



# PERSONS WITH ALBINISM IN TANZANIA

## Situational Analysis

### BACKGROUND

According to the World Health Organisation (WHO), albinism is a genetically inherited disorder resulting from lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. Tanzania has one of the countries with the higher incidences of albinism in the world with 1 in every 1429 live births being albino. In Africa approximately 1 in 4,000 people are born with albinism compared to 1 in 20,000 elsewhere in the world. Though it's difficult to know the actual number of PWAs in Tanzania, figures obtained from Tanzania Albinism Society (TAS) which is a national organization of Persons with Albinism (PWAs), show that there are 18,833 persons with albinism in the country. But going by 1/1429 albinism ratio to 58,000,000 Tanzanian population (World Bank data 2020), PWAs in Tanzania are estimated at 40,588 people which is a significant population, larger than the country of San Marino. Although most people are familiar with the term "albino," the most preferred term that they want to be called by in Tanzania is "person with albinism (PWA)."

As noted in 2015 by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism<sup>1</sup>, PWAs are a unique group whose human rights issues have generally gone unnoticed for centuries; the result being deeply engraved stigma, discrimination, violence against them and poverty across various countries. Although there are people with albinism throughout the world, the impact of the condition on human rights and the way it is perceived by others, including its effect on social inclusion, vary from region to region. As such Tanzania is known for brutal treatment and attacks on PWAs. The complexity and uniqueness of PWAs' condition means that their experiences significantly and simultaneously touch on several human rights issues including, but not limited to, discrimination based on colour, discrimination based on disability, special needs in terms of access to education and enjoyment of the highest standards of health, harmful traditional practices, violence including killings and ritual attacks, trade and trafficking of body parts for witchcraft purposes, infanticide and abandonment of children. At least 75 people living with albinism in Tanzania had been killed in targeted attacks between 2000 and 2015<sup>2</sup>.

The murder of people with albinism in Tanzania began to receive increased attention around 2008, when media debates and international newspapers started to highlight the outbreak of the alleged killings. Under United Nations and European Union pressure, the Tanzanian government took necessary measures against the killings and maiming/dismembering; and launched public awareness campaigns, creating a national task force for the purpose of suggesting ways in which to deal with the issue, identifying the murderers, suspending the certificates of traditional healers suspected in the use and trafficking of the body parts of people with albinism; and More than 200 witchdoctors and traditional healers have been arrested in Tanzania in a crackdown on the murder of albino people.<sup>3</sup> The then president also nominated a person with albinism as a member of parliament<sup>4</sup>, all to ensure the rights and privileges of PWAs are preserved. The fire that was then has now gone out leaving much of the bulk of support to charities and well-wishers.

Today, Persons with albinism though not at a higher risk of murder are still considered the poorest, categorized as persons with disability in government programming with little or no attention to their welfare, access to education, health, access to employment or civic engagement opportunities. The most at risk in the whole situation of persons with albinism are women and children. Women, because they are often abandoned by their husbands when they give birth to children with albinism. Children because they mostly live with their grandparents or single parents (mothers) in rural areas with limited opportunities to access education, notwithstanding the associated challenges in the available education system when looking at their visual

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<sup>1</sup> <https://www.ohchr.org/en/issues/albinism/pages/iealbinism.aspx>

<sup>2</sup> <https://www.bbc.com/news/world-africa-31709165>

<sup>3</sup> <https://www.bbc.com/news/world-africa-31849531>

<sup>4</sup> <https://albinism.ohchr.org/story-alsaymaa-kwegyir.html>

impairments and needs for protection against the sun. PWA led organizations especially Tanzania Albinism Society (TAS) whom ADRA has partnered with to implement some of the projects in education and health have kept the pressure on government, sometimes attracting donations from development partners to implement service—oriented projects; which are seen as a distractor from the advocacy role.

Against the unfortunate situation of the people with albinism in Tanzania,

## ACCESS TO HEALTH SERVICES

### Skin Cancer Serial Killer

*Even though brutal killings of PWAs gets a lot of attention, skin cancer is said to be the silent killer which limits persons with albinism to a life expectancy of less than forty (40) years especially in Africa<sup>5</sup>.* In comparison, people with albinism living in Sub-Saharan African are about 1,000 times more likely to develop skin cancer than the general population.<sup>6</sup> With appropriate protection from UVA and UVB rays, people with albinism can enjoy a normal lifespan.

