Submission in response to the call for inputs: Social development challenges faced by Persons with Albinism

This is a joint submission led by the Africa Albinism Network in collaboration with albinism organisation from Ghana, South Africa, Tanzania and Zambia. The submitting organisations includes; Ghana Association of Persons with Albinism, National Albinism Taskforce of South Africa, Tanzania Albinism Society and Albinism Foundation of Zambia.

The Africa Albinism Network (AAN) works to protect the rights of people with albinism in Africa from targeted violence, ritual attacks, and discrimination through the promotion of the AU Plan of Action on albinism (2021-2031) human rights advocacy and the capacity development of albinism groups.

Contact: info@africaalbinismnetwork.org

Website: www.africaalbinismnetwork.org

Consent Needed to Publish:

To protect our collaborators from reprisals, please do not publish this input without the express permission of its contributors. You may email the Africa Albinism Network for further discussion as needed.

INTRODUCTION

An Intersectoral Issue

People with albinism face multiple and intersecting forms of discrimination based on their disability and skin colour. The Africa Albinism Network, a human rights advocacy organization, has observed that persons with albinism encounter almost identical barriers to the enjoyment of their human rights as other people with disabilities. Ironically, due to the prevalence of the medical model of disability in the region, persons with albinism often encounter additional obstacles when seeking the same protections afforded to individuals with disabilities, as they are frequently considered either non-disabled or "not disabled enough."

Furthermore, owing to their distinctive appearance, persons with albinism also contend with harmful practices rooted in age-old beliefs about their looks. These practices encompass stigmatizing language, such as referring to albinism as "monkey" in South Africa or "ghost" in Tanzania, ritual attacks, human trafficking, the trafficking of body parts, ritual banishment from specific communities, and more.

Moreover, people with albinism are at a heightened risk of skin cancer, with prominent organizations in this field, such as Beyond Suncare and Standing Voice, indicating that an estimated eighty to ninety percent of persons with albinism succumb to fatal skin cancer, often before the age of 40. This issue is particularly critical as climate change intensifies UV exposure across Africa. People with albinism continue to advocate for the inclusion of sunscreen on the essential medicine list, both at the World

Health Organization (WHO) and on the national level, while also striving to ensure its affordability and accessibility.

These concerns have led to the African Union explicitly including albinism in its disability protocol (although it has yet to come into force). The African Union has also adopted a dedicated AU Plan of Action on albinism that addresses a broad spectrum of human rights issues, including the right to health.

Methodology

This submission is compiled by Africa Albinism Network based on inputs received from leaders of albinism groups and organisations working to promote the rights and welfare of Persons with Albinism in their respective countries in Africa. These inputs were collated through one-on-one interviews as well as written submissions using the questionnaire provided by the OHCHR on the social development challenges faced by Persons with Albinism.

Country: Ghana

Organisation: Ghana Association of Persons with Albinism

Contact Person: Newton K. Katseku, Executive Director. Email: gapa4all@gmail.com

Responses

A. General

1. How many Persons with Albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

   There is no national statistics on the number of Persons with Albinism in Ghana. However, the Ghana Association of Persons with Albinism have a membership of 2533.

2. How many of those people are women? How many are children, as defined in your country?

   There are 656 women and 394 children captured in the data base of the association.

3. Please describe the overall social and economic status of people with albinism in your country?

Persons with Albinism in face discrimination, stigma and prejudice and banishment from some communities in Ghana. These negative attitudes impact their access to social services such as health, education, employment. Economically, many Persons with Albinism engage in small businesses and menial works such as subsistence farming. Many others are teachers in private of public school. There is high rate of unemployment fuel by the negative perceptions about the condition.

4. Are there any public or private institutions in your country responsible for Persons with Albinism? If yes, please list the most important institutions.

   There are a few institutions responsible for Persons with Albinism n Ghana. These include National Council for Persons with Disabilities, Engage Now Africa, Ghana Federation of Disability Organisations and Ghana Association of Persons with Albinism.

B. National legal and policy framework

5. Are there any national legal or policy frameworks concerning the issues of Persons with Albinism? If yes, please provide details and source of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards Persons with Albinism?

There is no specific national law or policy on the issues of albinism in Ghana. However, there is the National Disability Act of 2006, Act 715. This act is currently being reviewed to capture the needs of Persons with Albinism and also recognise albinism as a disability.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

   In theory, the disability act 715 made no mention of albinism in its provisions. However, in practice, Persons with Albinism benefit from the social interventions such as the District Disability Common Fund. They are also included in all disability related programmes.

