

## SITUATION OF PERSONS WITH ALBINISM IN ZAMBIA

By John Chiti

Executive Director/ Music Activist

Albinism Foundation of Zambia

Persons with albinism are individuals with a light skin condition resulting from the absence of the pigment called melanin in their skin, eyes and hair. Persons with albinism in Zambia are classified as persons with disabilities on the ground that in them interacting with various attitudinal and environmental barriers, these same barriers hinder them from participating on an equal basis with other people in society. Thus the Persons with Disabilities Act of 2012 categorize them as persons with disabilities, as per its definition of disability.

Persons with albinism in Zambia face various problems emanating from traditional myths and stereotypic beliefs about the condition of albinism. These myths and beliefs have led to serious stigma and discrimination of persons with albinism in almost all sectors of human development. The discrimination they face in their daily lives needs to be resolved through strategic advocacy work by them who are affected.

The Government of the Republic of Zambia (GRZ) recognizes persons with albinism as persons with disabilities. It is in this view that GRZ in its draft amendment Bill of the Persons with Disabilities Act of 2012 has included issues affecting persons with albinism directly. For instance, the Bill directly states persons with albinism shall receive free sunscreen creams. At national level, the Ministry of General Education is already making proclamation that persons with albinism should be taken into mainstream schools because they can be able to be included with awareness raising among the communities, other learners and teachers. In order to fully realise this, there should be strong strategic advocacy work from the albinism community. The government has specifically located a fund, through the Yellow Book, to support the International Day on Albinism which falls on 13<sup>th</sup> June each year. This is a day for awareness raising on issues affecting persons with albinism. Without strategic advocacy skills, the albinism community would not utilise the day meaningfully and effectively. So, there are already some policy openings within the Zambian government which require effective advocacy to be actualized.

The society in general don't know much about albinism and so people have put many myths, beliefs and misconceptions on the condition. Most of these beliefs are negative and do affect albino people negatively. Some of the common beliefs are *that*;

- "Albino people don't die but just disappear "
- "Spiting in your shirt whenever you see an albino to avoid having or becoming one yourself"

Such beliefs make persons with albinism to stand out and make them feel inferior to other people. Another one of the common beliefs is that;

- "*Albino body parts can be used to cure certain diseases and make one rich*"

This particular belief affect the albinism community greatly because it comes to offer a solution to sicknesses and poverty. As people look for solutions to their poverty and diseases then they come across this belief, they have high expectations because the belief itself offers them the

solution to their problems; *“you can cure diseases and make money if you use body parts of albino persons”* so they believe

To this regard people who are looking for these solutions have been on the lookout for albino body parts and when they find persons with albinism they hunt and kill them, take away their body parts and use them in rituals/witchcraft. For this reason different people with albinism, young and old have been murdered for their body parts. Many lives have been lost across Africa, male and females have died and their body parts removed.

It started small like fire in the bush, from 2010 to 2014 our neighbouring country Tanzania recorded many deaths as more than 100 albino persons were hunted and killed for this ritual purpose. Then it spread to other countries like Kenya, Nigeria, Malawi etc. many people have been murdered and others left physically disabled because people have attacked them and removed some parts from their bodies. This shocking sad development has been on world news for some time as it has been happening from one country to another. It is shocking but it is real

Zambia is a peaceful nation and because of our Christian values most Zambians have condemned the killings of people with albinism happening in other countries. Nevertheless these killings are now coming to Zambia and sooner or later our Christian country may be on the world map with numerous killings of innocent people.

We recorded the first case in March 2014 when an albino girl aged 12 from Kanyama compound of Lusaka was murdered and some body parts were removed from her. In June 2015 a woman from Lundazi eastern province was also attacked and killed for the same purpose. Her breasts and other body parts were removed. In January 2016 a young man with albinism aged 24 was also murdered in Mandevu compound of Lusaka whereas some body parts were also taken away. These organised ritual killings kept increasing year by year from about 5 cases every year to now about 20 attacks. The latest records of 2019 has 5 reported cases from which 2 of them happened in the period of 2 weeks. The attacks have concentrated in the rural areas especially provinces/districts which share a boarder with other countries. So far eastern province (which share a boarder with Malawi) has the highest number of ritual attacks. It is suspected that these attacks also involve trafficking of body parts from one country to the other.

Therefore, Zambia is sitting on a time boom which may explore at any time if nothing is done about it. If the society and the government in particular don't make efforts to put up deliberate measures to protect the lives of the vulnerable albinism community it will have more bloodshed and it will be held responsible for the killings of its citizens

In Zambia the population of persons with albinism may not be adequately captured. According to the 2010 Census on population and housing, the albino population at national level was 25,324. The population in rural areas was higher than urban areas at 16,937 and 8,387, respectively. Lusaka Province had the highest population of albinos at 3,495 while North-Western Province had the lowest at 1,387. The literacy rate for the albino population was 66.1 percent. In Zambia, the majority of the children with albinism attend segregated schools for children with visual impairments. This is as a result of two reasons:

- 1) they face a lot of stigma and bullying when they are in mainstream schools;

II) They are believed to completely lose sight as they grow because of their visual impairment, thus they are introduced to Braille in the first grade of primary school. Due to these reasons persons with albinism feel more confident and safer when socially interacting with persons with visual impairments.