### Vulnerability under UVA and UBA rays:

Albinism as a condition results in the lack of the body's ability to make pigment, and results in very pale skin, eyes and hair. People with albinism also have varying degrees of visual impairment. As a result, many albinos are legally blind (NOAH 2011), and extremely light sensitive. Albinism is a stable condition, and has no impact on mental capacity. With appropriate protection from UVA and UVB rays, people with albinism can enjoy a normal lifespan.

*Forms of Albinism:* There are various forms of albinism based on the amount of pigment present in one's skin, hair of iris. These brings about albino classifications: namely Oculocutaneous Albinism (OCA) and Ocular Albinism (OA). OCA is the most recognizable form of albinism which results in milky white skin, white hair and white or pink irises. OA occurs mainly in the eye, with normal hair and skin color. Affiliated genes are inherited from the parents; carriers would have normal appearance and no family history because it is an autosomal recessive inheritance. Children are only born with albinism if they receive an albinism gene from both parents; heterogeneous and dominant homogenous carriers have one normal gene with one altered gene or two normal genes can still obtain enough DNA information to produce pigments. Pigments called melanin exist in human body to provide protections against UV ray, when exposed to sun shine, normal skin with enough amounts of pigments have a certain level of resistance to the damaging UV ray, tanning means more pigments are produced for greater protection. The skin of albino organisms is much more sensitive to exposure of sunlight, without the pigments. It has little to none protection against UV ray.

### Cancer Protection, detection and treatment

People with Albinism certainly those with Oculocutaneous Albinism (OCA) which usually affects the eyes, hair, skin should always be treated as having skin type 1. Sun protection Factor (SPF) provides protection against UVB rays (B for burning) and UVA rays (A for ageing). Someone needs to choose sun protective products that provide both UVB and UVA protection. In the following table, we elaborate about the PWA skin types and SPF needed against the number of stars needed for UVA protection.

Skin type	SPF needed	No. of stars needed for UVA protection
1 & All people with OCA	SPF 25 or more	****
2&3	SPF 15	***
4	SPF 8	**
5&6	SPF 2 to 6	*

**Note:** PWAs and particularly those with OCA should use sunscreen with a SPF of at least 25 and more and the corresponding 4 stars for UVA protection. UVA rays are the longest of all the ultraviolet rays that reach the earth while UVB rays are the medium length rays; some of which are prevented from reaching the earth by the ozone layer. UVA rays tend to penetrate deep into our skin and can cause premature ageing, wrinkles and dryness while triggering a number of skin allergies. UVB rays that reach us are mainly absorbed in the upper layers of the skin. It is in the base of these upper layers, that the pigment

<sup>5</sup> <https://www.bbc.com/future/article/20170425-the-silent-killer-of-africas-albinos>

<sup>6</sup> Morton, T. (2014). Watu Kama Sisi: *Reducing Skin Cancer, Stigma and Violence Against Albinos in the Mara Region (Report)*. Canada / Tanzania: Under the Same Sun.

producing cells (melanocytes) are found. Thus, PWA skins lack the ability to absorb the UVB rays which causes burning on their skin if there is direct contact with UVB rays causing skin cancer. The high risk of developing skin cancer makes it essential that children with albinism are taught about and are enabled to implement effective sun protection from an early age.

#### Inaccessibility to specialists and treatment.

The number of dermatologists in Tanzania as in all of Africa, is largely insufficient implying that prevention is even more relevant. Tanzania Albinism Society reported that only 7 out of 31 regions on the mainland have dermatologists in the regional hospitals, moreover situated hundreds of kilometers from most PWAs who live in remote rural areas. Even though PWAs in Tanzania do not live past 30 years on average due to skin cancer, to a great degree, this unfortunate statistic is preventable. The common and cheapest method to manage skin cancer among persons with albinism that has been widely used in Tanzania and found to be effective is cryosurgery. Cryosurgery uses liquid nitrogen to remove pre-cancerous lesions from the skin before it develops into a cancer. According to the Regional Dermatology Training Centre (RDTC) situated Moshi, 85% of PWAs in Tanzania develop precancerous lesions before the age of 20, which unattended to, advances to stage 3 or 4 cancer that is expensive for PWA to manage or treat. The only public facility that provides such advanced treatment is Ocean Road National Cancer Institute situated in the eastern part of the country, Dar es Salaam. Cryosurgery has been championed by ADRA<sup>7</sup> in Morogoro, Standing Voice UK in various parts of the country plus other partners through organized medical outreaches, bringing services closer to the vulnerable women and children with albinism. This is necessary given that according to TAS, only 7 regional public hospitals have dermatologists. From the mobile clinics, the patients with advanced cancers are referred to the National Cancer Institute in Dar es Salaam. It's however difficult for most of the PWAs to travel to the only center for examination and then treatment schedules with all associated costs. According to TAS, it costs \$1,308 and above to undergo chemotherapy and other advanced cancer treatment procedures, excluding transport, accommodation and care costs. From ADRA's experience, at least 8% of PWAs are diagnosed with advanced cancer in mobile clinics.