C. Social development: Health

7. How would you describe the health situation of Persons with Albinism?

   The health situation of Persons with Albinism is very deplorable as many of them suffer from skin cancer. There is no specific health intervention to care for the health needs of this community. For instance, Persons with Albinism are not provided with sunscreens or other protective clothing.

i. Are dermatology and ophthalmology services readily available to them?

There are a few dermatologists in Ghana and most of them are based in the big cities. These services are not readily available especially in the remote parts of the country. Persons with Albinism have to pay to access these services as they are not covered by the national health insurance scheme.

ii. Is there information made available to them about health risks linked with albinism?

There is no form of information available to Persons with Albinism regarding their condition and its health implications.

iii. If so, how is this information disseminated and communicated?

Refer to (ii) above

D. Other Selected Social Development Issues

1. Education

8. What is the educational situation of Persons with Albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of Persons with Albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

The majority of individuals with albinism typically enrol in regular mainstream schools. Unfortunately, these schools often lack the necessary resources for assistive devices and reasonable accommodations within the classroom. This deficiency creates significant challenges for students with albinism, as they frequently experience bullying and name-calling, hindering their educational progress.

While many Persons with Albinism do attend school, their academic performance is adversely affected due to the absence of reasonable accommodations. Consequently, those who complete junior high school often struggle to progress to senior high school, primarily due to their poor academic performance. Moreover, those who manage to reach senior high school face similar obstacles and often fail to advance to universities or colleges due to the persisting lack of necessary support and accommodations.

9. Given the low vision issues present in most Persons with Albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, for e.g., large print material, low vision, and assistive devices?

As mentioned above, there is no reasonable accommodation and support for Persons with Albinism in schools. No large print textbooks are provided, and no assistive devices are given.

E. Employment

10. What is the employment situation of Persons with Albinism? Please provide statistics or other information concerning employment and unemployment rate of Persons with Albinism, if applicable?

    The combination of limited educational opportunities, stigma, discrimination, and a lack of employable skills has resulted in a significant unemployment issue among individuals with albinism. Many of them struggle to find employment, with only a handful resorting to low-paying, often menial jobs to make ends meet. Some individuals with albinism turn to subsistence farming for their livelihood, placing them at higher risk of developing skin cancer due to prolonged sun exposure.

    Even those with the necessary qualifications and employable skills face the daunting challenge of being stigmatized and discriminated against, largely driven by misconceptions and misunderstandings surrounding their condition.

11. What obstacles exist for Persons with Albinism in seeking paid employment in the open labour market?

    The major obstacles include, discrimination, stigmatisation, social exclusion and lack of adequate employable skill resulting from lack of quality education.

12. Are there any applicable laws or policies concerning the employment of Persons with Albinism? If yes, please provide details and source of the major laws and policies.

    There is currently no dedicated legislation addressing the employment of individuals with albinism. While the disability act does include a provision that encourages employers to hire individuals with disabilities in exchange for task rebates, the enforcement of this provision remains a significant challenge. In practice, employers who do hire individuals with disabilities often find that the promised rebates are non-existent, causing many of them to shy away from such initiatives.

13. Are there special measures in place to promote and integrate Persons with Albinism in employment and in the labour market?

    No such special measures exist to promote the employment of Persons with Albinism aside what was mentioned earlier in the disability act.

F. Recommendations

14. Please provide specific recommendations for further action to be taken by your Government and other stakeholders to address challenges to the full and equal participation of person with albinism in society and development?

i. Ghana should consider adopting the African Union (AU) Plan of Action on Albinism and translating its provisions into a comprehensive National Action Plan on Albinism. This national-level plan would serve as a structured, strategic framework for addressing the specific challenges faced by individuals with albinism in Ghana.

ii. Enact and Enforce Anti-Discrimination Legislation: Governments should introduce and enforce laws that explicitly prohibit discrimination against Persons with Albinism in all areas of life, including education, employment, healthcare, and public services.

iii. Raise Public Awareness: Conduct public awareness campaigns to combat stigmatization and misconceptions about albinism. These campaigns should educate the public on the rights and needs of individuals with albinism.

iv. Inclusive Education: Implement inclusive education policies that provide accessible and quality education for Persons with Albinism. This includes providing assistive devices, reasonable accommodations, and support to ensure they can thrive in mainstream schools.

v. Promote Skill Development: Offer vocational training and skill development programs tailored to the needs and abilities of individuals with albinism. These programs should focus on enhancing employable skills to facilitate their entry into the workforce.

vi. Incentivize Employers: Create incentives for employers to hire Persons with Albinism, such as tax breaks, subsidies, or

task rebates, and ensure that these incentives are effectively enforced.

