



Don't just stare, ASK !!

ALBINISM SOCIETY OF KENYA

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ALBINISM REPORT 2019

Introduction

Albinism Society of Kenya (ASK) is a National not-for-profit Civil Society Organization (CSO) established in 2006 to bring together and assist people with albinism (PWA) to live dignified lives. ASK seeks to address violation of human rights of PWAs including their social exclusion, access to better medical attention and services for their sensitive eyes and skin. The organization also strengthens their confidence and self-esteem; undertakes advocacy and lobbying; provides socio-economic opportunities and empowerment, access to education and training and general management of their health while considering the main core values of ASK- i.e.

- **Right to Life**
- **Courage**
- **Transparency**
- **Dignity**

Albinism is a rare, non-contagious, genetically inherited condition characterized by a lack of pigmentation in the hair, skin and eyes. It occurs regardless of ethnicity or gender. Both parents must carry the gene for it to be passed on, even if neither have albinism themselves¹. The majority of 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 do not require Braille, they cannot see a blackboard in a regular classroom setup. In most cases, structural barriers prevent their participation in society on an equal basis with others².

ASK strengthens the economic capacity of PWA’s and parents of children with albinism in order to free them from economic destitution. The Constitution of Kenya prohibits discrimination against persons with physical, mental, sensory, or intellectual disabilities. Nevertheless, the government does not promote or protect the rights of persons with disabilities with regard to employment, education, or access to health care. The law does not address the rights of persons with disabilities to air travel and other transportation. Although persons with albinism are eligible to free health care through social programs targeting vulnerable groups, the benefits are not widely distributed or provided. The employment practice of requiring health certification from the National Council for Persons with Disabilities (NCPWD) sometimes results in discrimination against persons with albinism.

Despite the health challenges (low vision and skin cancer) persons with albinism in Kenya face stigma, discrimination, abuse, dehumanization and

¹ Brilliant, Murray H. “Albinism in Africa: A Medical and Social Emergency.” *International Health*, 2015;7: 223-225

² From the Convention on the Rights of Persons with Disabilities, Article 1, paragraph “e”

sometimes - brutal killings for money rituals. In most communities across the world, albinism is hardly (or not) understood. In some communities in Kenya (read Western Province), married women who gave birth to children with albinism were believed to have been unfaithful by cheating with white men. The women were divorced and went away with the children. Among the Maasai, children with albinism were thrown in the forest and left for dead. In addition, learners with albinism are sometimes turned away due to assumptions held by the school community that they are all blind, relegating them to learn in special schools for the blind and to use Braille, which affects their employability and productivity.

For the first time in the history of the country, the Kenya Population Census of 2009 established the population of Persons with Disabilities (PWDs) to be 3.5% of the total population translating to 1,330,312 was PWDs against a population of 38,610,097 people. In 2007, a Household Survey on PWDs had found that 79% of PWDs live in rural areas while the remaining percentage lives in urban areas, mostly in the informal settlements. While the distribution of this population is diverse in terms of location, sex, age, race and socio-economic status, neither the Kenya Population Census nor the household survey captured data on persons with albinism. This poses a challenge in planning programmes that are responsive to their unique needs - access to education, medical care (prescription eyeglasses and sunscreen lotion).

Persons with albinism continue to suffer double discrimination as employers assume that their capacity to deliver within the workplace is below par. They are also subject to hostile working conditions such as under the hot sun or bright light, which puts them at risk of skin cancer or further eye impairment.

In the whole of Africa, there is no facility that can bring together all the services needed by Persons with Albinism. Kenya, for instance, does not have a rescue centre for PWAs. The Tanzanian government has made a good step by setting up special protective centres for people with albinism after many had to flee their homes from traffickers. Non-PWAs also live there, many of whom fled villages with family members who have albinism.

Other problems suffered by PWAs in Kenya and Africa include;

- ***Incomplete and Non-implementation of Legal Frameworks on Persons with disability***

The Constitution of Kenya prohibits discrimination on the grounds of colour and disability, which speak to albinism: S 27(4) "The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth"³ (emphasis on **color** added). The Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Ikponwosa Ero, notes that discourse on discrimination based on colour has rarely been applied to albinism. This may be due to the lack of visibility of albinism and the strong historical ties of racial discrimination discourse to race or ethnicity⁴. While there is potential to address albinism under the International Convention on the Elimination of All Forms of Racial Discrimination (CEDAW), as the governing concept is not "race" but "racial discrimination", which may be based on any of five "grounds": race, color, descent, national origin and ethnic origin, there is inadequate political will or enthusiasm by Kenya's legislators to focus on legislation that elevates the status of women. This might be a key reason why the implied reference to albinism in CEDAW was stereotyped and overlooked.