#### Awareness creation on prevention

Simple means, such as using sunscreen and wearing appropriate clothing, can prevent these cancers according to health care experts. The Regional Dermatology Training Centre (RDTC) in Moshi has a Care Unit for Persons with Albinism where local manufacture of sunscreens and skills training workshops take place targeting both Tanzania and other health workers from the neighboring countries. Public awareness on avoidance of exposure to the sun and improved access to sun protection materials such as sun screen lotions, wearing of long sleeved dresses and sunhats, experts say, prevents 98% of the infections. Whereas RDTC produces the sun screen lotion called Kilimanjaro sunscreen lotion, the supply is very limited, keeping the prices of the much needed product very high i.e. a 60g of SPF-60 tube costs TZs 35,000 (\$15.3). This is much higher than an average PWA can afford. Moreover such a tube if used sparingly with all other precautions adhered to, one person would need a tube per quarter which implies  $\$15.3 \times 4 = \$61.2$ . Given that most PWAs are children and women in rural areas, the majority stay without the lotion, the reason for 30-years' life expectancy in Tanzania. According to TAS regional office in Morogoro only 500 tubes of sunscreen lotions are accessed against 5000 tubes that are needed annually. This implies that only 10% of the PWAs in Morogoro region access the life-saving product annually. Morogoro had 840 PWAs in 2017 according to TAS estimates based on 2012 national census.

Currently, awareness creation is done by NGOs such as ADRA, Standing Voice UK, Tanzania Albinism Society, Peace Makers Development, KCBRP, Raleigh International, Sight Savers and others through mobile clinic outreaches. During the outreach events, the CSOs also provide sunscreen lotions, sunhats and long sleeves. This is however not sustainable. Producing sunscreen locally which addresses the needs of persons with albinism is indeed the best way of ensuring a regular and sustained supply of this essential medicine to persons with albinism. Even more important is the economic empowerment of PWAs especially women who take care of majority of children with albinism so that they can have and control their livelihoods and means to care for themselves and the children under their care.

#### The right to health

As noted above, skin cancer remains the number one killer of persons with albinism, with life expectancy standing at 30 years of age Vs 40 years on the continent of Africa. This is particularly concerning, as most skin cancer related deaths of young people are preventable through low-cost measures according to health experts.

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<sup>7</sup> <https://adra.org/news-release-adra-addresses-people-in-tanzania-with-albinism-on-skin-cancer>

According to United Republic of Tanzania's constitution, health is a right and not a privilege. As Article (11), (1) of the Constitution states, "The state authority shall make appropriate provision for the realization of a person's right to work, to self-education and social welfare at time of old age, *sickness*, or disability and in other cases of incapacity. Without prejudice to those rights, the state authority shall make provisions to ensure that every person earn his livelihood."

Moreover, the 2017 UN Independent Expert Report<sup>8</sup> on the enjoyment of human rights by persons with albinism recommended to the Government of the United Republic of Tanzania that it should,

- (a) Ensure that sunscreen is available, including by providing strong support for domestic production of sunscreen lotions and other assistive devices within the framework of multi-stakeholder partnerships,
- (b) Support early intervention and detection programmes, including through mobile clinics;
- (c) Provide training and information on albinism and related health issues to mothers of children with albinism and their families immediately after the births of their children to ensure that their skin and vision are adequately protected;
- (d) Facilitate access to skin cancer treatment, including chemotherapy and radiotherapy, by reducing indirect costs or, where necessary, by providing financial support to ensure prompt access to treatment;
- (e) Provide free clinical assessments, both dermatological and ophthalmological, to persons with albinism, along with glasses, adaptive devices and other visual aids, within the framework of efforts to provide reasonable accommodation and fulfil international obligations regarding their right to the highest attainable standard of health;
- (f) Consider rolling out a national skin cancer prevention strategy similar to those that have been rolled out for the 10 other kinds of cancer most commonly affecting Tanzanians.