vii. **Access to Healthcare: Provide accessible and affordable healthcare services, with a particular focus on skin cancer prevention and treatment for individuals with albinism.**

viii. **Data Collection: Collect and maintain accurate data on the population of Persons with Albinism to inform policymaking and resource allocation.**

ix. **Engage with the Albinism Community: Consult and involve individuals with albinism and their representatives in the development and implementation of policies and programs, ensuring that their voices and perspectives are heard and considered.**

G. Further remarks

15. Would you have any further comments on the social situation of people with albinism in your country?

In certain Ghanaian communities, individuals with albinism are subjected to ritual banishment, a grave violation of their fundamental rights to freedom of movement and residence within the country. The discrimination and stigma they endure have detrimental effects on their social well-being. To rectify this situation, it is advisable for the government, in collaboration with civil society, to lead continuous public education efforts aimed at shifting societal attitudes toward individuals with albinism in Ghana.

Country; South Africa

Organisation; National Albinism Taskforce (NAFT)

Contact Person: Nontsikelelo Loteni, National Secretary, Email: ntsikieloteni@gmail.com / info@natf-sa.org.za

Responses

H. General

1. How many Persons with Albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

   South Africa does not have data through census or an estimated data of Persons with Albinism.

2. How many of those people are women? How many are children, as defined in your country?

   See the response in Question 1

3. Please describe the overall social and economic status of people with albinism in your country?

   Persons with Albinism are still subjected to high degree of discrimination and marginalisation. Most Persons with

Albinism in South Africa lack educational skills and qualification that position them to participate fully in economic opportunities. There is a large number of Persons with Albinism who drop out of school due to bullying and lack of reasonable accommodation in schools.

4. Are there any public or private institutions in your country responsible for Persons with Albinism? If yes, please list the most important institutions.

   There are a number of civil society organisation that represent and advocate for Persons with Albinism. These include, Department of Women, Youth and Persons with Disability, National Albinism Taskforce, Albinism Society of South Africa, and Albinism Advocacy for Access

I. National legal and policy framework

5. Are there any national legal or policy frameworks concerning the issues of Persons with Albinism? If yes, please provide details and source of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards Persons with Albinism?

   The South African Constitution provides a legal foundation for the Republic, spelling out the rights and responsibilities for all citizens who reside within it. Contained within it is the Bill of Rights, which under Chapter Two Section 9 asserts every citizen's equality before the law and guarantees

freedom from discrimination, including discrimination based on disability.

The State is tasked according to the Constitution to put in place legislation that must prevent or prohibit unfair discrimination. Thus, in 1998, the Employment Equity Act was promulgated to give effect to the Constitution; in addition to this, the Promotion of Equality and Prevention of Unfair Discrimination Act of 2000, which aims to prevent and prohibit unfair discrimination, harassment and promote equality.

However, the Act was not enough to address the complex needs of persons with disabilities. As a result, the Cabinet approved the White Paper on the Rights of Persons with Disabilities on 9 December 2015 for public information.

The White Paper intended to achieve several objectives, including to improve the lives of persons with disabilities and ensure inclusion in all societal spheres. The policy document was also a call for action for the Government, civil society and the private sector to work together to secure and accelerate the socioeconomic inclusion of persons with disabilities. Furthermore, the State envisaged that the White Paper on the rights of persons with disabilities would be a vehicle for a tangible platform to expedite improving the quality of life of persons with disabilities and their families.

With all the above legislation the challenge in South Africa there is still confusion about albinism being a disability.

Until a clear disability act is enacted where albinism must be specified, this challenge will persist and is currently mitigated through advocacy and awareness

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

   Yes, albinism is recognised as a disability however as mentioned the government relies on the UN declarations to justify albinism as a disability. There is no specific mention of albinism in any disability related policy document such the white paper on disability.

J. **Social development: Health**

7. How would you describe the health situation of Persons with Albinism?

   i. Are dermatology and ophthalmology services readily available to them?

   There are dermatology and ophthalmology services in major cities. These services are not available in all nine of the (9) provinces in South Africa. Also, those in remote areas do not have access to these services. Skin cancer is widespread among those in remote regions of the country due to lack of access to dermatological services.

ii. Is there information made available to them about health risks linked with albinism?

Hospitals that provide dermatology and ophthalmology services have sufficient knowledge about albinism however, this information is not cascaded as it should as most health professional are not sufficiently knowledgeable about albinism especially in provinces that have none of such health facilities.

iii. If so, how is this information disseminated and communicated?

It is fragmented, some have managed to make pamphlets available.

