policies and programmes. The Policy identifies the following 10 intervention priority areas for implementation⁵⁷:

- 1) Elevating Disability Sector to a high Profile Ministry for Visibility;
- 2) Training and Education (Capacity Building): Promoting special needs education at all levels including: apprenticeship, vocational, functional education and life-long multi-skilling and training; Equipping service providers with disability-friendly skills and knowledge for effective service delivery and management; Establishing centres for special programmes designed for empowerment of persons with disabilities; Promoting East African Community

⁵⁷ See Paragraph 6 of the East African Community Policy on Persons with Disabilities, March 2012- East African Community Secretariat, PO Box 1096, Arusha, Tanzania.

Country Specific Networks to promote best practices and learning among member states.

- 3) Economic Empowerment: Recognizing that persons with disabilities tend to be persons living in poverty, the policy calls for the following interventions: Establishing a Regional Disability Development Fund to cater for their special needs; Promoting centres for Special programs for persons with disability; Promoting Research documentation and dissemination on strategies that have worked in economic empowerment of persons with disabilities; Promoting affirmative action for employment of people with disabilities.
- 4) Accessibility to facilities and services: The promotion and development of disability user- friendly facilities including education, health etc.; the promotion of sign language, braille, tactile; establishing tax-free regime on all assistive devices.
- 5) Social Protection: To ensure that persons with disabilities have special social protection safety nets the policy calls for the introduction of dedicated budget lines for disability oriented safety nets; establishment of mechanisms to respond to the needs of persons with disabilities in situations of humanitarian emergencies; establishing special psychosocial and counseling services; establishing social protection mechanisms dedicated to the social protection of children, youth, women and the elderly with disabilities; integrating social protection of persons with disabilities in all programmes; and conducting research into best social protection strategies for persons with disabilities.
- 6) Participation and Representation of Persons with Disabilities: ensuring persons with disabilities participate in developing, implementing, monitoring and evaluation of programmes that concern them; supporting organizations of persons with disabilities; ensuring that persons with disabilities effectively participate in the political and public life.
- 7) Care and Support: Provision of guidelines and basic physical and psychosocial support; Developing standard guidelines for service delivery; Increasing awareness on the needs and rights of persons with albinism especially among members, Heads of state and other policy-makers; Promoting positive attitude

and cultural values that protect and benefit persons with disabilities; Promoting capacity building of families, caregivers, guardians and professionals providing services for the persons with disabilities; Promoting conformity with international standards of the assistive devices used by persons with disabilities; Promoting the provision of disability health service needs of persons with disability as close as possible to their community; development of measures and incentives to support employment and self-employment of persons with disabilities.

- 8) Research and Management Information systems: Putting in place mechanisms to collect, analyze, document and disseminate comprehensive information on persons with albinism; Conducting disability related research; Creating a full disaggregated data bank for persons with disabilities in terms of the category, gender, age, education and socio-economic status and other variables; Establishing information channels (media programmes, films, documentaries, documentation of best practices, web sites etc.); Establishing Management Information and Monitoring and Evaluation systems on persons with disabilities.
- 9) Sensitization and awareness creation: Creating effective publicity mechanisms and channels to portray persons with disabilities in a positive manner; Promoting positive perception and greater social awareness towards disability and persons with disabilities; Promoting fundamental rights and freedoms of persons with disabilities through lobbying and advocacy; Fostering respect for the rights of persons with disabilities at all levels of society; Promoting recognition of the skills, merits and abilities of persons with disabilities.
- 10) Affirmative action: Developing a system of affirmative action to integrate access to basic social services by persons with disabilities in the following areas: Access to universal free education; Access to quality health care including sexual and reproductive health; Access to clean, safe water and sanitation; Access to decent shelter (Housing); Access to food security and adequate food and nutrition; Access to justice and effective remedy; Access to disability user friendly facilities.

3.3. National Legal and Policy Framework

3.3.1. The Uganda Constitution.

Chapter 4 of the Uganda Constitution of 1995 provides the basic framework for the protection and promotion of the human rights of everybody, including persons with albinism, in Uganda. Article 45 of the Constitution however provides that the rights and freedoms in Chapter Four of the Constitution are not exhaustive, allowing for the application of those other rights that may not be expressly mentioned in the Constitution. It is important to note that under the Constitution “*All persons are equal before and under the law in all spheres of political, economic, social and cultural life and in every other respect and shall enjoy equal protection of the law*”⁵⁸. And the Constitution is explicit that “*.....a person shall not be discriminated against on the ground of sex, race, color, ethnic origin, tribe, birth, creed or religion, social or economic standing, political opinion or disability*”⁵⁹.

The Uganda Constitution also provides for affirmative action in favor of marginalized groups⁶⁰. It imposes on the State the duty to take affirmative action in favor of groups marginalized on the basis of gender, age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them.

Persons with disabilities have a right to seek redress, as provided for under the Constitution, if their rights are violated. The Constitution provides that any person who claims that a fundamental or other right or freedom guaranteed by the Constitution has been infringed or threatened, is entitled to apply to a competent court for redress which may include compensation⁶¹. A victim may also lodge a complaint with the Uganda Human Rights Commission (UHRC) which is empowered under the Constitution⁶² and the Uganda Human Rights Commission Act to investigate any complaints alleging the violation of any human right⁶³. The UHRC also has a duty to monitor if state organs and agencies are complying with the human rights standards

⁵⁸ Article 21(1): Constitution of Uganda

⁵⁹ Constitution of Uganda, 1995; Article 21 (2).

⁶⁰ Constitution of Uganda, 1995, Article 32.

⁶¹ Constitution of Uganda. Article 50 (1).

⁶² Constitution of Uganda, Article 52 (1) (a).

⁶³ Ibid. Article 52 (1) (a)

on persons with disability⁶⁴. It also has a duty to create awareness on the rights of persons with disability⁶⁵ and to recommend to Parliament effective measures to promote human rights, which include the human rights of persons with disabilities⁶⁶. The Constitution also requires that the States establishes the Equal Opportunities Commission⁶⁷Article for the purpose of eliminating discrimination and inequalities against any individual or group of persons.

3.3.2. The Equal Opportunities Commission Act

The Equal Opportunities Commission Act, 2007 was enacted to, among others, “give effect to the State’s constitutional mandate to eliminate discrimination and inequalities against any individual or group of persons on the ground of sex, age, race, colour, ethnic origin, tribe, birth, creed or religion, health status, social or economic standing, political opinion or disability, and take affirmative action in favour of groups marginalised on the basis of gender, age, disability or any other reason created by history, tradition or custom for the purpose of redressing imbalances which exist against them⁶⁸”.

The Commission’s main function is to monitor, evaluate and ensure that policies, laws, plans, programs, activities, practices of all organs and agencies of the state, private businesses, non-governmental organizations, social and cultural communities comply with equal opportunities and affirmative actions in favour of f groups marginalized on the basis of sex, race, colour, ethnic origin, tribe, creed, religion, social or economic standing, political opinion, disability, gender, age or any other reason created by history, tradition or custom⁶⁹. The Commission can investigate any matter regarding discrimination or marginalization on its own initiative or upon a complaint. It can also examine policies, laws, practice to determine their compliance with equal opportunity standards and make appropriate orders or recommendations.

⁶⁴ Ibid. Article 52 (1) (h)

⁶⁵ Ibid. Article 52 (1) €

⁶⁶ Ibid. Article 52 (1) (d).

⁶⁷ See Article 32 (2) of the Uganda Constitution, 1995

⁶⁸ The Equal Opportunities Commission Act, 2007: Long Title.

⁶⁹ Ibid› Section 14 (1).

The Commission also receives and investigates complaints relating to discrimination, marginalization, or any act which undermines or impairs equal opportunities. Therefore, in the event of the violation of the rights of persons living with disabilities, and in this case persons living with albinism, one can seek redress from the Equal Opportunities Commission.

3.3.3. The Persons with Disability Act

The Parliament of Uganda enacted the Persons with Disabilities Act, 2006 in line with the provisions of Article 35 (1) of the Constitution to introduce measures that uphold and promote the rights of Persons with disabilities. Section 2 of the Act defines "person with disability" as *"a person having physical, intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person."* The same Section defines "disability" to mean *"a substantial functional limitation of daily life activities caused by physical, mental or sensory impairments and external barriers resulting in limited participation"*. By recognizing that disability is the result of the interaction between impairment and external barriers, the Act, to a large extent, aligned the legal definition of disability in the Ugandan law to that enshrined in the CRPD,⁷⁰ implying a significant paradigm shift away from the medical/charitable models, to understanding disability as a social phenomenon. Furthermore, of particular value is the recognition that physical, mental and sensory impairments, can all result in a disability.

The definition of a *"person with disability"* and *"disability"* under Act, was, however, not fully in conformity with the Preamble of the CRDP which provides that *"disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others"*. Notably the Act did not cover disability occasioned by attitudinal and environmental barriers that would capture the kind of disabilities encountered by persons with albinism. For example, the definition in the Act did not cover the disability arising from the risks of exposure to the sun by persons with albinism, a risk which disable them from doing outdoor work for fear of sun burns and cancer. It also did not cover the disadvantage

⁷⁰ CRPD, Article 1 "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"

or discrimination persons with albinism encounter because of society's negative attitudes, myths, superstitions, and stereotypes.

Some other pieces of legislation, particularly those that were enacted before the Persons with Disability Act of 2006, do not, however, conform to the CRDP definition. For example the Worker's Compensation Act 2000,⁷¹ the Employment Act, 2006⁷² and the National Social Security Fund Act, 1985⁷³ contain varying definitions of disability, which are not in tandem with the CRPD.

Therefore, it was not very clear if the Persons with Disability Act 2006 applied to persons with albinism. Nevertheless, organizations of persons with albinism are known to be working with the National Union of Disabled Persons of Uganda (NUDIPU), an umbrella NGO that brings together various categories of persons with disabilities including those with physical, mental and sensory impairments.

The 2006 Persons with Disability Act specifically required government to promote the education of persons with disability. It required the State to do this through several interventions that included: inclusive education; implementation of policies and programmes that promote the special needs and requirements of persons with disabilities; implementation of policies and programmes to support the girl child and children in rural areas; the training of teachers on the special needs of persons with disabilities; the provision of learning and instruction materials and assistive devices suitable for learners with special needs; the enforcement of recruitment and retention of special needs education teachers in all schools and institutions; ensuring all educational institutions have structural and other adaptations suitable to the needs of persons with disabilities; promotion of specialized institutions that facilitate research and development of the education of persons with disabilities; the commitment of not

⁷¹ The Workers' Compensation Act, chapter 225, defines a person with disability as a person "who experiences a restriction or lack of ability to perform any activity in the manner or within the range considered normal for human beings within the cultural context".

⁷² The 2006 Employment Act interprets "disability" as "any permanent: a) physical disability or impairment; b) physical illness; c) psychiatric illness; d) intellectual or psychological disability or impairment; e) loss or abnormality of physiological, psychological or anatomical structural functions; f) reliance on guide dog, wheelchair or any other remedial means; g) presence in the body of organisms capable of causing illness.

⁷³ The National Social Security Fund Act, chapter 222, does not contain a definition of disability. Article 22 states only that a person who has a physical or mental disability that makes such person totally or partially incapacitated with the result that such person is "unable by reason of that disability to earn a reasonable livelihood".

less than 10% of all educational expenditure to the educational needs of persons with disabilities at all levels; and the provision of assistive services during examinations, including giving extra time suitable for students with special disability needs⁷⁴.

Other Sections of the Act prohibited discrimination against persons with disabilities in all spheres including in education⁷⁵, health services⁷⁶ and employment⁷⁷. In addition, the Act required all organs and agencies of government and all persons to respect, uphold and promote the rights in Chapter 4 of the Constitution with respect to persons with disabilities⁷⁸. Government was obliged to take affirmative action in favour of persons with disabilities⁷⁹. And the Act prohibited the subjection of any person with disability to cruel, inhuman, or degrading treatment or punishment⁸⁰.

The Persons with Disabilities Act, 2006, took into account the special circumstances of children with disabilities in education and established the duty of Government to formulate policies that give children with disabilities access to education at all levels, paying particular attention to the requirements of children in rural areas.⁸¹ It also recognized the right of children with disabilities to live with their family.⁸²

In 2018, a new Persons with Disabilities Bill was developed to address the shortcomings of some of the existing laws governing the matter of persons with disabilities, including the Persons with Disabilities Act 2006. In April 2019, the Parliament of Uganda debated the Bill and passed into law, so repealing the 2006 Persons with Disabilities Act. The 2018 Persons with Disabilities Act, which is currently pending assent by the President of Uganda and therefore will not be analyzed in this work, expressly recognizes persons with albinism as a category of persons with disabilities.