#### **RIGHTS ABUSE, STIGMATIZATION, DISCRIMINATION, MARGINALIZATION AND EXCLUSION OF PWAS:**

Whereas the Constitution of the United Republic of Tanzania (1977) recognizes equality for all human beings irrespective of their economic, political and disability status, people with albinism face multiple forms of discrimination worldwide. Albinism is still profoundly misunderstood, socially and medically both by the community and PWAs themselves. Below are *common myths and misconceptions* regarding albinism;

- People with albinism are evil and a curse from God and will bring bad luck on the household
- People with albinism never die, they simply vanish
- Children with albinism are born by a woman who has slept with a white man
- Albinism is very contagious and people can get through contact
- Weaving albino hair into a net improves the chances of catching fish
- Albino body parts worn as amulets bring good luck, fortune, and health
- Albinos have magical superpowers and can cure diseases
- Intercourse with an albino lady will cure human immunodeficiency virus (HIV) infection
- Spitting on an albino prevents the condition in one's family
- Mother of albino child was laughed at by an albino during pregnancy
- Albinism is caused by a missing top layer of skin
- Albinos and their mothers are possessed by evil spirits
- The devil stole the original child and replaced it with an albino
- Albinos are housed by ghosts of European colonists
- Albinos have low brain capacity and cannot function at the same level as others

#### **Deroqatory labels (names) for PWAs in Tanzania:**

Emanating from the above beliefs and myths which are centuries old and are present in cultural attitudes and practices in Tanzania and beyond, stigmatization of people with albinism is represented by the various demeaning labels that are commonplace in the country. In Tanzania, the terms include **zeru zeru** (meaning nothing or double zero – 0\*0) according to TAS Chairman, Morogoro region. Other people say that zeru zeru means ghost. The second most common word is **dili** which literally means 'deal', referring to the trade in the body parts of people with albinism on the black market. This literally means

<sup>8</sup> <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/364/13/PDF/G1736413.pdf?OpenElement>

that in some communities where belief in superstition is common, a sight of a person with albinism is like seeing gold. The Office of the UN High Commissioner for Human Rights (OHCHR), the UN agency that deals with human rights issues, reported in 2016 that albino hunters sell an entire human corpse for up to \$75,000, while an arm or a leg could fetch about \$2,000. The other derogatory label used in referring to PWAs is “Mbulimwelu,” which means “white goat”

#### Children and women with albinism are at high risk:

Although all PWAs are extremely vulnerable, women and children have a bigger burden of victimization and discrimination. Women who give birth to a child with albinism often face ostracism, discrimination and rejection by husbands and partners, accusing them of adultery and blaming them for giving birth to a child with albinism; generally seen as a curse or bad omen. Gender-based sexual assaults on women with albinism is also common in Tanzania due to the bizarre belief that having sexual intercourse with women with albinism could cure the perpetrator’s HIV/AIDS. These misconceptions and pernicious beliefs not only contribute to rape in women and young girls, but make them more susceptible to HIV/AIDS infections, which – due to poor medical conditions in Tanzania – infringes on their right to life and security. Various reports also point at the fact that most murders are committed on young girls. School-going children also suffer discrimination from their peers and sun burns make it even worse as TAS reported that children with albinism often dropout for fear of skin cancer contracted as they walk to and from school and because of the stigma and being laughed at due to their skin appearance.

As reported by the *European Parliament resolution of September 4, 2008* on the killing of PWAs in Tanzania a study by the United Nations Development Programme (UNDP), revealed that

*“nearly half of the parents of albino children in Tanzania felt humiliated at the time of the child's birth; whereas albino women are subject to discrimination from other women and whereas women who give birth to albino babies are often mocked or rejected and suffer discrimination at work; whereas some two thirds of parents were reported as saying that specific health interventions for albino children were expensive, and half said that their children had serious vision problems; whereas, however, 83% said that their children did as well at school as any other children”*

Mother and Child Displacement: Both women with albinism and women who give birth to children with albinism are often displaced. In the past, many went into safety shelters set aside by the government to provide temporary protection. Some entered voluntarily and others entered through government and community interventions. Given that the shelter concept lost meaning when services therein became poorer and conditions exposed the women and children more, the women often run back to their parents with children and end up either looking after them as single parents or even hand them over to their grandmothers, leading to further suffering. A psychological needs assessment done by standing Voice on some women in this category found them living in poorer conditions, with severe levels of depression and high rates of trauma symptoms.

Reprisals on women: Women whose spouses are reportedly involved in attacks against their children often face actual and threats after testifying against their husband in investigation of cases. Reprisal comes from both the family of the husband and the community at large.