K. **Other Selected Social Development Issues**

1. **Education**

8. What is the educational situation of Persons with Albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of Persons with Albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

Such data is not available in South Africa's schools. There are currently a lot of challenges in mainstreaming albinism to public school. There are no resources to provide reasonable accommodation. Most importantly, there are still attitudinal

barriers from teachers as well. It is for this reason that most Persons with Albinism drop out of school.

9. Given the low vision issues present in most Persons with Albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, for e.g., large print material, low vision, and assistive devices?

   Due to lack of knowledge in school some schools are not able to provide proper reasonable accommodation. This task is left to parents to always notify teachers about the needs of their children. South Africa has a White paper which addresses inclusion at schools, but this has not been fully implemented especially in public school. Children with special needs in general are still struggling.

2. Employment

10. What is the employment situation of Persons with Albinism? Please provide statistics or other information concerning employment and unemployment rate of Persons with Albinism, if applicable?

    Data is not available however the assumption is that the number is very low due to all the educational challenges mentioned above. The lack of educational qualification and skills makes it difficult for Persons with Albinism to be fully employed. The continuous stigmatisation of Persons with Albinism poses serious attitudinal barriers in the workplace

as well. Lack of understanding that albinism is a disability subject person with albinism to discrimination and they are not afforded the opportunities that people with disabilities always benefit from.

11. What obstacles exist for Persons with Albinism in seeking paid employment in the open labour market?
    - **Proper Qualifications**
    - **Relevant employable Skills**
    - **Discrimination and marginalisation**
    - **Lack of understanding that albinism is a disability.**

12. Are there any applicable laws or policies concerning the employment of Persons with Albinism? If yes, please provide details and source of the major laws and policies.

    The Employment Equity Act covers Persons with Albinism under the umbrella of disability however the above is a challenge that makes them not fully benefit from this act.

13. Are there special measures in place to promote and integrate Persons with Albinism in employment and in the labour market?

    No, except for the National Action Plan that the sector developed and submitted to government for adoption. Until that plan is adopted and operationalised issues of Persons with Albinism are still not prioritised by government departments. Secondly the absence of disability act that declares albinism as a disability the private sector is not

obliged by the other legislation such as the white paper on the rights of persons with disabilities.

L. Recommendations

14. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of person with albinism in society and development?

The Albinism sector needs sustainable programmes that will support the National Action Plan to address all the priority areas such as health, education, and employment of Persons with Albinism.

The Sector needs a commitment from government to implement all the recommendations made by the international community such as the UPR and the IE addressing challenges to the full and equal participation of person with albinism in society and development.

Institutions such as the Human Rights Commission to conduct annual assessments of the challenges to the full and equal participation of persons with albinism in society and development.

Government to fund the implementation of the National Action Plan so that the identified programmes can be implemented and that the NATF can drive some of these programmes.

M. **Further remarks**

15. Would you have any further comments on the social situation of people with albinism in your country?

Addressing the situation of people with albinism in SA is reactive and fragmented and mostly driven by CSO's. There is no clear commitment from Government of what programmes are in place to respond to the needs of Persons with Albinism.

Budget must be set are aside to respond proactively to the above. Collaborative efforts between government and CSO are needed urgently there must be clear memorandum of understanding of who does what and how are we going to measure progress using the tools made available by institutions such as the Human Rights Commission.

Country: Tanzania

Organisation: Tanzania Albinism Society

Contact Person: HASSAN S. MIKAZI, Morogoro Regional Chairperson.
Email: hassanmikazi@tasmorogoro.or.tz / infor@tasmorogoro.or.tz

Website: www.tasmorogoro.or.tz

Response

A. General

1. How many Persons with Albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

   According to the 2012 Tanzania National Population and Housing Census, it was revealed that 0.04% of the mainland population and 0.03% of the island population have albinism. However, other sources believe that the actual numbers are significantly higher and estimate a total population of 30,000 individuals.

   Records from the Tanzania Albinism Society (TAS) head office, a national organization of Persons with Albinism,

show that there are 18,833 Persons with Albinism in the country. However, based on the 1/1429 albinism ratio reported by various reliable sources, there is an estimated 40,588 people with albinism in Tanzania among the total population of 58,000,000 (World Bank data 2020). This constitutes a significant population.

2. How many of those people are women? How many are children, as defined in your country?

   Currently, there are no official statistics from the National Bureau of Statistics (NBS) that show the number of women and children. Official statistics are expected to be published by the NBS next year, based on the National Census of Population and Housing conducted in 2022.