3.3.4. The Witchcraft Act

Uganda has a law against witchcraft, the Witchcraft Act, 1957. Section 1 of the Act, which is the interpretation section of the Act, does not define “witchcraft” for the

⁷⁴ Persons with Disabilities Act, 2006; section 5 (1).

⁷⁵ Ibid. Section 6 (1)

⁷⁶ Ibid. Section 7

⁷⁷ Ibid. Section 12

⁷⁸ Ibid. Section 32

⁷⁹ Ibid. Section 33

⁸⁰ Persons with Disabilities Act, 2006; section 34 (1).

⁸¹ PWD Act, article 5 (a)

⁸² PWD Act, article 36 (3)

purposes of the Act apart from stating that “*witchcraft*” does not include *bona fide spirit worship or the bona fide manufacture, supply or sale of native medicines*”. The Act creates the offence of witchcraft but the use of body parts in fortune seeking rituals is for example not included among activities or conduct that would constitute the offence of practicing witchcraft⁸³. In the absence of a law defining and regulating the medical practice of a traditional healer, or harmless practices of a witchdoctor, a witchcraft practitioner could easily pass of as a traditional healer while practicing activities that can involve fortune seeking rituals using human body parts.

The Medical Practitioners and Dental Surgeons Act of 1968 prohibits unlicensed persons from practicing medicine, dentistry, or surgery. However, Section 36 allows the practice of any system of therapeutics by persons recognized to be duly trained in such practice by the community to which they belong, provided the practice is limited to that person and that community. The Ministry of Health presides over allopathic practitioners, while the Ministry of Gender, Culture, and Social Development presides over traditional medicine practitioners. The absence of a regulatory framework for traditional healers is dangerous and can allow witchcraft practitioners to pass of as healers to the detriment of the population and persons with albinism for that matter.

3.3.5. The Prevention and Prohibition of Torture Act

The Prevention and Prohibition of Torture Act (PPTA) has a specific provision that can be applied to prosecute persons who attack and kill or cut off body parts of persons with albinism for ritual sacrifice. Such killings or hacking off body parts amount to torture, cruel, inhuman and degrading treatment. Under the PPTA, it is an aggravated offence of torture attracting life imprisonment if an offender subjects a person with disability to any act that amounts to torture or cruel or inhuman or degrading treatment or punishment⁸⁴.

⁸³ See the offences created under Sections 2, 3 and 4 of the Witchcraft Act, 1957

⁸⁴ The PPTA: Section 5 (c).

3.4. Policy framework

3.4.1. National Development Plan

Uganda's overarching policy document guiding development planning and service delivery is the Second National Development Plan (NDP II) adopted in 2012. The Plan recognizes the need to address the concerns of persons with disabilities and particularly recognizes the interrelatedness of disability and poverty by stating that: *“Disability and poverty operate in a vicious circle. Disability often leads to poverty and poverty, in turn, often results in disability. People with disabilities face multiple discriminatory barriers. Disability must be integrated into all facets of planning, recognizing that there is no one-size-fits-all approach.”*

The NDP II recognizes that many persons with disabilities are not able to develop to their full potential because they face various forms of barriers ranging from negative societal attitudes; discrimination, inaccessible physical environment, information and communication technology to those resulting from regulatory frameworks that are insensitive to disability issues. These result into unequal access to services in the area of education, employment, healthcare, transportation political participation and justice in communities by persons with disabilities. The NDP II correctly lists these barriers as:

- Physical barriers, which may prevent persons with disabilities from accessing educational facilities;
- information barriers, which may leave persons with disabilities without the use of essential educational materials and lacking information;
- Communication barriers in educational settings, which may prevent persons with disabilities from accessing information and/or participating fully in the learning experience;
- Such barriers as may prevent students with disabilities from interacting fully with their peers without disabilities; and.
- Attitudinal barriers, which may lead to assumptions regarding the capabilities of persons with disabilities, and whether it is wise to commit resources to their education and healthcare. This could lead to people with

disabilities receiving substandard education – or even being denied access to education and healthcare – a problem that especially affects girls and women with disabilities.

Community Based Rehabilitation for equalization of opportunities, rehabilitation and inclusion of persons with disabilities in their communities, is the current Government strategy towards interventions on the unique challenges faced by persons with disabilities. However, as of 2017/2018 government budget, funding was available to only 26 districts in the Country which leaves the majority of districts without disability funding⁸⁵. The Special Grant for persons with disability is a Country wide affirmative programme for employment creation. The funding for the grant is still meagre and cannot cater for the overwhelming demand by persons with disability groups.

While the NDP II articulates well the challenges facing persons with disability, it does not expressly recognize persons with albinism as being a component of persons with disabilities. The Plan's understanding of disability to include information, communication, attitudinal barriers and barriers to education is, however, broad enough to accommodate the types of disabilities encountered by persons with albinism. Nevertheless, the fact that the plan does not single out persons with albinism as a very disadvantaged group within persons with disabilities minimizes their chances of benefitting from disability grants. This is likely to be the case given that the Special Grant for persons with disabilities is meagre and is currently available in a limited number of districts.

⁸⁵ Uganda Functional Difficulties Survey 2017 Indicators Report page 9.

Chapter 4: Human Rights issues affecting persons with albinism.

Persons with albinism face specific human rights challenges linked to their condition and beliefs surrounding albinism.

4.1. Right to life: Targeted killings

Grave concern has been expressed at the international level about “attacks against persons with albinism, including against women and children, which are often committed with impunity”⁸⁶Violence against persons with albinism takes various forms, including the killing of, and attacks against, persons with albinism with a view to using their body parts for ritual purposes. . A report by OHCHR states that “in some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at constant risk. These beliefs and myths are centuries old and are present in cultural attitudes and practices around the world.”⁸⁷ The belief that the body parts of persons with albinism possess magical powers that can be used to gain wealth and prosperity and/or to gain power via winning elections are some of the reasons for the killing of, and attacks against, persons with albinism. Arising from the attacks and the use of body parts is the trade of organs linked to trafficking in persons and the sale of children, infanticide and abandonment of children⁸⁸. The often transnational nature of the crime of trafficking and the complexity of identifying the parties involved makes it challenging to investigate these crimes.

The exact number of victims of such abuse is unknown, and is widely believed to be underreported. Under The Same Sun, an organization that promotes the human rights of persons with albinism, reports that as of October 2014, over 340 attacks against persons with albinism, including 134 killings, had been recorded in 25 countries⁸⁹. In that same report, it is reported that within the East African region, Tanzania had experienced 182 attacks, Democratic Republic of Congo 69 attacks, Burundi 38 attacks,

⁸⁶ UN Human Rights Council resolution 24/33, preamble.

⁸⁷ A/HRC/24/57, para. 15.

⁸⁸ *Ibid.*, para. 18

⁸⁹ See “Reported Attacks of Persons with Albinism” March 23, 2017:

https://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf

Uganda 8 attacks and Kenya 5 attacks. However, the number of attacks is likely to be higher than that reported. In particular, the secretive and superstitious nature of witchcraft practices, which is the main reason of attacks perpetrated against persons with albinism, make it very difficult to document cases and collect data..

4.2. Right to the highest standard on health: special health needs

Some of the health problems encountered by persons with albinism have been discussed in section 2.4.3 above. The major serious health issues that afflict people with albinism are visual impairment and vulnerability to skin cancer.

A remedy to visual impairment may be wearing appropriate dark glasses and prescription spectacles to improve refractive errors in the eye. Above all, treatment of eye conditions in albinism consists of visual rehabilitation or surgical treatment to correct the eye vision. Apart from the visual handicaps affiliated with albinism, sun exposure is highly detrimental to the skin. Lack of melanin exposes persons with albinism to extreme skin damage, subsequently resulting in skin cancer. The majority of these lesions are in the most sun-exposed parts of the body such as the face, ears, neck and shoulders. Skin lesions include sunburns, blisters, and superficial ulcers. Ultimately, skin cancers may occur.

People with albinism's skin is threatened by cancers. Several die before the age of 40 in some parts of Sub-Sahara Africa due to a lack of information on skin care and protection, as well as a lack of access to sun protection lotions and sun protective clothing. It may also be partly because people with albinism are forced to work outdoors or undertake work that requires them to work outside in the sun than indoors. More often than not, this is a result of the quality of education obtained as work indoors often require better or higher educational qualifications.

The myths and misconception about albinism promote their exclusion, stigma and discrimination in employment and in society.⁹⁰ The discrimination may be direct or indirect, which creates an impediment for them to access services such as access to

⁹⁰People with Albinism not Ghosts but human Beings accessed at <http://albinism.ohchr.org/human-rights-dimension-of-albinism.html#human-beings>.

health care, education and claim for their legal or human rights- all compounding their health risks.

4.3. Rights of women with albinism

Women and children with albinism suffer multiple and intersectional discrimination. General Comment No. 3 on Women and Girls with Disabilities by the CRDP Committee at para 4 defines multiple discrimination as “*a situation where a person can experience discrimination on two or several grounds, in the sense that discrimination is compounded or aggravated*” and intersectional discrimination as “*a situation where several grounds operate and interact with each other at the same time in such a way that they are inseparable.*”⁹¹ The Committee notes at para 10 that women with disabilities are very concerned about the prevalence of multiple discrimination and intersectional discrimination on account of their gender, disability and other factors which are not sufficiently addressed in legislation. The Committee adds in para 17 (e) that women are also vulnerable to structural or systemic discrimination which are usually “hidden or overt patterns of institutional behavior, cultural traditions, social norms and/or rules. Harmful gender and disability stereotyping can lead to such discrimination. For example, due to stereotyping based on the intersection of gender and disability, women with disabilities may face barriers when reporting violence because of the police disbelieving and dismissing their complaints.

The Human Rights Council Advisory Committee has pointed out specific challenges faced by women and children with albinism⁹² stressing that discrimination against women takes various forms: in some regions of Africa, women with albinism have reportedly been victims of sexual violence as a result of the myth and misbelief that sexual intercourse with a woman with albinism can cure HIV/AIDS⁹³. Women who give birth to a child with albinism may be ostracized or shunned and subjected to discrimination. They are also at high risk of rejection by their husbands or partners, accused of adultery or infidelity and blamed for giving birth to a child who is generally seen as a curse or a bad omen. The rejection of mothers of children with albinism

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⁹² See A/HRC/28/75, paras. 35-38.

⁹³ Ibid paragraph 44

exposes them to poverty and isolation and increases the vulnerability to attacks of both mother and child with albinism⁹⁴.

The myth and superstition surrounding albinism exposes women with albinism to unique circumstances of discrimination including with regard to marriage. Women with albinism are discriminated in marriage and have found it difficult to find genuine partners. A student (girl) explained that women with albinism are normal persons with sexual desires and ambitions to get married and found a family with children of their own. She decried the fact that often men only approach women with albinism for sex with no intention of forming a serious relationship but just to satisfy their sexual curiosity.

4.4. Rights of children with albinism

Discrimination of persons with albinism may be manifested already upon birth and is indicated in the neglect of children with albinism right from birth by parents especially in Africa. As a result of myths and superstitions and lack of understanding of albinism, most parents in Africa and society believe children with albinism are a curse or are born because of sexual union between a black woman a white man or simply abnormal and not worth the effort to support and raise them. The birth of such a child may therefore not be well celebrated in their families or in the whole community. The children are either abandoned, neglected and left to die or even killed or left solely in the care of their mothers. Often the birth of such children is blamed on the mother hence the practice of the men abandoning the mother and the child to fend for themselves.

Children with albinism are often singled out as targets of attacks driven by witchcraft-based belief that the innocence of a victim from whom body parts are taken increases the potency of the potion for which the body parts are used⁹⁵. Cases reported by civil society indicate that children constitute a large proportion of victims of ritual attacks⁹⁶. The Special Representative of the Secretary-General on Violence against Children has noted that children with albinism are at high risk of abandonment, stigmatization and

⁹⁴ Ibid paragraph 44

⁹⁵ See A/HRC/31/63 paragraph 42

⁹⁶ Ibid

marginalization as a result of their appearance, and due to disability factors associated with their condition, such as impaired eyesight and sensitive skin⁹⁷.