Vulnerability to attack: The rejection of mothers and children with albinism exposes them to poverty and isolation which increases the vulnerability to attacks of both mother and child with albinism. Children are more vulnerable to attacks as they are easy to find and capture and do not have the physical strength to fend off attackers.

Separation, divorce and infanticide: Women giving birth to an infant with albinism are also at risk as the persistent beliefs that children with albinism are a potential source of misfortune and/or the proof of unfaithful wives. As a result, most of the time they are chased away from home (divorced). Killing of their infant children brings lifetime pain and tears.

## **ACCESS TO EDUCATION**

*“Education is the most powerful weapon which you can use to change the world”- Nelson Mandela.* The PWA world needs that change more than any other. The fact that children with Albinism live under a constant threat of attack, means that they’re not able to freely and comfortably participate in day-to-day activities including schooling. The country’s Inclusive Education Strategy (2012–2017) was adopted to ensure that all children in Tanzania have equal access to quality education in inclusive settings. This included ensuring that teachers were able to respond to the diverse needs of learners and that educational support was available to all learners.

However, children with albinism cannot benefit from the strategy if the teachers are not trained or oriented on the issue or if they (children with albinism) are not provided with necessary reasonable accommodation, including visual aids such as glasses, monoculars and large-print material. The Government recognizes that there is a shortage of assistive devices for persons with albinism, a gap that is being partially filled by civil society organizations. A 2017 report by the UN Independent

Expert on the enjoyment of human rights by persons with albinism in Tanzania<sup>9</sup> noted that many items needed by persons with albinism, such as monoculares or glasses, are being imported primarily by civil society organizations and that it is important for the government to encourage those initiatives by expediting import processes and facilitating the refund of import taxes and duties on such goods. Besides, the Independent Expert welcomed the instructions given to the Ministry of Industry and Trade by the Prime Minister's Office to reduce the cost of importing assistive devices for persons with disabilities, including persons with albinism

Similarly, discrimination against and bullying of children with albinism are still being experienced in Tanzania. Children with albinism thus drop out of school, with significant consequences for their life expectancy, as a lack of education often means working outdoors in the sun and/or living in poverty. Relatedly, given the need for indoor work for the health and safety of persons with albinism, efforts should be made to include persons with albinism in vocational training opportunities, regardless of their academic performance to increase chances of having befitting livelihoods.

#### Learning environment and dropouts.

According to a 2016 Social Science Research Network (SSRN) report titled *Experience of Students with Albinism in Tanzania: An Exploration of Barriers to School Completion*, students with albinism are doubly vulnerable, they are visually-impaired and strikingly different in appearance. Looking like "a Mzungu", with "four eyes", in a black student population, makes them the target of bullying and name – calling while facing low vision impairment in classrooms. It is therefore recommended that government needs to take varied approaches towards addressing the PWA's dilemma and cascading the change down to the level of school and classroom teachers hence improving the learning environment in the classroom. Special attention needs to be paid to students with albinism who mostly are most likely to drop-out of school due to unconducive learning environment. It is important that they be given support to stay in school and get the same education as their peers who do not have albinism

The 2020-2024 National Action Plan for Persons with Albinism in Tanzania affirms that constraints of accessing education by PWAs include unfriendly environment at school, accounting for 68% of the problem, limited financial resources accounting for 12.8%, insecurity (10.4%), others (8.8%). Infrastructural challenges include,

- Lack of educators who adequately trained to meet the particular needs of PWA and provide inclusive education;
- Lack of facilities and resources for the implementation of inclusive education and provision of the particular needs of PWA;
- Lack of large-font textbooks for children with low vision;

Failure to access education, makes the bad situation of persons with albinism in Tanzania worse as low or no education perpetuates notions of discrimination, stigma and unemployment; all together leading to a vicious circle of poverty. Ensuring a free, safe and dignified access to education is key to upholding the fundamental human rights of people with albinism and to combatting the stereotypes and stigma that continue to expose them to mistreatments and fatal risks. Mr. Hassan Mikazi, the Chairman of TAS in Morogoro region who's a PWA asserted that *only the educated PWAs are respected in Tanzania*. Mr. Mikazi further suggests that educated people know their rights and can speak for themselves as opposed to uneducated adding that access to employment depends on education. He envisions that an educated community of PWAs will stop at nothing in changing the situation of PWAs in Tanzania as it will lead to generational transformation.

More effort is also needed in sensitizing family-members and communities about albinism, to ensure that children with albinism in Tanzania can thrive both inside and outside the classroom.