3. Please describe the overall social and economic status of people with albinism in your country?

   Persons with Albinism, despite being at a higher risk of murder, are still considered one of the poorest and are often categorized as persons with disabilities in government programs. Unfortunately, they receive little to no attention when it comes to their welfare, access to education, healthcare, employment opportunities, or civic engagement.

   The most vulnerable in the entire situation of Persons with Albinism are women and children. Women, in particular, face abandonment by their husbands when they give birth to children with albinism. Children, on the other hand,

typically live with their grandparents or single parents (usually mothers) in rural areas, where they have limited opportunities to access education. This is compounded by the challenges they face due to their visual impairments and the need for protection against the sun.

Despite the support of numerous partners in Tanzania, persons with albinism continue to be left behind in their quest for meaningful livelihoods.

4. Are there any public or private institutions in your country responsible for Persons with Albinism? If yes, please list the most important institutions.
   Institutions responsible for Persons with Albinism include, Ocean Road Cancer Institute in Dar es Salaam, Standing Voice, Sight savers - (civil Society), Adventist Development and Relief Agency (ADRA), Under the Same Sun, Karangwa Community Based Rehabilitation Programme, (KCBRP), Kilimanjaro Christian Medical Center (KCMC) private, Education Gauge for growth Tanzania, Voice global

B. National legal and policy framework

5. Are there any national legal or policy frameworks concerning the issues of Persons with Albinism? If yes, please provide details and source of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards Persons with Albinism?

Tanzania has enacted several laws and policies aimed at addressing the challenges faced by Persons with Disabilities (PWDs). These laws include the Convention on the Rights of Persons with Disabilities, the Education Act, the Local Government (District Councils) Act of 1982 (as amended from time to time), the National Policy on Disability (2004), and the Persons with Disabilities Act of 2010.

Additionally, the Tanzanian government is in the process of approving a national action plan for the promotion of human rights for Persons with Albinism. The country has also signed several international legal instruments designed to address the challenges faced by PWDs. These measures create an enabling environment for Persons with Albinism, offering various opportunities such as financial inclusion, participation in decision-making, and political engagement.

However, despite Tanzania having supportive legal frameworks in place for people with disabilities, Persons with Albinism haven't fully benefited from their rights and socio-economic opportunities, as outlined in the laws mentioned above. This is due to several reasons, including the fact that some technocrats and decision-makers do not enforce these laws.

Moreover, many Persons with Albinism are unaware of the existence of these laws, preventing them from demanding their full implementation and enforcement. There is also a

lack of robust advocacy efforts by organizations like the Tanzania Albinism Society (TAS) to demand these rights and opportunities, primarily due to financial constraints. The situation is even more dire for women and children with Albinism, who are among the most marginalized in society. Notably, there is no specific law or policy dedicated to protecting the rights of Persons with Albinism; instead, they are included under the broader umbrella of People with Disabilities laws, policies, and regulations.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

   The Persons with Disabilities Act (2010), and the National Policy on Disability (2004) are regarded to cover Persons with Albinism as persons with disabilities.

C. Social development: Health

7. How would you describe the health situation of Persons with Albinism?
   - Are dermatology and ophthalmology services readily available to them?
   - Is there information made available to them about health risks linked with albinism?
   - If so, how is this information disseminated and communicated?

Dermatology and ophthalmology services: Skin cancer prevention and treatment services remain challenging for Persons with Albinism in Tanzania, particularly in regions that have not been reached by the government and NGOs. Many households with children with albinism lack knowledge about skin cancer prevention, with children often wearing nothing more than short trousers when exposed to the sun.

Tragically, deaths due to skin cancer continue to occur. Between 2019 and 2022, the Tanzania Albinism Society recorded 28 such deaths. Statistics from other parts of Africa indicate that Persons with Albinism often succumb to skin cancer at an early age, typically between 30 and 40 years old. This suggests that cancer is likely the leading cause of death for Persons with Albinism.

Despite the significant attention given to brutal killings of Persons with Albinism, skin cancer is often referred to as the silent killer, limiting the life expectancy of Persons with Albinism in Tanzania to less than 40 years.

The shortage of dermatologists in Tanzania, as in the rest of Africa, underscores the importance of prevention. The Tanzania Albinism Society's head office reported that only 7 out of the country's 31 regions have dermatologists in regional hospitals, and they are often situated hundreds of kilometres from most Persons with Albinism who reside in remote rural areas. Although Persons with Albinism in Tanzania typically do not live past 30 years due to skin cancer, this unfortunate statistic is largely preventable.