4.5. Right to equality and non-discrimination

Persons with albinism are often discriminated against in society, and in accessing services such as education and health care because of myths, beliefs and superstition associated with their condition. In addition, they are also discriminated against on account of their condition notably their skin colour and because of certain impairments that can come with albinism. This unfounded and unfair discrimination tend to prevail without adequate check notwithstanding the existence of international, regional and national human rights provisions prohibiting discrimination of any kind based on skin colour or disability. The CRPD prohibits all discrimination on the basis of disability, including sensory impairments, and requires State parties to take all appropriate measures to eliminate discrimination and ensure the full and equal enjoyment of all human rights and fundamental freedoms⁹⁸.

The State's obligation to "guarantee" the enjoyment of all human rights without discrimination of any kind includes eliminating discrimination against all persons both formally and substantively. Eliminating formal discrimination requires that State laws, policies and practices do not discriminate directly or indirectly on prohibited grounds. Eliminating substantive discrimination requires the State to take necessary and practical measures to prevent and eliminate the conditions, attitudes and conducts that cause or perpetuate substantive or de facto discrimination. For example, ensuring that all persons with albinism have equal access to education will help to reduce and overcome discrimination against them. Eliminating discrimination in practice is important because merely addressing formal discrimination will not ensure substantive equality as envisaged and defined under international, regional and national laws.

In order to eliminate substantive discrimination, the State in some cases, like that of persons with albinism, must adopt and implement special measures to respond to

⁹⁷ Ibid paragraph 43 referring to A/69/264, para. 34.

⁹⁸ CRPD Articles 4 to 7

conditions and conducts that perpetuate discrimination as long as such measures are reasonable, legitimate and proportional to the need to address the objectives of eliminating the discrimination.

4.6. Right to education

Children with albinism face challenges accessing and remaining in education. Because of eye impairment, they may need the necessary school environment and appropriate assistive devices. Such devices include the right eye glasses and magnifying glasses. Other factors that affect their education are stigma and bullying by fellow pupils or students. Lack of understanding by teachers and school management about albinism may render them unable to effectively handle the issues of discrimination that may occur in schools against learners with albinism. The education dropout rate for persons with albinism in some countries is linked to their vision impairment and the absence of any reasonable steps taken to accommodate it and because of stigma and discrimination⁹⁹. While it is ideal to have inclusive education for persons with albinism, circumstances of each child with albinism may require such a child to be accorded special needs education that takes into account their special needs.

⁹⁹ Supra (Ikyomwosa Ero, Protecting the Rights of persons with Albinism, Open Global Rights February 26 2016 accessed at <https://www.openglobalrights.org/end-attacks-protecting-rights-of-persons-with-albinism/>)

Chapter 5: Findings, Concerns and Priorities

5.1. Prevalence of albinism in Uganda.

The non-specific reference of albinism as a disability in Persons with Disability Act, 2006 has marginalized the inclusion of issues associated with albinism in government programs. For example, data collection on vulnerable groups in society is very instrumental for inclusive government planning. Because persons with albinism are not listed as persons with disabilities, the Uganda Bureau of Statistics has never included them in any census on persons with disability. As a result, no official record on persons with albinism exists. The household surveys and national census questions used by UBOS are not designed to capture the disability concerns of persons with albinism except their visual impairment. Both the 2002 Uganda Population and Housing Census and the Demography Health Survey of 2006 formulated questions on disability guided by the Persons with Disability Act, 2006 and the Washington International Protocol. Therefore on disability, UBOS sought information about disability related to movement, seeing, hearing, speaking and learning which do not cover all the disability concerns of persons with albinism.

The Uganda Bureau of Statistics has never conducted a census that identifies persons with disabilities as a category of vulnerable people except in the Uganda Functional Difficulties Survey in 2017. The Functional Survey is not a tool that can indicate the demographic of persons with albinism because its objectives do not include determining the number of persons with disabilities or with albinism but to determine only the nature of functional difficulties they encounter in their daily lives. In the same vein the Ministry of Labour, Gender and Social Development has never considered them as a vulnerable group in its community profiling for community development purposes¹⁰⁰. Therefore, one of the concluding observations on the initial report of Uganda to the CRPD Committee on the CRPD, that were adopted in April 2016 about statistics and data collection on disability in Uganda, rightly expressed concerns about the lack of systems to collect information on the situation of persons with disabilities, including refugees. The Committee recommended that Uganda systematically

¹⁰⁰ Bernard Mujuni, Commissioner for Equity and Rights; and Everest Mwesigye, Commissioner for Community Development and Literacy Ministry of Labour, Gender and Social Development, Uganda.

facilitate the collection, analysis and dissemination of disaggregated data about persons with disabilities and the barriers they face.

The scanty data that is available is estimated or compiled by different organizations working to support persons with albinism. These data however are incomplete and do not purport to represent the number of persons with albinism and their disaggregated distribution in the country. The organizations have only compiled a record of the number of persons with albinism who seek or receive assistance from them or who are registered by Community Based Organizations of persons with albinism. The Tables presented below show the figures obtained from some of the organizations. This information does not cover all parts of Uganda and does not contain full information on the number of persons with albinism in a particular area. The figures, however, can serve to indicate which areas covered have relatively high prevalence.

The African Albino Foundation Uganda (AAFU) estimates the population of persons with albinism in Uganda to be around 3,000 to 5,000 but does not provide the basis for that estimate¹⁰¹.

The number of persons with albinism registered with an organization called Albinism Umbrella as of December 2017 is 426. The information from this organization shows that it registered persons from various part of the country i.e. from western, central and northern parts of the country. As of December 2017 the association had registered 258 persons with albinism from Central Uganda, 78 from Western Uganda and 63 from Northern Uganda- (See Table 1 below for the details which shows the break down by gender, age and region). Albinism Umbrella works with a number of community-based organizations (CBOs) registered in various districts. Some of these CBOs have also compiled a register of persons with albinism in their areas of coverage, raising the possibility of double registration.

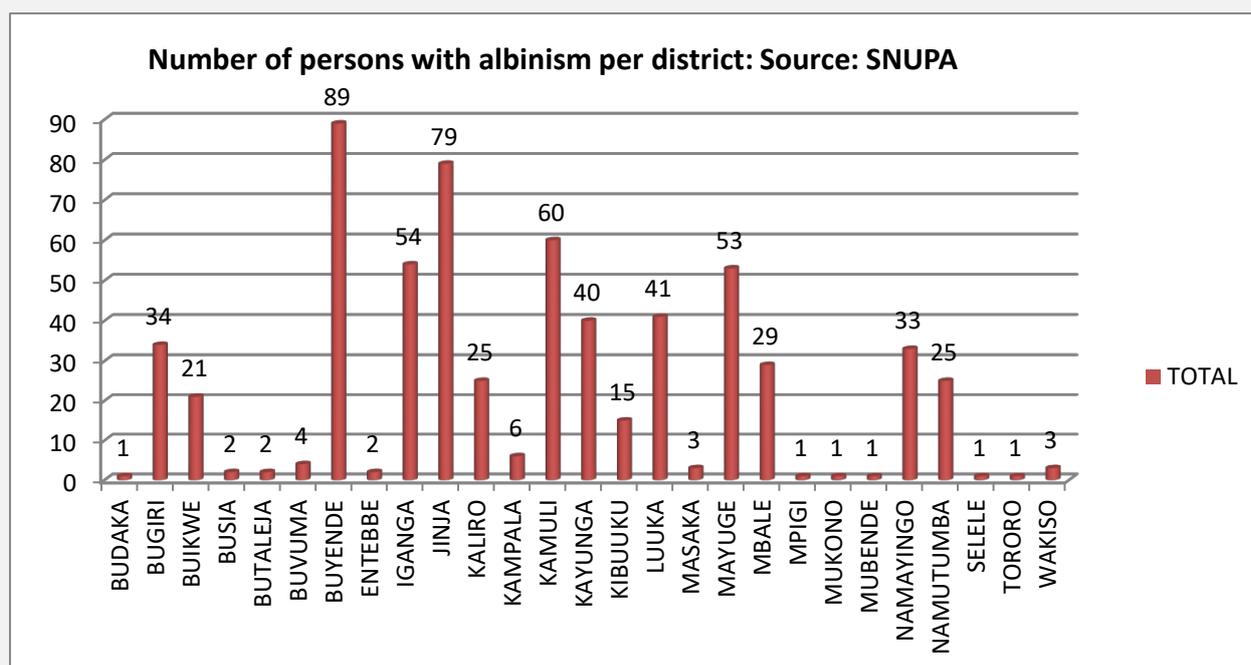
¹⁰¹ See 51 *ibid*.

Table 1: Persons with albinism registered with Albinism Umbrella as of December 2017: Source Olive Namutebi.

DISTRICT									
AGE GROUP	Under 5		6 to 12		13-18		18 +		Totals
	Female	Male	Female	Male	Female	Male	Female	Male	
Luwero			6	5	4	2	21	7	45
Mubende			6	6	4	3	2	1	22
Sheema			2		3	3	4	5	17
Masaka				6	5	3	6	4	24
Lira			1	4	6	7	7	3	28
Wakiso	18	17	14	10	15	16	26	11	127
Kayunga									40
Gulu									35
Hoima									20
Kabale									58
Totals	18	17	29	31	39	34	66	31	416

On its part, the Source of the Nile Union of Persons with Albinism (SNUPA), based in Jinja, has registered 626 people from different parts of the country but mainly from the Busoga sub region. See Table 2 below. SNUPA also has many affiliated CBOs round the country.

Table 2: Total number of persons with albinism (626) registered with SNUPA's: Source Peter Ogik



In the Bugishu sub region and the Sebei sub region of eastern Uganda, the number of persons with albinism registered in Mbale on 13 June 2018 was 277. These numbers consist of persons with albinism in the two sub regions recorded in Mbale when they attended celebrations to mark the International Day for Albinism on 13 June 2018.

Table 3: PWA from Bugishu and Sebei registered in Mbale on 13 June 2018: Source Naomi Muganwa

District	Females	Males	Total
Mbale	26	26	54
Bududa	33	25	58
Manafwa	28	20	48
Namisindwa	13	19	32
Sironko	12	20	32
Bulambuli	18	20	38
Kapchorwa	09	06	15
Totals	139	136	277

In the absence of credible data on the number of persons with albinism in Uganda, it is a safer bet to base an estimate on the statistic provided by the World Health

Organization. The WHO estimates that in Africa 1 in every 5,000 to 15,000 people have albinism although some selected populations, Uganda not included, have estimates as high as 1 in 1,000¹⁰². Applying this rate of prevalence to the population of Uganda that, according to the 2014 population census, was 34,900,000 people, the approximate number of persons with albinism in Uganda is between 2,327 and 6,980. This however, is an estimation of the possible number in the country without an indication of the prevalence region by region. It is important that in its next Household Survey, UBOS should collect disaggregated data on persons with albinism as a group in order for their number and prevalence to be determined. In the meantime, the Ministry of Gender, Labour and Social Development could work with the National Council for Disability and Local Councils to collect this data pending the next household survey.

On 16 of November 2018, this report was presented for validation by persons with albinism and other participants drawn from ministries, departments and agencies of government. In response to the lack of data on albinism, a representative of the Uganda Bureau of Statistics¹⁰³, a government agency, talked of the enormous demand for data and therefore on disability UBOS still follows international protocols that do not classify albinism as a category of disability except some of their functional disabilities such as sight impairments. He therefore expressed doubt that albinism specific data will be captured in the next census unless influence is brought to bear on the ongoing preparations for the next census. The information suggests that Uganda does not have a country tailored persons with albinism disability model. This is a gap that could be filled by emulating the good practice in the region where the Tanzania National Bureau of Statistics has official statistics on albinism. In Tanzania's 2012 National Population and Housing Census, the country's National Bureau of Statistics collected information on the number of persons with albinism in Tanzania as a specific category of persons with disabilities.¹⁰⁴ The data allowed the Tanzania National Bureau of Statistics to

¹⁰² 2 See Preliminary Report of the United Nations High Commissioner for Human Rights, Persons with Albinism, 12 September 2013 ["UN Preliminary Report"] at para 14, available at http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_ENG.doc, citing Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", BMC Public Health, vol. 6, No. 212 (August 2006). Available from www.biomedcentral.com/1471-2458/6/212.

¹⁰³ Mr. Richard Robert Makombe, Senior Statistician UBOS.

¹⁰⁴ See the Report of the Independent Expert on the Enjoyment of human rights by Persons With Albinism on her mission to Tanzania-26February-23 March 2018- UN A/HRC/57/Add.1

draw conclusions in its Disability Monograph published in 2016 which analyzes and gives information on albinism and difficulties faced by persons with albinism in such areas as social protection, seeing etc. This clearly demonstrates that it is not too much to include albinism demographics in a national census and is a best practice that Uganda can emulate for the benefit of her population of persons with albinism.