#### *The right to education*

Under international human rights law, persons with albinism enjoy normative protection covering all their fundamental human rights, including the right to life, physical integrity, liberty and security, the right to the highest attainable standard of physical and mental health and the right to an adequate standard of living. Further protection is afforded by the Convention on the Rights of Persons with Disabilities and the International Convention on the Elimination of All Forms of Racial Discrimination, which proscribes "racial discrimination" on the basis of color.

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<sup>9</sup> <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21919&LangID=E>



Tanzania's inclusive education programme that is currently being implemented is commendable as children with albinism are free to attend schools. This is in line with the Persons with Disabilities Act 2010<sup>10</sup> which sets the framework for policies in order to ensure realization of the rights of persons with disabilities.

However, the 2017 UN Independent Expert Report<sup>11</sup> on the enjoyment of human rights by persons with albinism recommended to the Government of the United Republic of Tanzania that it should:

- (a) Ensure full implementation of the inclusive education policy, not least by allocating the necessary resources;
- (b) Ensure provision of reasonable accommodation to students with disabilities by making low vision aids, adaptive devices and large-print materials available in all schools;
- (c) Ensure systematic training of teachers on the special needs of children with albinism, who should know that children with albinism should be seated in the front row, that such children should be given teachers' notes, that large-print writing should be used on the blackboard and that other teachers and students should learn about albinism;
- (d) Ensure that schools that have children with albinism are equipped with the necessary basic protections, such as fences, and that teachers and staff are aware of the situation of students with albinism and trained to respond adequately;
- (e) Facilitate access to vocational training opportunities, so that persons with albinism, regardless of their performance in academic subjects, can prepare for careers that would allow them to work indoors and lift themselves out of poverty.

#### STAKEHOLDERS SUPPORTING PERSONS WITH ALBINISM IN TANZANIA AND WHAT THEY DO

Besides ADRA, the major players supporting PWAs include the following:

Sn	Name of the Actor	What they do	Where
1.	Ocean Road Cancer Institute (government)	National referral centre for cancer treatment & research	Dar es Salaam
2.	Kilimanjaro Christian Medical Center (KCMC) private	Cancer treatment & sunscreen lotion production	Kilimanjaro
3.	Karagwe Community Based Rehabilitation Programme(KCBRP) CSO	Mobile clinics, M&E on PWA in the hospitals	Lake Region
4.	Under the Same Sun (UTSS) - (civil Society)	Education support, Research & Advocacy	countrywide
5.	Tengeneza Generation (TEG) - (civil Society)	Livelihood promotion for PWAs	Countrywide
6.	Sight savers - (civil Society)	Protecting sight and fighting for disability rights	Countrywide
7.	Raleigh Tanzania - (civil Society)	Youth inclusion with sustainable development	Countrywide
8.	Voice Global - (civil Society)	Livelihoods and advocacy campaigns	Countrywide
9.	Standing Voice	Skin Cancer Mobile clinics and advocacy	Countrywide

Besides, there is also SHIVYAWATA, an umbrella organization for all association of persons with disabilities and many other Civil Societies Organizations working to improve the livelihood of PWAs.

#### GAPS IN PWA PROGRAMMING OR INTERVENTIONS BY PARTNERS & PWA ASSOCIATIONS THAT ADRA WISHES TO PLUG

Even though Tanzania has more players supporting PWAs especially after the infamous killings between 2013 and 2016 which attracted the attention of the international community, major gaps still exist in ensuring that PWAs access and enjoy their rights including access to services such as health and education.

<sup>10</sup> <https://tanzlii.org/tz/legislation/act/2010/9-0>

<sup>11</sup> <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/364/13/PDF/G1736413.pdf?OpenElement>

#### **A. Partners' failure to work jointly with synergy.**

Only until recently, have partners made efforts to come together in order to have concerted efforts in striving to emancipate PWAs with sustainable solutions and advocacy at a national level. Indeed the 2020-2024 National Action Plan for Persons with Albinism is still in its draft form and it can only be hoped that it will be assented to by international, regional and local partners as well as government to play the role for which it has been drafted.

#### Proposed intervention (s) by ADRA in Tanzania between Jan 1, 2021 and December 31, 2024:

1. **Facilitate ADRA's capacity and participation and promotion of the 2020-2024 National Action Plan objectives** alongside other national and international players.
2. **Support development and implantation of high value consortia aimed at impactful programing** for PWAs in the country
3. **Support local area initiatives especially by PWAs** aimed at expanding horizons for service delivery and PWA empowerment in the country.
4. **Facilitate research and documentation advocacy** issues at reginal, national and international level.