Cryosurgery, a common and cost-effective method for managing skin cancer among Persons with Albinism, has been widely used in Tanzania and found to be effective. It involves using liquid nitrogen to remove pre-cancerous skin lesions before they progress to stage 3 or 4 cancer, which is costly to treat. The Ocean Road National Cancer Institute in Dar es Salaam is the only public facility offering such advanced treatment.

Organizations like Standing Voice and various partners conduct medical outreach programs to bring services closer to vulnerable women and children with albinism throughout the country. This is crucial because only 7 regional public hospitals have dermatologists. However, many patients with advanced cancers find it difficult to travel to the only examination and treatment centres, incurring significant costs, including transport, accommodation, and care expenses. According to ADRA's experience, at least 8% of those diagnosed with advanced cancer in mobile clinics require advanced cancer treatments.

Availability of information and dissemination: Access to information remains a challenge, particularly for Persons with Albinism residing in rural, remote, and hard-to-reach

areas. Currently, awareness is raised by organizations like TAS and NGOs, including ADRA, Standing Voice, Peace Makers Development, KCBRP, Sight Savers, and others, through mobile clinic outreaches. During these outreach events, they also provide sunscreen lotions, sunhats, and long-sleeved clothing. However, this approach is not sustainable.

The production of sunscreen locally, tailored to the needs of Persons with Albinism, is the best way to ensure a consistent and reliable supply of this essential medicine to this group. Furthermore, it is crucial to economically empower women, who often care for the majority of children with albinism, enabling them to have greater control over their livelihoods and the means to care for themselves and the children under their supervision.

D. Other Selected Social Development Issues

1. Education

8. What is the educational situation of Persons with Albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of Persons with Albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

Although there is no official data indicating the enrollment of children with albinism in school, only a few are enrolled due to the myth that children with albinism will die young and that it is not worth devoting resources to their education. According to Standing Voice, an international NGO based in Tanzania, in the country, only half of the children with albinism complete primary school, and just 10 percent have access to secondary school.

9. Given the low vision issues present in most Persons with Albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, for e.g., large print material, low vision, and assistive devices?

Students with albinism face various challenges in school, including bullying, insufficient reasonable accommodation for their low vision, and heightened vulnerability to skin cancer. In some schools, teachers have been reluctant to admit students with albinism, fearing they may not know how to properly care for them. Safety concerns further hinder Persons with Albinism from fully participating in school activities.

The constant threat of attack faced by children with albinism means they cannot engage freely and comfortably in day-to-day activities, including schooling. Unfortunately, these children often lack necessary

reasonable accommodations, such as visual aids like glasses, monoculars, and large-print materials.

2. Employment

10. What is the employment situation of Persons with Albinism? Please provide statistics or other information concerning employment and unemployment rate of Persons with Albinism, if applicable?

In Tanzania, Persons with Albinism face significant economic marginalization, limited employment opportunities, and denial of access to political participation. Many of them encounter challenges that prevent them from seizing and making use of the opportunities created by various pro-Persons with Disabilities (PWDs) laws and policies. Additionally, most individuals with albinism are unaware of the opportunities provided by these laws and policies. This situation is particularly dire for women living with Albinism.

11. What obstacles exist for Persons with Albinism in seeking paid employment in the open labour market?

Persons with Albinism in Tanzania encounter numerous barriers when it comes to equal access to productive resources, financial inclusion, and employment opportunities. The primary avenue for employment is through self-employment. However, the majority of Persons with Albinism lack vocational and business skills, access to

capital, and supportive structures to engage in entrepreneurial activities.

12. Are there any applicable laws or policies concerning the employment of Persons with Albinism? If yes, please provide details and source of the major laws and policies.

    Legal frameworks that promote inclusive employment for Persons with Disabilities (PWDs) have not been effectively implemented. For instance, the Persons with Disabilities Act, Number 9 of 2010, Section 31, which mandates that employers with more than 20 workers must have at least 3% of their employees be persons with disabilities, remains largely unimplemented. Furthermore, PWDs have not fully embraced paid formal employment due to self-stigma, a lack of information, and a deficiency in career development skills.

13. Are there special measures in place to promote and integrate Persons with Albinism in employment and in the labour market?

    Despite the support of numerous partners in Tanzania, Persons with Albinism continue to face challenges in accessing meaningful livelihoods. According to an analysis by ADRA on the situation of Persons with Albinism in Tanzania, the employment statistics are as follows: 65% of Persons with Albinism are unemployed, 21.8% are self-employed in agriculture, 8.6% are self-employed within

enterprises, 3% are employed within private institutions, and 1.4% are employed within the government. Among the unemployed category, 53% are female, and 47% are male.