- ***Ignorance of factual information about albinism as a disability***

Ignorance of some law and policy makers, the public and the community on factual information on Albinism sustains discrimination against Persons with Albinism. In some communities in Kenya, some women who give birth to children with albinism are believed to have been unfaithful by cheating with white men. In the early 1980s, a prominent long serving lawmaker since Kenya's first Parliament in 1963 and fiery politician from Western Kenya who has since died divorced his wife for giving birth to a daughter with albinism. Among the Maasai, children with albinism were thrown in the forest and left for dead. In addition, learners with albinism are sometimes turned away from schools due to assumptions held by the school community that they are all blind, thereby relegating them to learn in special schools for the blind and to use Braille, which ultimately affects their employability and productivity. Lack of factual information perpetuates exclusion of PWAs from mainstream policy and programs at all levels.

- ***Violation of the Human Rights of PWAs***

Article 54 1 (a) of the Constitution Kenya (2010) states that, "A person with any disability is entitled to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning." PWAs are ridiculed, face stigma and social exclusion. In Kenya's schools and on the streets they are continually teased and bullied, leading demoralization and

³ Constitution of Kenya 2010 <http://www.kenyalaw.org/lex/actview.xql?actid=Const2010> Accessed June 23, 2019

⁴ UNHCR, "Report of the Independent Expert on the enjoyment of human rights by persons with albinism." Jan.2016

psychosocial issues⁵. These names are deeply derogatory and dehumanizing and include, “zeru zeru” - a mystical or ghostlike being or “mzungu’ a name used to refer to Caucasians.”

In March 2017, then Senator Mike Sonko, now current Governor of Nairobi County publically claimed that Hon. Peter Kenneth, then his competitor for the gubernatorial seat, is an “albino” just because of his skin color –though the later does not have the condition. The situation is exacerbated through further discrimination of People with Albinism (PWAs) by other Persons with disability on perception that those with Albinism are not disabled enough to be covered in their programs. PWAs therefore find themselves in a dilemma of ability against disability, as eligibility to free health care through social programs targeting vulnerable groups is not easily utilizable since specific benefits to PWAs are not widely distributed or provided.

In Kenya in 2010, Robinson Mukhwana from Bungoma County was lured by a friend to accompany him to Tanzania for a job. Robinson never suspected his friend had other intentions and innocently accompanied him, and he only escaped murder for his body parts after being rescued by police in Tanzania whose awareness to such crimes had been heightened following gruesome killings in his country. In 2015, ASK with the leadership of the National Coordinator rescued twins(Andrew and Adrian) from being sold by a neighbour to a Tanzanian witchdoctor by the Bwaga moyo. In 2016, ASK came to learn of a father who had plans to sell his son with Albinism. Fortunately got drunk and bar tenders alerted the mother who showed up on time to rescue the little boy. In 2016, an unknown man raped Furaha Mulenga, a woman refugee from DR Congo who stayed in Kangemi informal settlement in Kenya. She was assisted by ASK to seek medical assistance and to relocate from the place. The case could not proceed to court because the suspect was at large.

In other African countries such as Tanzania and Burundi, there has been an unprecedented rise in witchcraft-related killings of persons with albinism in recent years and relatively in Kenya, because their body parts are used in potions sold by witchdoctors. Numerous authenticated incidents have occurred in Africa during the 21st Century. For example in Tanzania, in September 2009, three men were convicted of killing a 14-year-old boy with albinism and severing his legs in order to sell them for witchcraft purposes. Again, in Tanzania and Burundi in 2010, the murder and dismemberment of a kidnapped child with albinism was reported from the courts, as part of a

⁵ Hannah M. Njenga, Publics Perceptions of Albinism And Their Impact On Persons With The Condition: A Case Study of Nairobi City (January 2011).

continuing problem. National Geographic estimates that in Tanzania a complete set of body parts of persons with albinism is worth \$75,000.

People with Albinism have also been discriminated against by other Persons with disability on perception that those with Albinism are not disabled enough to be covered in their programs. They therefore find themselves in a dilemma of ability against disability. Moreover, the management of the felt personal needs of PWAs is very close

Within Africa, out of every 3,900 people one person has albinism. Going by this figure, Kenya has an estimated 10,000 persons with albinism. This is a huge population that cannot be ignored in development planning and budgeting. This is an area of policy advocacy, lobbying and dialogue.