#### **B. Limited PWA ownership and involvement in advocacy efforts for their emancipation of PWAs in the country.**

Although Tanzania Albinism Society (TAS), one of the most active and widely spread local organizations managed and owned by PWAs is considered the best partner for international and government, they have turned out to be another service delivery organization competing for funds to implement projects which undermines their coordination and advocacy roles. Even though TAS has 26 offices/chapters in 26 regions, they are faced with two challenges i.e. lack of focus and functional sustainability. Lack of focus, because they are tempted to be fully immersed in project implementation, in most cases, implementing on behalf of partners which makes them (TAS) lose the mandate to advocate for the rights and dignity of persons with albinism. Lack of functional sustainability because, regional offices do not have the capacity to mobilize resources in order to sustain their operations. Only about 7 offices are reported to be active mainly because they are the ones which have partners that are implementing projects therein.

#### Proposed intervention (s) by ADRA in Tanzania:

1. **Facilitate capacity building programs for TAS to leadership at national, regional and district levels to initiate and implement advocacy programs** able to include national policies, local bylaws and governance.
2. **Build capacity of TAS in sustainable resource mobilization and management** for sustainable delivery on their mandate of to advocate for the rights and dignity of PWAs

#### **C. Limited livelihoods, access to employment or economic empowerment opportunities**

In spite of a dozen partners supporting PWAs in Tanzania, PWAs generally continue to lag behind in access to meaningful livelihoods. According to the 2020-2024 National Action Plan for PWAs, 65% of PWA are unemployed; 21.8% were self-



employed in agriculture; 8.6% self-employed within enterprises; 3% employed within private institutions; and 1.4% employed within the government. Within the unemployed category, 53% are female while 47% are male. All PWAs without formal education were unemployed. Even among those PWA who completed their secondary education, 46% were unemployed while 28.6% were self-employed in agriculture: a hazardous occupation for the dermatological health of PWAs because of exposure to the sun, a leading skin cancer infection.

#### Proposed intervention by ADRA in Tanzania:

To ensure sustainable attainment of dignified lives especially for women and children, who constitute over 70% of PWAs, ADRA proposes the following interventions between January 1, 2021 and December 31, 2024.

1. Supporting unemployed women and youth to:

- a. **Self-mobilize and organize in groups for unified voices in pursuit of access to business and employment opportunities** in their localities including developing capacity to tap into government poverty alleviation initiatives such as Persons with disability loan facilities in local governments and 3% employment quota as well as self-help initiatives such as Village Savings and Loan Associations (VSLAs).
- b. **Access Farmer Market School and RIPAT interventions aimed at improving farm income** which hitherto perpetuated poverty among farming communities at the hands of unfair market forces and players.
- c. Access training and empowerment especially non-literates through the reflect approach aimed at improving their engagement and participation in agriculture, business and other economic activities.
- d. Access career guidance and pre-employment support, linkage creation and training aimed at enabling access to salaried or self-employment opportunities.
- e. Access start up kits including capital, in-kind inputs for farm inputs, equipment, technologies etc.

#### **D. Limited community knowledge & engagement for elimination of discrimination, mythology & protection of PWAs**

In as much as a lot has been achieved in curbing murders and dismemberment of PWAs, a lot of misinformation, discrimination and a feeling of social insecurity among PWAs continue to exist. This is apparent situation is responsible for the dehumanizing labels (names) that PWAs continue to carry as well as stigma that they constantly suffer in communities, schools and public offices.

As documented in the 2020-2024 National Action Plan for PWAs, albinism is shrouded in myth and superstition in many parts of Tanzania. Some myths include that PWA are ghosts, or curses from God, while others argue that sex with a woman with albinism will cure infertility and AIDS. The body parts of PWA more generally are considered to possess magical properties, conferring fortune when used in witchcraft. This belief has precipitated an upsurge in reports of ritual violence against PWA in Tanzania over the last two decades. As of January 2020, there had been 211 documented murders of PWA, and a total of

596 attacks, across 29 African countries since 2006. Tanzania presents a uniquely severe case, with 76 murders and 86 non-fatal incidents. Most victims have been children<sup>12</sup>

Proposed intervention by ADRA in Tanzania:

To contribute towards dispelling myths and elimination of stigma, discrimination and insecurity suffered by PWAs in the community and in accessing social services including health and education, ADRA shall;