All those without formal education are unemployed. Even among Persons with Albinism who completed their secondary education, 46% are unemployed, while 28.6% are self-employed in agriculture, which is a hazardous occupation for dermatological health due to sun exposure and the risk of skin cancer.

E. Recommendations

14. Please provide specific recommendations for further action to be taken by your Government and other stakeholders to address challenges to the full and equal participation of person with albinism in society and development

National Legal and Policy Framework:

i. **Reinforce and effectively implement existing legal and policy frameworks.**
ii. **Endorse the draft national action plan on Persons with Albinism developed in consultation with Civil Society Organizations (CSOs).**
iii. **Review the Person with Disabilities Act no 9 of 2010 and the Disability policy 2004 to explicitly include issues of Persons with Albinism in consultation and cooperation with relevant stakeholders.**

iv. Collect accurate population and needs assessment data on Persons with Albinism and make the data easily available to stakeholders.

v. Continue cooperation with the United Nations Independent Expert on the Enjoyment of Rights of people with albinism by consulting and updating her on issues pertaining to human rights of Persons with Albinism in Tanzania.

vi. Print and disseminate user-friendly national legal and policy frameworks in Kiswahili language.

Health:

vii. Educate people with albinism on how to care for their skin and promote health-seeking behaviour practices.

viii. Subsidize costs for accessing optometry, skin cancer prevention, and treatment services for Persons with Albinism and invest in training more dermatologists and optometrists.

ix. Establish mobile clinics for skin cancer detection and prevention for remote Persons with Albinism.

x. Train nurses and midwives on albinism to counsel parents at the birth of babies with albinism, reducing chances of rejection and abandonment of such mothers and their babies.

xi. Provide affordable health insurance that accommodates skin care and eye care for Persons with Albinism.

Education:

xii. Educate parents and communities to demystify the belief that children with albinism will die young and that it's not worth investing in their education. Encourage the enrolment and retention of children with albinism in school.

xiii. Allocate funds specifically for providing assistive devices to students with albinism, especially costly items like eyeglasses, large-print materials, and magnifying lenses.

xiv. Endorse and disseminate the revised draft guidelines for teachers and educators of children with albinism developed by CSOs in collaboration with the government.

Employment:

xv. Raise Public Awareness: Conduct public awareness campaigns to educate the general population about albinism, dispel myths, and combat social stigma.

xvi. Anti-Discrimination Laws: Enact and enforce legislation that explicitly prohibits discrimination against Persons with Albinism in employment.

xvii. Vocational Training: Provide vocational training programs tailored to Persons with Albinism, equipping them with relevant skills.

xviii. **Access to Quality Education: Ensure equal access to quality education.**

xix. **Employer Incentives: Offer incentives to employers who hire Persons with Albinism.**

xx. **Job Placement Programs: Establish job placement programs.**

xxi. **Entrepreneurship Support: Provide training, mentoring, and financial support for those interested in entrepreneurship.**

xxii. **Workplace Accommodations: Encourage employers to make reasonable accommodations.**

xxiii. **Advocate for the creation of employment opportunities for Persons with Albinism through vocational and entrepreneurship skills development.**

F. Further remarks

15. Would you have any further comments on the social situation of people with albinism in your country?

In Tanzania, individuals with albinism confront pervasive social challenges and discrimination, primarily rooted in cultural superstitions. They endure stigmatization due to myths associating them with curses or magical powers, leading to social exclusion, bullying, and violence. The most distressing concern is the threat to their personal safety, as some believe that their body parts bring good fortune, resulting in targeted attacks and killings. Recent years have witnessed increased advocacy and awareness campaigns by

local and international organizations and government initiatives aimed at addressing these issues. While these efforts have brought about some positive changes, there remains a significant journey ahead to attain full equality and social acceptance for people with albinism in Tanzania.

Country: Zambia

Organisation: Albinism Foundation of Zambia

Contact Person: John Chiti, Technical Adviser, Email: Johnchiti@ymail.com

Responses

A. General

1. How many Persons with Albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

   According to the 2010 population census of Zambia, there are 25,000 Persons with Albinism in the country. We are yet to have new figures from the 2020 census.

2. How many of those people are women? How many are children, as defined in your country?

   Data not disaggregated

3. Please describe the overall social and economic status of people with albinism in your country?

Socially, Persons with Albinism are increasingly participating in social activities, particularly in urban areas. However, discrimination and stigma against Persons with Albinism remain prevalent across the nation.

Economically, there is a low level of employment among Persons with Albinism in Zambia due to misconceptions about their condition, which contribute to stigma and discrimination. Most Persons with Albinism are involved in small businesses, while a significant portion remains unemployed, primarily due to limited educational opportunities and the discrimination mentioned above.