5.2. Myths, superstitions and stereotypes

In Chapter 2 of this report, examples have been given about myths, superstitions and stereotypes about persons with albinism. Interactions and discussions with a number of individual persons with albinism and those without albinism during this study have confirmed the existence of several unfounded myths, superstitions, beliefs and stereotypes about albinism in eastern, central and northern Uganda. It was clear from these interactions that albinism in Uganda is associated with varying beliefs and superstitions some of which are presented here.

In Acholi and Lango (northern Uganda), the study came across the belief that persons with albinism are sired out of weird sexual union between a woman and evil spirits or Satan. Accordingly, persons with albinism is believed to be “jok” meaning evil spirits. They are also considered a curse. In the long past they would be abandoned to die in order to get rid of the evil spirit¹⁰⁵. Others believe that a child with albinism is the result of sex between a black woman and a white man. In Gulu, an old lady¹⁰⁶ was adamant that she first saw children with albinism on the advent or after the coming of white men in her area.

In a case in Lira, in the Lango sub-region, the birth of a child with albinism resulted in serious misunderstanding in a family leading to a clan meeting to discuss the “phenomenon”: In the meeting, the father of the child and the clan accused the mother of infidelity alleging she was having sexual affairs with white men who employees of an institution near their home¹⁰⁷. One person with albinism interviewed in the sub region talked of the bitterness he feels each time he is referred to as “obang munu” meaning “a fake white man”. The labelling of a person with albinism as a fake white

¹⁰⁵ Joy Omara, Lira, 85 years old

¹⁰⁶ Yunia Okumu, 84 years old

¹⁰⁷ Phone iinterview Twon Too, a lawyer in Lira Municipality.

person is not only indicative of a negative stigma but supports the belief that a child with albinism is a product of mixed black and white blood. In the region, the black spots on the skin of a person with albinism is believed to be caused by flies jumping and breeding on the skin of people with albinism condition¹⁰⁸.

In Bugishu sub-region, a child with albinism is considered a great misfortune and its birth is not celebrated and is blamed solely on the mother of the child. The mother is blamed and abused for bringing forth a “pig” or a “ghost” in the family. The Bagishu derisively call persons with albinism by the nickname “namakoye” instead of their real given names. When a person with albinism walks by, onlookers are known to commonly remark “there goes a pig”. The Bagishu also believe that children with albinism are found only in certain clans and not in others. That is enough reason for many men in the region to deny parentage and abandon such children like in the case of one man who disowned his wife using the excuse that he or his clan cannot sire such a “thing”¹⁰⁹. One man narrated the constant pressures and urge from his clan and friends to divorce his wife because “she had given birth to a pig and brought a curse to his family and clan”. In Manafwa District, also in Bugishu sub-region, a man and a woman rejected and abandoned his child with albinism but the child was saved by neighbours who entrusted it under the care of one of them.

Also in Bugishu, male persons with albinism who are of age for circumcision are denied opportunity to take part with others in the communal “Mbalo” circumcision ceremonies, an important Bagishu cultural ceremony for initiation into adulthood that traditionally confers the right to marry and participation into the public and social affairs of the community. The myth is that persons with albinism are a curse and if they stand together or share the ceremony with other “normal” boys the “normal” boys would be rendered impotent and a whole generation would be wiped out. If persons with albinism are to be circumcised, they have to come last after everybody else have undergone the ceremony and left. In the context of societal practice in the region, exclusion from circumcision is a serious discrimination that can exclude male persons with albinism from marriage and societal responsibilities on the ground that they are

¹⁰⁸ Joy Omara in Lira and Jonathan Lukwiya, Student, Gulu University.

¹⁰⁹ Justus Watulo of Nabisindwa.

“omusinde” i.e. unclean and not real men. In the same Bugishu, some believe that the hair and nails of a person with albinism can be used as a ritual to acquire good fortune or to cure disease. In the words of Watulo of Namisindwa, “we are considered medicine for wealth creation”.

Doctor Harry Mpewo¹¹⁰, who has worked with stakeholder organizers to treat skin problems of persons with albinism in Buganda, Bugishu, Busoga, and northern Uganda including the West Nile sub-region has come across several myths and superstitions about albinism. According to him, the Basoga, Banyoro and Baganda believe that albinism in a family is a curse from the gods to punish the family for something wrong a family member committed. It is also believed that a pregnant woman will give birth to a child with albinism if she laughs at or scoffs at or despises a person with albinism- reinforcing the prevalent stereotype that it is always the woman to blame. Like in Acholi and Lango, the Basoga, Banyoro and Baganda also believe that an albino child is fathered by a white man and it is the woman who bears the blame for alleged infidelity. It is also believed in the three regions of Busoga, Buganda and Bunyoro that persons with albinism do not die- they disappear. Doctor Mpewo has a credible explanation for this myth: In the past, it was the practice to abandon persons with albinism in the bush for them to die. If anybody were to inquire about them the answer would be that the person had disappeared. They were therefore abandoned and left to starve to death.

Doctor Mpewo had come across another strange myth, from the West Nile region of Uganda associating the rainbow with the birth of a child with albinism. It is believed there that a child with albinism will be born if the mother had the misfortune of drawing water from a well at a time when a rainbow is “drinking water from the well”. Again the misfortune and blame for the birth the child is placed squarely on the mother of the child- this time for sharing a well with a rainbow.

The myths and superstitions surrounding albinism in Uganda stem from lack of understanding of albinism which is a result of its rare occurrence and the lack of scientific knowledge about albinism. The myths and superstitions illustrate that traditional societies do not understand how albinism occurs. The research however

¹¹⁰ Medical Doctor, skin specialist based in Hoima Referral Hospital, Western Uganda.

came across an old and illiterate man from Omot, Agago District¹¹¹ who gave a surprisingly scientific explanation to dispel the evil myth about albinism. Mzee Okwir explained that albinism has nothing to do with evil stating that as far as he knows, albinism is a result of the existence of the albinism “blood” in the history of a family. He added that it may disappear in the family for years (recessive) and reoccur at a much later time. He said that in the past his society knew that albinism is an inherited condition and dispelled the belief that it had anything to do with evil or sin in the family.

5.3. Forms of Discrimination

Interviews with persons with albinism and persons who do not have albinism confirmed that persons with albinism experience and suffer extensively from discrimination in Uganda. Persons with albinism encounter in their daily lives socio-economic and environmental challenges that accrue from superstitions, myths, stereotypes and ignorance about albinism. First and foremost discrimination against them begins with the myth and belief that they are less than human beings. Thus, for example, the Bagishu consider them “pigs” and the Acholi treat them as “lagoro” (i.e. lacking in ability or capacity) and in Lango they are considered “fake white persons”. Many more negative labels are given to them in different parts of Uganda-labels like evil spirits or ghosts. By these very labels, discrimination against them is considered normal and tolerated and is rampant in several spheres.

Several situations of discrimination were cited by persons with albinism themselves indicating how discrimination begins from birth and starts with the parents. A number of mothers interviewed talked of fathers denying paternity and abandoning the children in the care of mothers. One person with albinism was thrown away by the mother but had the luck to be found and adopted by another woman who brought her up. In one case a mother recounted how her husband treated her child with albinism as if the child is not a human being. She has 5 children one of whom is a child with albinism. One day when her husband was asked how many children he has, he replied:

¹¹¹ Nakol Okwir, aged 85

“I have 4 children plus that thing there”. The albino child was referred to as “that thing”. The father did not consider the child his, let alone consider the child a human being.

Persons with albinism are therefore discriminated right from home, the community, in schools, health facilities and in employment opportunities. They are marginalized by societal beliefs and superstitions. They tend to be isolated because they find difficulty socializing with peers because of superstitions and because they are called derogative names or considered a curse. In Acholi, persons with albinism hardly socialize with other people because people do not want to touch or even come closer to them¹¹².

One person with albinism told of how he was despised and subjected to discrimination. On reaching adulthood he wished to get married but the society around him did not expect and want him to marry. He however eventually found a woman and they got married. He and his wife were never left in peace to enjoy their marriage. His wife in particular was a target of persistent chastisement and harassment for marrying a person with albinism and was persistently encouraged to abandon the marriage. In addition, some men did not consider him worthy of his wife and therefore incessantly lured her into infidelity, something that made his married life very difficult.

Some families in Buganda isolate and keep their children with albinism indoors and out of sight of visitors because they do not want the public to know that the family has anyone with albinism in their home and family. Their fear is that the sons and daughter of the home will have diminished prospect of finding marriage partners if people get to know that the family has produced a person with albinism. It is common for people to be warned and discouraged from marrying into such a family¹¹³.

Discrimination against persons with albinism in Uganda is also reflected in the lack of inclusion in government programmes. It was obvious after talking to the Ministry of Gender, Labour and Social Development and to persons with albinism themselves that they are not planned for in government programmes. Until recently they were not considered persons with disability neither have their unique challenges been reflected

¹¹² Jonathan Lukwiya Labongo, a PWA, a student at Gulu University.

¹¹³ Doctor Misaki Wayengera, M.D, Co-Chair, Genomics Education and Coordinated Training Working Group, H3Africa Consortium, Unit of Genetics and Genomics. Department of Pathology/Microbiology Immunology and Molecular Biology School of Biomedical Sciences, Makerere University.

in, for example health, education, operation wealth creation, youth and women livelihood programmes that are implemented by the government.

5.4. Health issues.

5.4.1. Skin problems including cancer of the skin

According to Doctor Misaki Wayengera, albinism is one of several genetic disorders that prevent the body from fully or partially producing melanin pigment in the skin, eyes and hair. The absence of pigment in the skin exposes persons with albinism to the risk of skin cancer. In Uganda, this is a very serious threat because of the often hot weather and clear skies to which the unprotected skins of a person with albinism can be exposed throughout the year. The doctor, who examines and treats many persons with albinism inspection and treatment camps organized by organizations supporting persons with albinism, confirms coming across many persons with albinism in Uganda who have skin conditions including cancer resulting from exposure and inadequate protection from the sun. He explained that many persons with albinism he has met including parents of children with albinism are ignorant of the danger the sun poses to the unprotected skin of a person with albinism and therefore do not take the necessary precaution. In addition, he says many persons with albinism and their parents are too poor to afford proper gears that can protect them from sun rays namely long trousers, long-sleeved shirts, wide-brimmed hats, proper dark glasses and importantly sunscreen body creams. Doctor Mpewo confirmed that many have developed advanced skin cancer because of lack of protection from the sun, failure to seek medical help due to ignorance and because there is no national system that facilitate early detection and treatment of lesions.

Dr. Mpewo, a skin specialist, decries the fact that most hospitals and health facilities in the country do not operate skin clinics and have no trained personnel to handle persons with albinism. According to him, there are very few skin specialists in Uganda. Until recently, when a course for skin specialists was introduced in Mbarara University of Science and Technology, Uganda has never had a school for skin conditions. Peter Ogik¹¹⁴ says because of the shortage of specialists, his organization

¹¹⁴ Director, Source of the Nile Union of Persons with Albinism (SNUPA)

SNUPA has often sought assistance to refer some of the serious cancer cases for treatment outside the country.

All of the persons with albinism and their organizations that were interviewed complained bitterly about the inadequate or total lack of access to sunscreen lotions by most persons with albinism. They complained that sunscreen lotions are not treated by the government as essential medicine to meet their everyday health needs and are imported into the country and taxed highly as cosmetics. Sunscreen lotions continue to be subject to very high rate of tax and the Uganda Revenue Authority only waives the tax on them on a case by case basis because the official tax rate has never been legally removed¹¹⁵. The creams are still very expensive and unaffordable by most persons with albinism. The Government, that bears the legal duty to take measures to meet the health needs of persons with albinism, has never imported or supplied these creams to any health facility let alone to any person with albinism. The situation is that those persons with albinism who have accessed these creams get them as charity from organizations supporting persons with albinism. These organizations supply the creams to persons with register with them and therefore to individuals who can be described as informed and active. The majority of the persons with albinism, especially in the rural areas, who are never been reached and registered by these organizations do not get to use these essential creams.

The Brazzaville Declaration on Non-communicable Diseases Prevention and Control in the WHO African Region, adopted in 2011¹¹⁶, affirmed the awareness of African governments about the increasing health danger from non-communicable diseases, including cancers. Among others, the signatories undertook to develop strategies for prevention and control, to strengthen their health systems to enable them to reduce the burden of NCDs, to source the finances required for fighting these diseases, and to enable their national health information systems to generate data on NCDs and their risk factors. Paul Ebusu, the Executive Director of the Cancer Society of Uganda, singled out the lack of a national cancer policy as contributing to limited services

¹¹⁵ Lilian Namukasa, Programme Officer Research and Information and Documentation at National Council for Disability

¹¹⁶ http://www.who.int/nmh/events/2011/ncds_brazzaville_declaration.pdf

rendered to cancer patients including the inadequate response to the skin cancer afflicting persons with albinism. He points out the need for the prevention and treatment of cancer to be prioritized in the national health sector development and investment plan and stresses the need for establishment of regional cancer centres to decentralize and improve accessibility to cancer services offered by the State which is at now concentrated at the Uganda Cancer Institute in Mulago in Kampala.