1. **Initiate and implement Communication for Social Change (C4SC) initiatives** using media, music, dance and drama (edutainment) or creative art by PWAs aimed at mindset change of the community. This may involve of local and national radios/Television platforms as well as social media, community concerts, use of posters and T-shirts and caps.
2. **Organization of events such as marathons, walkathons, PWA beauty pageants or talent shows and cultural galas** showcasing the positives from PWAs for mindset change towards persons with albinism.
3. **Organize and implement a 12-months nationwide advocacy caravan across the country** engaging duty bearers, religious leaders, civil society and the general public on issues affecting PWAs. ADRA owns a Tata Bus which it intends to use to drive across the country in partnership with like-minded partners for greater education of the majority of Tanzanians who will be engaged through various caravan activities such as medical camps, Albino Child Education Fund (ACE Fund) promotion, district and regional leaders sign up to PWA protection and support charter.

**E. Limited focus on education as a tool for ultimate socioeconomic liberation of PWAs**

As the famous quote by Nelson Mandela goes that *“Education is the most powerful weapon which you can use to change the world”*- the same is for PWAs in Africa and Tanzania particularly. Unfortunately, the efforts offered by most partners in Tanzania are piece-meal. For example, most partners just like ADRA have for so many decades been focused on sponsorship of individuals using resources mobilized from overseas contacts. This method is however limited in breadth and depth as it is not only difficult to sustain but also limited in as far as the number of children supported. TAS estimates that of the 10,000 children with albinism (CWAs) of school going age, only about 4,000 are afforded access to education because of the constrained earlier on highlighted.

Proposed intervention by ADRA in Tanzania:

1. **Advocacy support** whereby PWA associations at district, regional and national levels will be empowered on how to identify critical advocacy issues in education and eventually self-mobilize and engage with duty bearers on the matter. These could include, improved education environment for CWAs, provision of assistive devices in schools,

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<sup>12</sup> Clarke, Sam and Jon Beale. 2018. “Albinism and Social Marginalisation.” In *Albinism in Africa: Historical, Geographic, Medical, Genetic, and Psychosocial Aspects*, edited by Jennifer Kromberg and Prashiela Manga, 257-270. New York: Elsevier. Page 260.

training of teachers in handling CWAs as well as establishment of SOPs or guidelines in accommodating CWAs in education institutions including curricular.

2. **Nationwide local community awareness creation, mobilization, engagement and participation in establishing and operationalization of Albino Child Education Fund (ACE Fund) - *Mfuko wa Elimu ya Mtoto wa Albino*.** This will be Tanzania supported and run whereby local interest and ownership will be solicited from the public hence promoting acceptance by non-albino community and limiting stigma and discrimination within the general public. This will be archived through a 12-months nationwide campaign involving media, a bus caravan that will traverse the entire country educating the public on the plight of Children with Albinism as well as the need to contribute from as low as \$5 towards the ACE Fund establishment which will be transparently managed through a 7-member multi-selected team comprising of institutions including ADRA, TAS, a local/international bank/insurance company, international audit firm, government's ministry of education and any other value addition partner (s) or institutions. Management of the fund will be done in such a way that it will provide sponsorship for the brightest CWAs to access quality education to the highest level possible as well as training for selected youth to obtain vocational or business skills that are geared towards access to employment as well business creation and management. Affirmative action shall be taken to ensure that females access at least 60% of the sponsorship under the ACE Fund.
3. **Advocate for and or facilitate training of all teachers in the public education system** so that they can adequately provide for the specific needs children with albinism
4. **Mobilize resources, support and advocate for schools to have at their disposal necessary resources** that meet the specifications by children with albinism, notably, textbooks and exams with larger fonts and assistive devices to read them to read what is written on the black or white board (s).

#### **F. Limited access to health services:**

Whereas skin cancer is said to be the silent killer for most PWAs in Africa where it is said to be responsible for one of the worst life expectancies capped at 40, in Tanzania it is at even lower at 30 years<sup>13</sup>.

#### Proposed interventions by ADRA in Tanzania:

1. **Support advocacy activities and campaigns for access to health services** by PWA in Tanzania including cancer awareness, early detection and treatment services.
2. **Support initiatives aimed at local production of skin cancer prevention supplies** including sun screen lotions, long sleeves and sunhats.
3. **Support organization of skin cancer mobile clinics, provision of supplies and equipment**

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<sup>13</sup> [SWCR2013\\_ENG\\_Lo\\_res\\_24\\_Apr\\_2013.pdf \(unicef.org\)](#)

## Glossary

PWA – Person(s) with Albinism

CWA – Child with Albinism

TAS – Tanzania Albinism Society

SPF – Sun Protection Factor