4. Are there any public or private institutions in your country responsible for Persons with Albinism? If yes, please list the most important institutions.

There are public and private institutions responsible for Persons with Albinism. These include, Ministry of Community Development, Zambia Agency for Persons with Disabilities, Zambia Federation for Persons with Disabilities, Albinism Foundation of Zambia, Zambia Albinism Matters Organisation etc.

G. National legal and policy framework

5. Are there any national legal or policy frameworks concerning the issues of Persons with Albinism? If yes, please provide details and source of the relevant laws and policies? Also,

please describe if and how these laws and policies take a non-discriminatory approach towards Persons with Albinism?

We have the disability Act of 2012 which recognised albinism as a form of disability. The Act make provision for Persons with Albinism to receive assistive device and essential medicine such as sunscreens. There is an ongoing advocacy for the ratification of the Africa Disability Rights Protocol as well as a national action plan on Persons with Albinism in Zambia.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

   Yes, Albinism is counted as a disability in Zambia as indicated above in the disability act of 2012.

H. Social development: Health

7. How would you describe the health situation of Persons with Albinism?
   i. Are dermatology and ophthalmology services readily available to them?

      The health of Persons with Albinism is a significant challenge in Zambia. Dermatology and Ophthalmology services are not readily accessible in the country. For example, there is only one Skin Cancer hospital located in Lusaka. Persons with Albinism often have to

undertake long journeys to Lusaka to receive treatment for skin cancer. Sunscreens are also not easily available to Persons with Albinism, and many struggle to afford the few services that do exist.

Ophthalmology services are primarily concentrated in urban areas, making it difficult for Persons with Albinism in remote regions to access these facilities. This is due to various concerns, including the cost of transportation and safety issues.

ii. Is there information made available to them about health risks linked with albinism?

Awareness efforts regarding albinism primarily focus on reducing attacks, stigma, and discrimination. Unfortunately, there is a lack of awareness about the health implications of albinism. As a result, Persons with Albinism who suffer from skin cancer often report to health facilities at advanced stages of the disease due to a lack of awareness about their condition.

iii. If so, how is this information disseminated and communicated?

Refer to the answer in (ii) above.

I. Other Selected Social Development Issues

1. Education

8. What is the educational situation of Persons with Albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of Persons with Albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

   According to the 2010 population census, most Persons with Albinism do not attend school. There is high dropout rate. Persons with Albinism face bullying and name calling in school which make it challenging for them to continue school. Additionally, reasonable accommodation is lacking in the classroom.

9. Given the low vision issues present in most Persons with Albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, for e.g., large print material, low vision, and assistive devices?

   There is no reasonable accommodation in mainstream schools. These only exist in special schools where teachers are trained to handle such students and provisions are made for assistive devices.

2. Employment

10. What is the employment situation of Persons with Albinism? Please provide statistics or other information concerning employment and unemployment rate of Persons with Albinism, if applicable?

    The low level of education among Persons with Albinism impacts negatively on the employment status. There is high unemployment rate among Persons with Albinism in the country. Most Persons with Albinism who are employed are teachers and other run small businesses.

11. What obstacles exist for Persons with Albinism in seeking paid employment in the open labour market?

    Discrimination and stigma are significant contributors to the unemployment rate among Persons with Albinism. Additionally, a lower level of education reduces their opportunities to acquire employable skills. Lack of self-confidence and self-esteem, stemming from the stigma and societal attitudes towards Persons with Albinism, also serve as significant barriers to their gaining paid employment in the open labour market.

12. Are there any applicable laws or policies concerning the employment of Persons with Albinism? If yes, please provide details and source of the major laws and policies.

    There are no specific laws that deals with albinism. We have a labour law that covers everyone.

13. Are there special measures in place to promote and integrate Persons with Albinism in employment and in the labour market?

    There are some measures in place to promote the employment of Persons with Albinism in the country. For instance, the President have appointed a number of Persons with Albinism into public offices and other institutions are following in the step to engage the services of qualified Persons with Albinism. Other institutions are also promoting the employment of Persons with Albinism.

J. Recommendations

14. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of person with albinism in society and development?

    There should be reasonable accommodation in every school to enable students with albinism have quality education. This is because, education affects employment, health, and other aspect of life.

K. Further remarks

15. Would you have any further comments on the social situation of people with albinism in your country?

The albinism community needs the support of everyone including the media to create awareness on the condition. The Zambia Netflix Movie "Can You See Us" is shedding more light on the challenges Persons with Albinism face. Therefore, more collaborations of this nature will help raise awareness on the condition.