5.4.2. Visual impairment

Albinism can be a disease burden due to the visual deficits it causes. A person with albinism may have nystagmus, an abnormal beating or shaking movement that the person may not be aware of. A child with albinism may develop an abnormal head position i.e. a preferred head position assumed to reduce the involuntary eye movements so as to improve vision. Persons with albinism can also suffer from high myopia (severe nearsightedness) or farsightedness. Their iris may also have little or no pigment to screen out light from the sun. The vision of a person with albinism can range from normal for those minimally affected to legal blindness i.e. have vision that is less than 20/200 or worse for those with severe forms of albinism. Generally those who have the least pigment will have the poorest vision and an estimated 50% of them have a half normal sight. The other 50% have worse than normal sight. Between 30 and 40 percent need special dark glasses to protect their eyes from sun rays.

Many people with albinism are “legally blind” and very sensitive to light. Eyeglasses can only partially correct this problem. While most can read large print and don’t require Braille, they cannot see a blackboard in a regular classroom setup. This limited vision when unaccommodated often results in disability. In most cases, structural barriers prevent participation in society on an equal basis with others. Persons with albinism interviewed complained of inability to access suitable eye glasses and other eye corrective services. Many who are fortunate, do receive these services through the support of organizations that support persons with albinism. Even those with opportunity to access these glasses must travel long distances to get them. For example those in northern Uganda are referred to an organization in Soroti in eastern Uganda and have to meet the travel expenses. Without financial support many, especially from the rural areas, fails to make these journeys.

5.4.3. Lack of national health programme for persons with albinism

Albinism is a neglected genetic disorder in Uganda. Currently, there is no national programme in place to address the medical concerns that may be unique to persons with albinism. There are no specialized clinics that handle the skin and eye related consequences of albinism. Persons with albinism who approach health facilities receive poor care because of a number of reasons that include lack of awareness on the part of medical staff about albinism, lack of the requisite resources such as sunscreen creams and because of outright discrimination against based on ignorance, myths, superstitions and stigma. That this is the case is borne out by two incidences narrated by Doctor Harry Mpewo: In one incident, a person with albinism suffering from malaria was sent away from a health facility by a health official who claimed he did not “know how to treat such people.” The patient had malaria and could have been treated in the same manner as any other person but was referred to him because he is known to handle their skin ailments.

In another incident, the doctor narrated the case of a woman who came to the hospital to deliver a baby. When she delivered a baby with albinism, the midwife who was attending to her ran away from the delivery room while exclaiming that the woman had given birth to something strange. In another hospital, a pregnant woman with albinism was turned away from receiving anti-natal services at the hospital.¹¹⁷

The health problems and or risks of persons with albinism is compounded by the fact that many of them, including parents of children with albinism, do not seek medical services or the services of those organizations that support persons with albinism. This is chiefly because of ignorance on their part about the health conditions associated with albinism. Relatedly because of stigma and superstitions, the majority of persons with albinism in villages receive no medical attention as their conditions are believed to be untreatable or not deserving of treatment. This is of concern because the findings indicate that medical aid and other support for persons with albinism is currently only received by those who have registered with relevant organizations and actively seek

¹¹⁷ Interview with Elizabeth Kwagala Mirembe, Luwero Community Based Organization for persons with albinism.

aid from these organizations. Many therefore do not seek help when they need it and many do not come out to register and seek assistance from these organizations¹¹⁸.

A Commissioner in the Ministry of Health¹¹⁹ did admit that the Ministry has no special health programme for persons with albinism but insisted that the Ministry's services are open to all. It is this kind of planning that unintentionally discriminates against vulnerable persons such as persons with albinism who because their needs are not integrated into planning end up being marginalized in the delivery of services. The Ministry official however seems to recognize the need for a special response to the health needs of persons with albinism noting that the Ministry will "begin to do something about it." She further pointed out that the Uganda Revenue Authority has continued to categorize sunscreen lotions as cosmetics inspite the fact that the Ministry has requested that they be put under the list of essential medicines.

In the face of lack of or inadequate responsiveness of the national healthcare system to the health needs of persons with albinism, organizations supporting persons with albinism in Uganda have largely been responsible for organizing and coordinating the provision of much of their health service needs. For example, SNUPA, UAA, AU and the Lions Club Gulu now and then organize skin cancer and eye clinics to screen for skin and cancer problems and carry out eye examinations. They also provide sunscreen lotions, sun protection eye glasses and other assistive device to aid vision. The expenses for these clinics are met by charity organizations mainly from abroad. There is however a positive development according to the National Council for Disability. The Council reports that of recent the Ministry of Health, working with UNICEF and Council have taken measures to ensure that the health issues of persons with albinism are captured and integrated within the Health Information Systems of the Ministry of Health¹²⁰.

¹¹⁸ Interview with Elizabeth Kwagala Mirembe and Lilian Anyinge heads of Community Based Organizations for PWA in the Districts of Luwero and Lira respectively.

¹¹⁹ Ms. Rose Bongole Nakasinde, Principal Health Officer, Ministry of Health speaking at the Validation Workshop on 16 November 2018 at Hotel Africana

¹²⁰ Lilian Namukasa, Programme Officer: Research, Information and Documentation at National Council for Disability

5.4.4. Best regional practice of response to health issues of persons with albinism.

Tanzania, Uganda's next door neighbour, has developed and implements some good strategies for responding to the health needs of persons with albinism. The country has established a Dermatology Training Centre that trains professionals and clinicians and provides dermatological services. Important for persons with albinism, the Centre regularly provides skin cancer prevention and treatment services. The centre operates mobile clinics on a regular basis, working with a Non-Governmental Organization (The Voice) to conduct the mobile clinic every six months. The mobile clinic conducts awareness raising, full screening for skin lesions on persons with albinism, treatment if needed, distribution of sun hats and sunscreen lotions and makes referrals of cases requiring surgery. Tanzania makes the sunscreens locally and the sun lotions are formulated for the specific general use of persons with albinism. Commendably the country has included sunscreen lotions in the list of priority essential medicines and in health kits delivered to all government hospitals and health clinics. According to Independent Expert on the enjoyment of the human rights of persons with albinism the model adopted by Tanzania has prevented early deaths from skin cancer¹²¹.

Tanzania's Persons with Disability Act addresses, among other issues, the healthcare and rehabilitation of persons with disabilities. It provides for healthcare fee waivers for persons with disabilities to facilitate access to healthcare services to persons with disabilities including for persons with albinism. Under the Act, Tanzania has developed guidelines on support services for children with albinism. Disability Committees have been established at the village, ward, district and regional levels and charged with the responsibility that include the collection of data and reporting on issues and challenges affecting persons with disabilities and persons with albinism.

Kenya, another neighbour of Uganda, also implements measures that Uganda can emulate and adopt as best practice. According to Mr. Alex Munyere of the Kenya National Council for Persons with Disabilities, the Kenyan Government has integrated the health needs of persons with albinism into the national healthcare provision system. The Government provides sunscreen lotion, sun protective lip balm and after

¹²¹ See Paragraph 84 page 14 of the Report of the Independent Expert on the Enjoyment of human rights by Persons With Albinism on her mission to Tanzania-26February-23 March 2018- UN A/HRC/57/Add.1

sun lotion to persons with albinism through Government hospitals. Protective clothing is also provided and the Government pays the medical bills for people with albinism who require cancer treatment as well as for comprehensive eye-care and free reading devices¹²². From 2015 the Kenyan Government has been implementing an albinism programme for the purchase and distribution of sunscreen lotions for persons with albinism. The lotions are distributed via the Kenya National Council for Persons with Disabilities and Kenya Medical Supplies Authority, and both have the responsibility of ensuring the success of the programme and sustaining access to the lotions for all persons with albinism in the country.

In northern South Africa, genetic counselors at large public hospitals are responsible for easing the shock associated with the birth of a baby with albinism, and empowering the mother with useful information on how to care for, and protect the child. The government also provides some level of support to the Albinism Society of South Africa (ASSA) and provides sunscreen.¹²³

5. 5. Education

Children with albinism in Uganda face several challenges accessing and remaining in schools. Their first challenge arises out of discrimination at the household level. There is evidence that parents choose not to send these children to school because they are considered less than human or having no future. In Gulu, for example, a man who had abandoned his child with albinism in the sole care of the mother used force to collect the child from the mother interrupting the child's education. His interest was to use the boy to attract donations from organizations that support persons with albinism. He kept the child out of school until the mother reported him to the authorities and reclaimed possession of the child¹²⁴.

In Lira, Lilian Anyinge¹²⁵, a person with albinism, has dedicated her time finding children with albinism and urging their parents to send them to school. She is met with

¹²² Alex Munyere, National Council for Disability Kenya, presentation at a Consultative Forum Action on Albinism in Africa 17-19 June 2016 Dar es Salam (United Republic of Tanzania): See Outcome Report, Paragraph 11

¹²³ <https://actiononalbinism.org/page/hfdk5lpzwnfqx7gyejg0c0udi>

¹²⁴ A mother from Gulu interviewed on 28 of July 2018.

¹²⁵ Interviewed in Lira on 29 July 2018.

disinterest from parents. She cited one case where the parents of a child stopped the child from going to school and instead used her as a nanny to look after her younger siblings while the parents are away at to work and her other brothers and sisters attended school. In this case, the child was deliberately kept out of school on the discriminatory ground that she is a person with albinism.

One common ground that was cited in three regions of Uganda (east, north and central) for keeping children with albinism out of school was lack of school fees. In all cases the complaint about lack of fees was from mothers whose partners had abandoned them following the birth of a child with albinism. The mothers were left to shoulder the burden of caring for the children as single parents. Many of these women were rural women who survive by subsistence farming. However, it could not be ruled out that the issue of school fees for children with albinism was a common complaint because the parents hope to get assistance from organizations supporting persons with albinism.

There was a case¹²⁶ where a child with albinism was withdrawn from school by his mother for fear of exposing the child to the risk of abduction by people looking for body parts. In Gulu, a mother stopped her son from attending school because on more than three occasions a stranger in a car approached the son on his way to school promising him assistance if he agreed to go with the stranger. She reported the matter to the school but the school authorities did not have a good solution leaving her with no option but to withdraw the child from the school. At the time of the interview, her appeal was for a boarding school that solve the problem of her child walking to and from school.

Many of the children with albinism drop out of school because of the unfavourable school environment and for reasons associated with their vision. At least four students interviewed reported constant abuse and bullying by fellow students because of their condition and teachers were unable to authoritatively intervene to stop the abuse. To a great extent they were besieged by low self-esteem as they were unable to socialize and participate fully in the life of their schools. Jack (not real name) recounted his

¹²⁶ A mother from Paico Gulu District.

experience in a Secondary school that made him run away from the school: he was a bright student with debating skills but was shocked when one of the teachers one day told him he could not understand why Jack was wasting time and resources attending school. His brilliance and resourcefulness attracted envy and hatred from some students who conspired and smashed his reading and magnifying glass and telescope. When he could not bear it anymore he fled the school.

A common complaint from the students interviewed was about teachers not understanding their needs as students or pupils with albinism¹²⁷. For example there are schools that do not understand that persons with albinism need to wear protective clothing like long sleeved shirts. Such schools have accordingly refused pupils with albinism to wear long sleeved shirts. In addition, students complained of being forced to sit far away from the chalk board and their complaints are ignored because teachers do not understand their vision problems. This lack of understanding extends to tertiary institutions as can be seen from the experience of Allen at the university. While during her Senior 6 examinations Allen was allowed extra 45 minutes for each paper she sat because of visual challenges, the university failed to recognize this special need and this affected her performance¹²⁸.

One example of outright discrimination of children with albinism in education was cited by the Equal opportunities Commission which received and dealt with a complaint where a child with albinism was denied a place in a boarding school by the head teacher claiming the school had no facilities to meet the child's needs. The refusal to admit the child was not only based on ignorance about albinism but also a deliberate act not to have the child sharing boarding facilities with other children. Persons with albinism are normal human beings with a genetic disorder. Given a chance, equal opportunities and protection, they have effective education and excel as well as other students.