There are no proper statistics on the number of persons with albinism in tertiary education. According to the 2010 census the literacy rate for males was 69.2 percent compared with 63.0 percent for females. There were more literate male albinos than female albinos in rural and urban areas at 61.9 and 54.6 percent for rural areas and 82.8 and 79.7 percent for urban areas, respectively. The proportion of the albino population that was currently not attending school was slightly higher than those currently attending school at 37.5 and 37.3 percent, respectively. The proportion of the albino population that had never attended school was 25.3 percent. The highest level of education attained by most of the albino population 25 years and older was primary education at 48.3 percent. However, it has been established that the first woman with albinism to graduate with a Master's Degree graduated in 2016 at the University of Zambia, School of Education. This is a landmark achievement for persons with albinism, especially women, in Zambia. Very few persons with albinism hold tertiary education qualifications currently. The majority hold teaching qualifications. Only one medical doctor with albinism has been recorded so far.

When it comes to employment, persons with albinism face the same problems faced by persons with visual impairments. This is as a result of the poor grades they get at secondary school examination level. There are no clear statistics on the numbers of persons with albinism in formal or informal employment but the majorities are in informal employment. The 2010 census indicated that the majority of the employed albino population 12 years and older was self-employed at 46.0 percent. Employers had the lowest proportion of the employed albino population at 1.0 percent. Agriculture and Animal Husbandry, Forestry and Fishing were the most common occupation at 71.2 percent for males and 80.0 percent for females. The general situation for persons with albinism is that for those who are in formal employment, they work as school teachers or telephone operators in the government.

Persons with albinism are susceptible to skin cancer due to their skin condition which does not protect them from ultra-violet light from the sun. In order to protect themselves from this cancer vulnerability they need to apply to their skin sun-screen cream. These creams are expensive in private pharmacies. The creams are rarely found in public clinics where they should be dispensed freely. In schools or colleges the children are required to put on dark glasses to protect them from the sun rays. Some schools that are not aware stop them from doing so thus exposing them to damage of their eyes. In order to improve the situation of persons with albinism deliberate interventions are required by the state and non-state actors.

Children with albinism are marginalized and highly segregated against. There has been no deliberate national programs to promote education of albino children at either primary or secondary levels. They have been left out in all social activities. Albino children cannot go out to play like any other child in the sun, they need special protective wear to enable them walk in the sun. Stigmatized and superstition has played a part. Further, most parents of albino children cannot afford to buy such clothing's. As a result, these children find it difficult to attend school

thus enters adult world with little information on HIV, reproductive health, Entrepreneurship skills yet they are more prone to HIV /AIDS due to poverty level. Poverty is one the strong factors that drives the spread of HIV. There is need to level the play field in social service delivery for the albino children on the equal basis with non-albino children by creating an opportunity for them to complete primary school course. It is my belief that there is need to combine and step up efforts if we are to achieve Millennium Development Goals number 2 and all children must be considered with no regards to race, religion, background or disability.

Albinism is considered a disability in Zambia and many other nations. This is because the condition itself is an impairment which puts a limitation on how persons with albinism can perform in society. Apart from the stigma and discrimination against albino people, the beliefs and misconceptions the society has put on albinism, persons with albinism have sight problems as they are partially blind. Their skin is also very vulnerable to the sun. This is because they lack melanin in the skin hair and eyes. Albinism puts a limitation on how far and how much persons with albinism can perform in the society.

Nevertheless, albinism was not been recognised or included in the disability movement in Zambia. Albinism issues were mostly been left out and albino people rarely participate or benefit from disability programs. There is therefore, a big gap between albinism and disability and the following are some of the contributing factors;

- Albinism was not mentioned in the definition, description of disability. It is not listed as one of the different types of disability and has not been referred to on any issues on disability.
- Persons with albinism have lost confidence in the disability movement and have no interest of participating and involving themselves in disability programs. This is also because they feel left out and don't see any benefit in disability projects.
- The Zambia agency for persons with disabilities (ZAPD) has not done well in balancing and giving equal opportunities to its affiliate organisation that deal with different types of disabilities. For a long time the albinism community have not benefited from ZAPD and therefore, feel left out even by this mother body umbrella organisation
- Some African countries have been dealing with albinism independently and enacting albinism policies thereby separating it from disability. Persons with albinism in Zambia have also started thinking of following such countries and therefore, refusing to collaborate with the disability sector and denying albinism to be a disability. They feel they can do it alone.
- Generally there is division among the albinism community where some advocate that albinism is not a disability and refuse to collaborate with the disability movement while the other group say albinism is a disability and they do involve themselves in disability programs.

The albinism foundation of Zambia has registered over 100 children with albinism from different parts of the country who have been rejected by their fathers and have denied responsibility because they are born with albinism. Most families don't understand what albinism is and how it happens. Therefore, families break and couple's divorce whenever albino children are born. Because these children are rejected by their fathers and stay with their single parents/mother who can't afford to take them to school, most children with albinism need educational and health support.