Kenya, for instance, does not have a rescue centre for PWAs, Albinism health research, PWA sunscreen production centre , availability of hats and eye care glasses for PWAs, Psychosocial support on trauma counselling on PWAs among other felt needs of PWAs and no reliable data on PWAs. On its part, the Tanzanian government has made a good step by setting up special protective centres for people with albinism after many had to flee their homes from traffickers. Non-PWAs also live in these rescue centers, many of whom fled villages with family members who have albinism. This programme will establish a one –stop centre that will have office space and the following services provided: conference facilities; rescue centre; sunscreen production unit; eye care centre including production of spectacles; skin care treatment unit; and research centre (ICT unit, library and exhibition).

The establishment of the One –Stop Centre will bring into context / perspective the plight of persons with albinism whose current visibility in the local, national and international media is progressively low due to programmes that are scattered and not well funded. The One- Stop Centre will, in the longer term, be self-sustaining, for example, production of the sunscreen and spectacles will be sold to governments at a profit; conference facilities will be offered at reasonable prices to attract clientele.

For the last 13 years, the Albinism Society of Kenya (ASK) has been implementing projects in Kenya, but there is little evidence of their outreach activities in many other parts of the country. Yet the challenges facing PWA are enormous and spread even beyond Kenya. The proposed One-Stop Centre will address this gap by providing training programmes including creating awareness on myths, causes, stereotypes and superstitions of albinism through education camps in schools and community forums at county and national level at a small fee. The camps will be organized at local

level by ASK staff to ensure cost effectiveness and value for money for community members.

The Albinism community in Kenya believes that their needs are borderless as what happens in one country has serious implications to the lives and rights of those living in the other countries. The killings in Tanzania have already spread to neighbouring Congo and there is fear that they may spill over to Kenya given the proximity of the affected districts in Tanzania to the Kenyan borders.

Regionally, Mubala of Tanzanian nationality carried out a retrospective assessment on skin cancers present in PWA. 64 patients were studied. The male to female ratio was 3:2. The median age of patients was 30 years. Most patients present at 20 years already had features of solar damages to the skin. The most common skin cancer in persons with albinism (73.5%) was squamous cell carcinoma with a predilection of the neck region. Few, if any programs involve widespread advocacy for provision of sunscreen products as well as regular screening for skin lesions. There has been a large social move towards advocacy for their equal rights as well as public awareness of the condition to minimize stigma.

In March 2016, ASK has held discussions with National Council of Persons with Disability (NCPWD) on addressing the worrying trend of PWAs at grassroots level not being able to report cases of human rights violations against them or seek legal aid. A key outcome of the discussions was that PWAs need a programme and practical action plans to deliver it. This concept note to create public awareness on Kenya's 2019 population and housing census is a timely step to promote and encourage the PWAs, their parents/ guardians to fully and physically participate in the exercise; and thereafter monitor and undertake social audits to ensure programmes and budgets meant for PWAs benefit them.

One of the biggest challenges in provision of regular medical care is access to health care of PWA. This has a number of faces to it; poor infrastructure, lack of preventive information by the primary healthcare workers (often the clinical officer or nurse at the health centre) and most of all, the cost of sunscreen products. All these factors combined calls for civic awareness of the society and economic empowerment of PWAs with the ability to reduce logistics/infrastructural challenges. This will then lay the basis for having fully trained resource persons at the One-Stop Centre as the first contact for PWAs in the area.

Since other Persons with disability in their programs have discriminated against People with Albinism, they need special attention such as will be covered by the One-Stop Centre programmes such as cancer screening and treatment among others.

STRIDES MADE TOWARDS A DIGNIFIED LIFE FOR PWAS

- Initiation of the first ever Mr. and Miss Albinism that has helped in toning down discrimination and exclusion.
- Successfully lobbied for PWAs Census to be carried out for the first time by Kenya government in August 2019.
- Lobbied and ensured the Kenyan government provided kitty for Albinism including provision of Sunscreen lotions and protective clothing.

ASK ASPIRED FUTURE FOR PWAS

- Inclusion of Albinism in the disability agenda outlawing the ritual killings
- Establish a fully-fledged and operational One Stop Centre that caters for the felt needs of Persons with Albinism in Kenya and the region
- Undertake research on issues affecting Persons with Albinism
- Publicize the One-Stop Centre and its services to all relevant stakeholders in Kenya and the region
- Strengthen the capacity of ASK staff and Board to deliver on the services provided by the One-Stop Centre
- Empower communities on the programs provided by ASK and One stop center
- Increased income for sustainability of services for PWAs
- Establish networking and partnerships at local, national and international levels.

As a society we are grateful for the far we have come and we look forward to be joined by national and International bodies in this journey of dignifying the lives of Persons with Albinism.