The Ministry of Education has and implements a policy on special needs education and the responsible Commissioner has promised to determine the number of pupils and

¹²⁷ Interview with a secondary student from Mbale

¹²⁸ Allen, speaking at the validation workshop of this report on 16 November 2018, at Hotel Africana, Kampala

students with albinism and plan for them appropriately including coming up with a budget to meet the special needs of these pupils and students while they are in school.¹²⁹ The Ministry has come to recognize the need to mobilize teachers to appreciate and understand albinism.

There were also positive stories from those who went through positive school environment where they got all the necessary support from teachers. Jonathan Lukwiya, a student of Gulu University had support from his teachers throughout his primary and secondary school education. Three other interviewed persons with albinism reported similar experiences. As a result, they said they developed self-esteem, which has supported them in their lives today. Education is therefore a great tool that help remove the vulnerability of persons with albinism to discrimination.

Although there is no formal documentation of the prevalence of discrimination against children or students with albinism in Ugandan schools, it is safe to conclude from the experiences cited that it is likely true that they face severe discrimination. In addition, the myths, superstitions, and societal misconceptions about albinism can lend credence to the few stories narrated by some of the interviewees. It can also not be doubted that persons with albinism who have the opportunity to go to school face additional forms of discrimination and are prevented from equal access to education, either directly or indirectly, from both peers and teachers.

The lack of sensitization about albinism as a genetic condition coupled with the prevalence of myths and misconceptions about the condition creates an environment of fear and discrimination. Commissioner Mutekaanga admitted that teachers are typically not fully informed about the condition and lack the knowledge and experience to handle learners with albinism¹³⁰. Not only does this make a teacher incapable of correcting other children's misconceptions, it prevents the teacher from catering to the special needs of albinism, such as seating them close to the front of the classroom, or excluding them from school activities that would expose them to direct

¹²⁹ George W.T. Mutekaanga, Commissioner Special Needs Education, Ministry of Education and Sports, speaking at the Validation Workshop 16 November 2018 Hotel Africana

¹³⁰ Ibid. Commissioner Mutekaanga, Ministry of Education and Sports, speaking at the validation workshop for this report on at H 16 November 2018 at Hotel Africana, Kampala.

sunlight. It is also a known fact that in Uganda, the management of the problems of children with special needs by schools is not working in practice because the programme is not sufficiently funded neither at national nor at local government levels¹³¹. Special education in the country is beset with lack of trained teachers in special needs education leave alone on the unique problems of individuals with albinism. Lack of access to assistive devices such as eye glasses, large print books, and magnifiers by the majority of individuals with albinism attending school is evidence enough of weakness in providing special needs education to this category of pupils or students.

5.5.1. Best regional practice of response to education issues of persons with albinism.

In 2012, Tanzania introduced the Inclusive Education Strategy¹³² for all children aimed at providing them with equal access to quality education in inclusive settings. The strategy includes training teachers to provide adequate support for all categories of students. As part of the strategy, the government has issued Guidelines for teachers of students with albinism in the teacher-training curriculum. The Government has also instructed the Ministry of Industry and Trade to produce assistive devices for persons with disabilities including for children with albinism. In Malawi, the Ministry of Education implements an intervention programme that aims at ensuring inclusive education for pupils with disabilities including those with albinism. Since 2012, the government has printed special texts that are low-vision-friendly for the benefit of pupils and students with albinism¹³³.

5.6. Adequacy of national policies and laws

Uganda does not have any policies and laws that specifically deal with persons with albinism. Other than the Constitution, which provides protection of the human rights of all persons within Uganda, no law recognizes the unique problems associated with albinism.

¹³¹ Naomi Muganwa, a teacher in special education in charge of special education programmes Bududa District Eastern Uganda and advocate for the rights of persons with albinism

¹³² <https://actiononalbinism.org/page/hfdk5lpzwnfqx7gyejg0c0udi>

¹³³ Ibid.

The previous 2006 Persons with Disabilities Act, which was enacted before the adoption and advent of the CRPD had a narrow definition of disability, which did not embrace all the disabilities associated with albinism. According to the Act 2006, disability was, “*a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation.*” And, “[a] *person with disability means a person having physical, intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person*¹³⁴.” This vague definition, for example, did not define what the word “substantial” in this context exactly meant and used to leave it to the discretion of the implementers of the law to determine what it meant. Under those circumstances, categories of disability that may be deserving of attention were excluded from the Act. Of greater concern was the fact that the definition excluded the categories of barriers that persons with albinism do encounter arising out myths, superstitions, and attitudes about albinism- all of which do not fall within the definition “physical, intellectual, sensory or mental impairments which substantially limits the activities” of a person with albinism.

The Persons with Disability Act 2006, which was enacted to provide for a comprehensive legal protection for persons with disabilities in accordance with Article 32 and 35 of the Constitution and to make provisions for the elimination of all forms of discrimination against persons with disabilities, did not therefore embrace all the disability concerns of persons with albinism except their sight related disability. The lack of skin and eye pigments by persons with albinism, for example, which is an impairment that prevent them from living a normal life, did not fall within the definition under the Act.

In 2016, Uganda, in compliance with the CRPD, underwent a review of its initial report to the Committee on the Rights of Persons with Disabilities. In its Concluding Observations,¹³⁵ the Committee noted that Uganda has not enacted a law to domesticate the CRPD and that Ugandan legislation contains provisions that are manifestly inconsistent with some of the obligations assumed under the Convention.

¹³⁴ Persons with Disabilities Act, 2006.

¹³⁵ UN Doc. CRPD/C/UGA/CO/1.

The Committee also expressed concern about the insufficient existing legal remedies to protect persons with albinism against discrimination and the non-recognition of reasonable accommodation for them in the law.¹³⁶ The Committee commended Uganda for the measures taken to promote the rights of persons with disabilities, including the reservation of five seats in Parliament to persons with disabilities, and the provision of a special grant for persons with disabilities to support income-generating activities. However, the Committee observed that despite these measures, there was persistent discrimination against persons with albinism in Uganda. The Committee was also concerned that persons with albinism are disproportionately affected by stigma, which limits their access to education, health and employment¹³⁷. It therefore recommended that Uganda strengthen efforts to raise awareness about the dignity and rights of persons with disabilities, particularly persons with albinism, and ensure the involvement of their representative organizations in any campaign aimed at eliminating stigmatization and myths that underpin discrimination and violence against them¹³⁸.

The National Council for Disability, a body through which the needs, problems and concerns of persons with disabilities can be communicated to government and its agencies for action¹³⁹, has been aware of the fact that the Persons with Disability Act, 2006 did not directly recognize albinism as a disability. The Council therefore advocated for the amendment of the National Council for Disability Act 2003 to specify albinism as a disability. The amendment, the National Council for Disability (Amendment) Act, 2013, has a new Section 31C introducing a new Schedule B on disability codings: *“The disability codings prescribed in Schedule B to this Act shall be used to determine whether an impairment has substantial functional limitation of daily life activities for the person to qualify to be a person with disability”*. The new schedule B expressly recognizes albinism as a disability but it would be more effective for the main law, the Disability Act to have a definition that would make the entire law on disability directly applicable to persons with albinism.

¹³⁶CRPD/C/UGA/CO/1 paragraph 8

¹³⁷ Ibid paragraph 14

¹³⁸ Ibid paragraph 15

¹³⁹ Section 6 (1) (a) of the National Council for Disability Act, 2003.

That the Persons with disability Act 2006 did not embrace disabilities associated with albinism has been also recognized by the Ministry of Gender, Labour and Social Development, which in 2014 initiated a process to amend the Act to, among others, bring it into conformity with the provisions of the CRPD. The Persons with Disability Bill, 2018, was drafted adopting, among other relevant principles on disability, the broader definition of disability that would take care of albinism disability concerns. The Bill, which was debated and passed into law by the Uganda Parliament in April 2019, and is pending assent, includes persons with albinism as a group of persons with disabilities.

Persons with albinism in Uganda do face a lot of challenges and have demands for affirmative action despite the provisions of the Constitution and the Persons with Disability Act that protect the rights of persons with disabilities. For example, to enable them access sunscreen creams, there is demand for government to change the law to list the creams as essential drugs needed by persons with albinism and not cosmetics as is currently contained in the books of the Uganda Revenue Authorities. They demand that in the education sector, albinism be considered a special need and that exams set by learners with albinism should be printed with bigger fonts in consideration of their visual challenges. They further demand inclusive employment, social inclusion and special grants that would respond to their unique special needs.

The weakness of the Uganda law in protecting persons with disabilities and therefore persons with albinism was comprehensively reviewed in 2008 by a publication of the OHCHR-“*A Review of the Ugandan Legal Framework Relevant to Persons with Disabilities: Comparative Analysis to the Convention on the Rights of Persons with Disabilities*”¹⁴⁰. The paper offers an ‘article-by-article’ analysis of the relation between the CRPD and national laws that are relevant for the protection and promotion of the rights of persons with disabilities. In addition to highlighting the important gaps in the definition of disability by the Persons with Disability Act that agrees with the discussion on this earlier in this report, the working paper correctly points out important weaknesses in the laws relevant to persons with disabilities and by extension persons with albinism. A similar

¹⁴⁰ A Working Paper Prepared by OHCHR, August 2008

analysis was carried out ten years later, in 2018, in an OHCHR report titled “*The Rights of Persons with Disabilities in Uganda - An Assessment of Selected National Laws in Relation to the Convention on the Rights of Persons with Disabilities*”. For example, the Children Act, in Section 9, imposes the duty to progressively implement measures related to: a) the early assessment of the child’s disability; b) availability of appropriate treatment and facilities for rehabilitation; and: c) equal opportunities for education. The Section however places this duty to both “parents of children with disabilities and the State” without demarcating which duties belong to the parents and which ones to the state. The lack of clarity may result in arguments about roles thereby affecting the implementation of these duties.

The problems of inadequate policies and laws to address the issues of persons with albinism has drawn the attention of the Rt. Hon. Rebecca Kadaga, Speaker of the Uganda Parliament, who found opportunity to express her concerns and ask cabinet to explain delays in formulating policies and enacting a law that support persons living with albinism.¹⁴¹ In 2017, the speaker had requested the government to come up with measures to address the needs of persons living with albinism. In the same newspaper article in which the speaker was quoted, persons with albinism asked Parliament to review the cancer policy alongside others in order to introduce measures that cater for their needs. In the opinion of the leaders of persons with albinism, “*the cancer policy is worse than Ebola [because] it does not mention skin cancer which is affecting persons with albinism*¹⁴²”. He added that many persons with albinism have lost lives due to skin cancer without much help from the government.

Persons with albinism also want the government to establish a special grant for them because under the current arrangements that manage and dispense special grants to vulnerable groups, they have not been recognized for assistance notably under funding facilities such as the Women’s Entrepreneurship Fund, the Youth Livelihood Fund.

¹⁴¹ www.monitor.co.ug/news/national/speaker-Kadaga-tasks_ministers_over_delayed_albino_policies: Daily Monitor of 22 January 2018.

¹⁴² Mr. Jude Ssebyanzi, the Executive Director, Uganda Albino Association

Policies and laws, should foster inclusion of persons with albinism in all aspects of political, social, economic and cultural life.

5.7. Social Support

Under Article 28 of the CRDP, State Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability. States Parties also recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right.

The legal framework as it exist today does not guarantee clear duty to provide persons with disabilities social support. One of the objectives of the Persons with Disabilities Act is to “encourage all sectors of government and community to promote and include disability issues into all economic, political, and social development policies and programs”.¹⁴³ The Act further confers obligation on the Government to provide supportive social services to persons with disabilities through assistive devices including personal services, specialized training, counseling and child care.¹⁴⁴ Persons with disabilities are also protected from discrimination in services by both the Constitution as well as the Persons with Disabilities Act.¹⁴⁵ In Uganda, financial support for persons with disabilities is recognized under two Acts of Parliament:

- a) Under the National Social Security Fund Act, 1985¹⁴⁶ disability benefits are payable only to a member of the Fund who is fully or partially incapacitated to work because of a physical or mental disability.¹⁴⁷

¹⁴³ PWD Act, article 3 (e)

¹⁴⁴ PWD Act, article 28 “Right to Supportive Services”

¹⁴⁵ For reference see section on “Equality and non-Discrimination”

¹⁴⁶ National Social Security Fund, chapter 222

¹⁴⁷ National Social Security Fund, chapter 222, art 22

- b) Under the Workers' Compensation Act, 2000, workers who are injured or disabled through industrial accidents or in the course of work are entitled to compensation from their employers.¹⁴⁸ Again, the law benefits only persons who acquire disabilities in the course of work.

The Constitutional provisions relating to social support relates only to the aged,¹⁴⁹ in line with the Objective VII of the National Objectives and Directive Principles of State Policy of the Constitution. It is obvious therefore that the law is lacking and the Persons with Disability Act requires amendment to bring it in line with the provisions of Article 28 of the CRPD on adequate standards of living for persons with disabilities and their families.

The study established overwhelming outcry by persons with albinism and their caretakers about the lack of social support to persons with albinism. Children with albinism are abandoned in the hands of poor mothers who are unable to properly look after them and especially to take proper care of their special needs. Their dilemma is compounded by the absence of a universal social welfare system in Uganda that take care of vulnerable individuals in society. The Ministry of Gender, Labour and Social Development runs a social protection programme whose accessibility criteria is based on age and beneficiaries must be needy senior citizens aged 85 years and above¹⁵⁰ which therefore excludes needy persons with albinism.

The Ministry of Gender, Labour and Social Development also implements a special grants programme for persons with disabilities. A Commissioner in Ministry of Gender, Labour and Social Development¹⁵¹ notes that persons with albinism are not accessing these programmes because of two basic reasons: first, persons with albinism have low self-esteem because of their circumstances rendering them incapable of claiming the benefit of these programmes; second, the people with physical disabilities

¹⁴⁸ The Workers' Compensation Act, Chapter 225, article 5 and 6

¹⁴⁹ Constitution, VII "Protection of the aged" "The State shall make reasonable provision for the welfare and maintenance of the aged"

¹⁵⁰ Bernard Mujuni, Commissioner Equity and Rights, Ministry of Gender, Labour and Social Development

¹⁵¹ Commissioner Masaba Sam Wekesa speaking at the Validation Workshop 16 November 2018 at Hotel Africana

who are better organized easily access the benefits under the special grants programmes and in the process marginalize other categories of persons with disabilities. If these two explanations are true, then the Ministry must take steps to implement affirmative action to ensure that other disability groups, such as persons with hearing and vision impairments and persons with albinism benefit from these programmes. For instance, an affirmative action would instruct extension workers under the Ministry to ensure that persons with albinism are included among the beneficiaries of the special grant.

Persons with albinism have been unable to access the poverty alleviation programmes run by the Ministry of Gender, Labour and Social Development. The Ministry admitted to that it has never included persons with albinism in the Youth and Livelihood Programme and as well as in the Women's Entrepreneurship programme. One reason for this exclusion is the requirement that the assistance be extended only to groups made up of at least a network of 12 persons with disabilities at the village level. This works at the disadvantage of persons with albinism who are most likely to be fewer than 12 in number in a given village unless they are counted directly as persons with disabilities. To avoid such situations, it is better to operate an affirmative action that requires inclusion of persons with albinism in these programmes if any is living in a beneficiary village. Councilors and extension workers should be instructed to identify and include persons with albinism in these programmes in all cases where they are available in a village.

In practice the country does not extend social support to persons with albinism. Some limited social support however are extended by wholly by some Non-Governmental organizations and in particular by organizations that work for the realization of the rights of persons with albinism. These organizations would be very effective vehicles for reaching and supporting persons with albinism if the government were to accept the recommendation to accord persons with albinism social support which they so badly need.

5.8. Attacks on persons with albinism

Across Eastern Africa many believe that the body parts of people with albinism can bring good luck and therefore this has motivated attacks on them to get their body parts. It was however not possible for this study to determine exactly how serious attacks on persons with albinism is in Uganda. The people interviewed could not cite concrete cases except general statements that attacks do occur. Individual cases however point to the possibility that these attacks have taken place in Uganda. For example, there have been newspaper reports of attacks or attempted attacks on persons with albinism. In an NTV Television Documentary, one Salongo, Bernard Mwanje from Buyende District, recounts of how he lived in fear of the safety of his children with albinism. He was very concerned about the risk of his children would be kidnapped or abducted from his home, from school or when going to and from school. This was after unknown people attempted, in broad daylight to abduct one of his children with albinism. He also recounts in the documentary how the grave of a person with albinism in his area was dug up and the body removed from the grave.

In Gulu, northern Uganda, a mother narrated a case of an attempt to kidnap her child. According to her, a man she did not know tried several times to lure her son, a school pupil, to go with him to unknown place. He promised the boy assistance and support that would change the boy's life for the better. The man claimed he was working on behalf of Peter Ogik, the head of SNUPA, but Mr. Ogik, when contacted, denied knowing the man, and stressed that he has never sent any person on such mission to Gulu. Concerned, the mother withdrew the boy from the school and opted to look for a boarding school in order to minimize the risk of her child being kidnapped as he walked to and from school.

In another case, persons with albinism in Luwero Sub County, Luwero District, have been living with the fear and strong suspicion that one of their own, Walugembe Mulangira may have been murdered in a witchdoctor's shrine for ritual sacrifice. According to a group of persons with albinism interviewed together in Luwero, Mulangira who hailed from Kito, Luwero Sub County, was reportedly taken to a witchdoctor in Luwero for treatment but has "simply disappeared" and has never been

seen again. They say Mulangira's disappearance has never been investigated even after they brought the matter to the attention of the area Councilor. If true this was a case where person with albinism can disappear without causing much apprehension and concern within their immediate society. Even the authorities seemed to have paid little attention to the case after receiving information about the disappearance. Could it be that this was the case because Mulangira was a person with albinism?

One of the current leaders of a community-based organization of persons with albinism, who is herself a person with albinism, recounted her story and how she survived an attempt to be sold by her husband to unknown people. At birth, she was abandoned by her mother and father but was picked by a woman who brought her up and sent her to school. One day her foster mother took her on a trip to one of the outskirts of Kampala City, introduced her to a man and told her that he was her husband. She was locked indoors and the man forced himself on to her forcing her to accept the inevitable of becoming his wife. She lived a life of confinement within the perimeter wall and was virtually a prisoner in the man's home. In 2015, after their third child, some strangers started frequenting the house and would hold discussions with her husband in a language she did not understand. On one of the visits, and during their discussions, one of the strangers made a comment in English and asked in English: "Who will look after her children when we take her?" Her suspicion of what was going on was strengthened and so when her husband escorted the strangers she escaped with her life from the home with her three children.

In addition to the individual cases narrated above, reports from Under the Same Sun, an organization that collects data from its own field research and also from its partners, the media and civil society, has reported recording 8 reports of attacks on persons with albinism in Uganda by October 2016¹⁵². Compared with the reported attacks in other countries within the East African region, the reported attacks in Uganda indicate that the situation was not as bad as in Tanzania (182 attacks), Democratic Republic of Congo (69 attacks), Burundi (38 attacks)¹⁵³. Under The Same Sun however notes that

¹⁵² See "Reported Attacks of Persons with Albinism" March 23, 2017: https://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf

¹⁵³ Ibid

the actual number of attacks & killings of persons with albinism are likely to be much higher than it has recorded since many attacks are never reported or documented

Attacks on persons with albinism, as has been explained in the earlier part of this report, is a result of myths, superstitions and unfounded beliefs and witchcraft practice which can serve to reinforce these myths and superstitions. In Uganda, it can be difficult to draw a clear distinction between what is a practice of witchcraft and what is the practice of a traditional healer because both could apply methods that involve rituals and application of some kind of “medicine”. It is also difficult to determine what activities they engage in would be legal or illegal in the absence of a law defining the practice of a traditional healer.

Tanzania has endeavored to draw a distinction between the practice of witchcraft and the practice of a witchdoctor by passing the Traditional and Alternative Medicines Act, 2002. The Act regulates the activities of practitioners of alternative medicine who have formal training and healers who dispense traditional medicine made from plants, animal and mineral stuffs. Under the Act all traditional healers must register prior to engaging in their practice and it is an offence for unregistered persons to practice traditional medicine. The Act importantly establishes a duty on a practitioner of traditional medicine not to harm patients. This is commendable because registration is one way of blocking out quack traditional practitioners. It also provides the legal basis for oversight over the practices of traditional healers and distinguishes between registered practices and illegal ones.

5.9. Organizations of Persons with Albinism in Uganda

There are several organizations in Uganda who are supporting persons with albinism. All but one of these organizations identified here are formed by persons with albinism themselves. The organizations fall in two categories: the first category are those with a national outreach and the second are those that operate within their sub regions or localities only but with some kind of linkage to one of the national level organizations. The national level organizations are registered as non-governmental organizations while the sub-regional or local level organizations are registered as community based organizations by their district local governments.

Table 4: Some organizations of persons with albinism in Uganda

No.	Name of Organization	Location	Coverage
1	Uganda Albinism Association	Kampala	Nationwide
2.	Albinism Umbrella	Kampala	Nationwide
3	African Albino Foundation Uganda	Kampala	Nationwide
4	Source of the Nile Union of Persons with Albinism	Jinja	Nationwide
5	Asante Albino Association	Mbale	Bugishu/Kapchorwa
6	Luwero District Albino association	Luwero	Luwero District
7	Nazigo Albino Association	Kayunga	Kayunga
8	Lira District Albino Association	Lira	Lango sub region
9	Northern Uganda Albino Association.	Gulu	Northern Uganda and West Nile
10	Lions Club Gulu	Gulu	Northern Uganda

The organizations of persons with albinism have done a commendable job creating awareness about albinism, and bringing their concerns into the public domain. They have made it possible for some persons with albinism to access much needed assistive devices such as sunscreen lotions, hats and eye glasses. Through the organizations, medical camps are organized to enable persons with albinism receive medical services that include cancer screening and treatment. The organizations have been fairly successful in bringing their concerns to the attention of the media, ministries, departments and agencies of government as well as to the attention of some important people in government. For example, their intensive advocacy have attracted the attention of the Right Honourable Rebecca Kadaga, the Speaker of Parliament who has become a passionate advocate for the rights of persons with albinism and has since employed a person with albinism as staff of Parliament. The Equal Opportunities Commission is now working together with organizations of persons with albinism to advocate for the realization of their rights. There is now increased appreciation of persons with albinism as human beings thanks to the efforts of these organizations. Much however remains to be done in the areas of policy and law and in reaching the

general public, service providers and the country side with information on albinism to dispel ignorance about albinism.

The organizations of persons with albinism have done commendable work to give persons with albinism some voice, which they have effectively utilized to reach some critical corridors of power including Parliament. The Uganda Parliament now has advocates who have been pitching for the introduction of a law against human sacrifice and for the protection of persons with albinism and who are putting pressure on the Uganda Revenue Authority to continue waiving tax on sunscreen lotions pending eventual removal of the tax altogether by Parliament. Moreover, thanks to the activism of these organizations, more children with albinism are now going to school and the Ministry of Health, working with UNICEF and the National Council on Disability, are working to integrate the concerns of persons with albinism into the Ministry's Health Information System. In the same vein, and as mentioned before, the Uganda Bureau of Statistics (UBOS) has yielded some ground by generating some statistics on albinism and including albinism as one of the indicators in its Functional Difficulties Survey 2017¹⁵⁴.

As can be seen from the Table 4 above, the number of albinism organizations in the country are many. Some of the organizations that were interviewed did raise concern that there is ongoing proliferation and ever increasing number of these organizations in the country. This, they say is introducing “unhealthy, though shuttle” competition between these organizations. In practice, they are replicating each other's work, competing for attention, registering the same persons with disabilities and seeking support from the same sources. It was, for example, pointed out that the national celebrations to mark the 2018 day of persons with albinism had to be held in two different venues, one in Jinja and the other in Mbale, because of the lack of coordination and agreement between the national mainstream organizations of persons with albinism. This resulted in the waste of scarce resources organizing two events serving the same purpose and amplifying division within the persons with albinism movement.

¹⁵⁴ See Uganda Functional Difficulties Survey 2017, Indicators Report July 2017, Uganda Bureau of Statistics, Kampala, Uganda.

The other area of concern about the proliferation of the number of organizations is a feeling that was expressed by some persons with albinism and their parents or caretakers: it was alleged that some of these organizations are formed for the benefit of their founders and officials but do little for persons with albinism. Because of this feeling and suspicion, some persons with albinism and parents of children with albinism have been reluctant to register with albinism organizations fearing that their names would be used to make money. It was difficult to verify these claims. However, there is a case to be made about the benefit of a single coalition bringing together organizations of persons with albinism. A coalition would unify their efforts, give it a united voice and message, and avoid uncoordinated action in the pursuit of the interests of persons with albinism. There is therefore a need for these organizations to come together and brainstorm about their work with a view to forming a common platform or at least a coalition with membership from existing organizations.

Chapter 6: Priority recommendations and conclusions

6.1. Recommendations

6.1.1. Recommendations on unfounded beliefs about albinism

Demystify myths, superstitions and stereotypes about albinism

Myths, superstitions and stereotypes about albinism is due to ignorance or lack of information about albinism leading to strongly held beliefs at society level including in public and private institutions that provide services. As recommended in the Regional Action Plan on Albinism in Africa - 2017 to 2021, the best solution to myths, superstitions and stereotypes surrounding albinism is to create awareness within the public and service providers about the condition. This should be done through the formulation and implementation of sustained programmes for raising awareness about albinism by the government through the Equal Opportunities Commission, the Uganda Human Rights Commission and the Ministry of Gender, Labour and Social Development. The programmes should include:

- Working with the Equal Opportunities Commission as the focal point institution to mobilize resources and coordinate all relevant stakeholders to contribute and participate in the awareness campaigns in a sustainable manner.
- Working with persons with albinism and their organizations to raise awareness and demystify albinism throughout Uganda using traditional and social media and approaches.
- Training media personal on the issue.
- Involving faith based organizations and traditional healers, family members and persons with albinism.
- Appointing person(s) with albinism to key leading roles, such as the department on disability, health, minority groups.
- Replicating positive image of persons with albinism in public materials.
- Educating persons with albinism and their parents about their condition, the need to prevent skin cancer and visual impairment by protection of exposure to the sun, and the need to build their self-esteem.
- Ensuring awareness campaigns reach the village level.

- Advocating for accurate portrayal of albinism and respect and promotion of the equity rights of persons with albinism.
- Educating health workers, including midwives, health care workers and paediatricians, and educators about Albinism.
- Integrating albinism awareness in school curriculum
- Encouraging the formation of local albinism organizations.
- Conduct further research (legal, anthropological, academic and other areas), including on cross-border trafficking in body parts.

6.1.2. Recommendation on national statistics on albinism

UBOS should determine the number and prevalence of persons with albinism in Uganda including their functional disabilities.

It is very important that accurate statistics about albinism in Uganda is determined. Lack of accurate data makes it difficult to develop appropriate interventions in the absence of information about actual numbers, areas of prevalence of persons with albinism and the nature of functional disabilities. Given the need to address the concerns of persons with albinism as soon as possible, UBOS should carry out a special National Household survey on albinism to capture these very important data on albinism in Uganda. In this survey, UBOS should include questions that capture the number of persons with albinism in Uganda and all the disability attributes they encounter namely:

- Sight impairment,
- Health concerns or challenges,
- Access to health and education services,
- Difficulty in accessing work or to do work that exposes them to the sun,
- Attitudinal barriers, and
- Physical and socio-economic security needs.

In addition, UBOS should:

- Collect disaggregated data and do a need assessment, including with regard to security needs.

- The national census should allow PWA to choose “albinism” specifically from the list.

6.1.3. Recommendation on health concerns of persons with albinism

Integrating albinism into the national health system: The Ministry of Health should develop and implement a programme to adequately respond, on a sustainable basis, to the health issues of persons with albinism.

Persons with albinism suffer a unique spectrum of medical (mainly skin and eye) as well as psychosocial problems. As has been noted in this report, response to these problems have been neglected by the health care system in the country. The national health care system has no dedicated program in place to address the medical concerns of persons with albinism notably photophobia, decrease in visual acuity, extreme sun sensitivity and skin disorders including skin cancer. This calls for the development and implementation of a programme to sustainably respond to the health needs of persons with albinism as a category of persons with disability. The objective of the programme should be to prevent, diagnose and provide a holistic approach to management of eye sight problems and skin disorders, including skin cancer in persons with albinism as a disadvantaged group. The programme should embrace the following:

1. Preventive measures:

- ✓ Early diagnosis: The Ministry of Health should set up within its free public health services a programme for routine identification of persons with albinism, reviewing and investigating their conditions including their visual impairment and suspicious skin lesions and making diagnoses and suitable medical responses and advice. This should involve the opening of referral clinics or running mobile clinics that are based on regular field visits.
- ✓ Primary prevention: The Ministry of Health should provide within its public health services: programme for education of persons with albinism and their caretakers on the importance of prevention of overexposure of the skin to the sun and the role of sunscreen lotions, suitable clothing, hats and eye shades in protecting the skin and the eyes from the sun;

providing persons with albinism with eye shades and sunscreen lotions, clothing, hats, for eye and skin protection respectively.

- ✓ Secondary prevention: The Ministry of Health should provide, within its free public health services, excision biopsy tests and surgery services to persons with albinism found with pre-malignant lesions of the skin.
- ✓ Tertiary prevention and management: The Ministry of Health should provide, within its free public health services, surgery, radiotherapy, palliative care and rehabilitation for PWA with malignant skin lesions.

2. Psycho-social management:

- ✓ The Ministries of Health should train personnel (health care workers and midwives).
- ✓ The Ministries of Health, and the Ministry of Gender, Labour and Social Development should develop a programme to provide counseling services that include important health and other information that persons with albinism need to live normal lives, and to dispel traditional myths and stigma associated with albinism.
- ✓ Victims and relatives of victims of an attack should receive psycho-social, medical, legal and socio-economic support to rebuild their lives.

Some individuals that were interviewed for this study expressed interest in knowing if there is a way of preventing albinism or reducing the risk of having children with albinism. In the same vein, the Right Honourable Rebecca Kadaga, the Speaker of Parliament, in her Speech on the occasion to mark the 2018 day for persons with albinism, requested that this report recommend means that can be adopted to avoid or reduce multiplication of albinism in the country. While these interests were expressed in good faith, the overall message of this study is that persons with albinism are normal human beings just as any other member of society. It is therefore problematic to make recommendations that would imply that measures should be taken to reduce their numbers or to prevent them from being born. Indeed, during the validation meeting for this study that took place at the Parliamentary conference Hall, there were strong opposing views on this issue coming from persons with albinism themselves. While

others supported the idea of controlling multiplication, others were very opposed to it. Proposing measures aimed at reducing the multiplication or prevention of the birth of children with albinism does not therefore only have ethical implications but also far reaching human rights implications. Calling for and implementing such measures has serious discrimination against persons with albinism as it can result in the violations of their right to life and right to reproductive health rights.

Dr. Misaki Wayengera and Dr. Harry Mpewo were, however, of the considered medical opinion that families or persons with genetic disorders like albinism or sickle cell anemia should be free to access genetic counseling, especially if they have limited or no understanding of the genetics of these conditions. They suggest that counseling, carried out by a trained genetic counselor, would include providing information on the disorders, explaining the management of the medical and psychosocial aspects of having the conditions and discussing reproductive options to enable couples with such conditions make informed decisions about their reproductive rights.

6.1.4. Recommendation on Education

The Ministry of Education should take measures to ensure that persons with albinism receive education on equitable basis with other pupils or students who are without albinism in a favourable learning environment.

A number of obstacles that deny persons with albinism access to education to persons have been captured in this report. To address them the following interventions are not only necessary but critical and should be addressed as a matter of priority:

- 1) Identification and placing of children with albinism in schools: The Ministry of Education and Sports, the National Council for Children and the National Council for Disability should work with local councils and local organizations of persons with albinism to identify and register children with albinism and assess their educational needs and ensure that they are enrolled and supported in schools as a matter of affirmative action.
- 2) Demystify albinism in educational institutions: The Ministry of Education and Sports through the relevant departments should take measures to ensure that teachers and school management understand albinism. In particular the

Ministry should issue information and guidelines on how teachers and school management should handle learners with albinism and how they can respond correctly to their educational, health, environmental, emotional and psycho-social needs.

- 3) Sensitize pupils/students on albinism and their rights to equality and non-discrimination: Teachers and or school management should sensitize pupils and students about albinism as a general rule but as a matter of priority in all schools that have enrolled pupils or students with albinism.
- 4) Preventing and addressing bullying or abuse: There is a need to sensitize and inform students about albinism as a matter of school policy and practice. Schools should be encouraged to take effective measures to prevent bullying or abuse, stigmatization and discrimination against pupils or students with albinism. In the case of such abuse, schools should engage the relevant students to ensure that they never repeat such behavior.
- 5) Protective wears: The Ministry of Education and Sports should issue, as a national school policy, sun protective wear and lotions to pupils with albinism. It should issue instructions and guidelines to schools permitting pupils with albinism to wear sun protective clothing including long trousers, long-sleeved shirts, shoes and socks, eye protection sunglasses and wide-brimmed hats.
- 6) Assistive devices: The Ministry of Education, should as a national school policy, supply persons with albinism in schools with assistive devices they may require notably magnifying glasses, special spectacles, text books, examination papers in large print.
- 7) Safety of pupils with albinism: The Ministry of Education and Sports should issue security guidelines and instructions to schools that have enrolled pupils with albinism and require schools to work with parents, the police and local security systems to local institute arrangements that ensure the security of pupils with albinism when in school and when walking to and from school.
- 8) Adaptive devices: Provide and ensure adaptive devices and vision support in classes and at the work places, including copies of teachers / student notes as needed.

6.1.5. Recommendation on policies and laws

- 1) The Ministry of Justice and Constitutional Affairs, working with the Ministry of Gender, Labour and Social Development should initiate the process for Parliament to amend various laws that are relevant to persons with disability but have contradictory provisions to bring them in line with the provisions of the CRPD.

It is recommended that an expanded definition of disability be adopted to include the kind of limitations that persons with albinism do encounter, notably risks of damage to the eye because of lack of eye and skin pigment and attitudinal barriers associated with myths, superstitions, and attitudes about albinism. All these limit the activities of a person with albinism yet they are not physical, intellectual, sensory or mental impairments. Expanding the definition will bring the meaning of disability in line with the provisions of the CRPD and capture NDP II's understanding of barriers that prevent persons with disability to achieve their potential.

- 2) The Ministry of Justice and Constitutional Affairs working with the Office of the Director of Public Prosecutions, the Judiciary and the Police should introduce measures that will combat impunity for attacks against persons with albinism.

These measures to be taken should include:

- Prioritizing prosecution of cases of attacks against persons with albinism,
- Training investigators and prosecutors,
- Issuing sentencing guidelines and assigning cases to higher courts, and
- Adequately resourcing the investigations, prosecution of cases involving attacks and or killings of persons with albinism.

6.1.6. Recommendation on Social Protection

The Ministry of Gender, Labour and Social Development should:

- ✓ Initiate a process to amend the Persons with Disability Act to recognize and actualize the rights of persons with disabilities and for that matter the rights of persons with albinism to adequate standard of living in compliance with Article 28 of the CRPD.
- ✓ Provide social services to persons with albinism in Uganda by including them as a special group in the Ministry's community development

programmes, Special Grants Programmes and poverty alleviation programmes. The Ministry should consider implementing affirmative action for persons with albinism to enable them access the programmes.

- ✓ Recruit and train specialized teams including persons with albinism to provide counseling services to persons with albinism and their caretakers.
- ✓ Encourage the formation of community self-help groups for persons with albinism or the integration of persons with albinism into such groups.
- ✓ Advocate for the inclusion of concerns of persons with albinism in national and local government programmes and budgets.

6.2. Conclusions

All persons are born free and equal in rights and dignity. Persons with albinism are human beings and deserve all rights and freedoms enjoyed by all persons. They are all a part of the society and the diversities therein. Any violation or abuse of rights affects the general humanity, so society ought to look at them and acknowledge their special needs especially in respect to health, education, personal security and existence.

As has been pointed out in this report, there exists the legal framework at the international, regional levels except that the domestication of the international and regional standards need to be strengthened to bring in the special needs of persons with albinism. The overarching development framework as contained in the NDP II properly identifies the problems faced by persons with disability and the approach therein would adequately tackle the problems of persons with albinism if properly implemented.

The challenge of implementing the international standards and the national policies to address the problems of persons with albinism should be considered a priority because they have been marginalized and forgotten for long due to failure to recognize them and integrate their concerns in policies and programmes. In particular, there is urgent need for sustained awareness raising, intervention into their health, education and security concerns to assure them their socio-economic and political rights as human beings. This calls for the mainstreaming of albinism in all development activities and involving persons with albinism in all stages of implementation of policies and programmes that

concern and build the capacity of organizations of persons with albinism to enable them participate effectively.

Uganda was a participant in the development of the United Nations Sustainable Development Goals, Agenda 2030 and publicly declared to implement that agenda that pledges to “leave no one behind” in the development process. Persons with albinism are among the vulnerable groups in Uganda who have been left too far behind because of ignorance, myths, superstitions, and lack of recognition in laws, policies and programmes. The time is now to recognize this and to give them priority in the development process.

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