

SITUATION OF PEOPLE WITH ALBINISM IN TANZANIA
Universal Periodic Review on TANZANIA
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Submission by:

1.



This
is a

Tanzania Albinism Society

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submission by Under the Same Sun (UTSS) and Tanzania Albinism Society (TAS), non-governmental organizations advocating for the rights and welfare of people with albinism (hereinafter referred to as PWA). UTSS has its headquarters in Canada but operates in Tanzania, and TAS has its headquarters in Dar es Salaam with branches throughout Tanzania. This report assesses the progress made by Tanzania in ensuring enjoyment of human rights by PWA. It is based on our own internal research, firsthand information and experience from partner organizations, credible media reports, as well as information from the reports of the Independent Expert on the enjoyment of human rights by PWA.

2. During the second review, the Government of the United Republic of Tanzania accepted 23 recommendations on the rights of persons with albinism. The accepted recommendations demanded legislative and administrative measures to ensure that their rights are protected and promoted.

Implementation Status of Recommendations on PWA Rights

- Recommendations 134.43, 134.54, 134.55, 134.72, 134.74, 134.80, 134.81, 134.82, 134.84 and 137.65 on protection measures for PWA were partially implemented.
- Recommendation 134.73 on inclusion of PWA in decision making processes continues to be implemented.
- Recommendation 134.56 on developing a comprehensive plan to address the problems faced by PWA was not implemented.
- Temporary shelters in recommendations 134.75 and 134.77 were dismantled for reintegrating PWA into their communities.
- Recommendation 134.76, 134.78, 134.79, and 134.85 on changing public attitude towards PWA through public awareness were partially implemented
- Recommendations 134.83, 134.86, 134.87, and 134.88 on legislative measures promoting PWA rights were partially implemented.
- Recommendation 136.23 on cooperation with the Independent Expert on the enjoyment of human rights by persons with albinism has been implemented.

Situation in Tanzania

3. The 2012 Tanzania National Population and Housing Census estimated that people with albinism make 0.04% of mainland population and 0.03% of the Zanzibar populationⁱ. However, there are concerns that these statistics are likely to be underrepresenting People with Albinism (PWA) because during the census families were reluctant to disclose their members with albinism for fear of putting them in dangerⁱⁱ.
4. Ongoing public awareness raising campaigns and prosecution of perpetrators have contributed to significant decrease of reported cases of human rights violation of PWA, from twenty, recorded in 2015 to eight in 2019ⁱⁱⁱ.
5. Some PWA have also been appointed to visible leadership positions including: Ambassador to Germany, former Deputy Solicitor General, Director of disability department in the Prime Minister's Office, and Member of Parliament (special seats). This plays a great role in promoting a positive narrative for PWA in the society.
6. The Persons with Disabilities Act (2010), and the National Policy on Disability (2004) are regarded to cover PWA as persons with disabilities. Moreover, under the Penal Code Cap 16, prosecution and sentencing of perpetrators of violence against PWA continues. For instance in October 2019, four suspects were sentenced to life imprisonment^{iv}.
7. On another note, PWA have been given access to non-interest loans issued by local government authorities under the Local Government Finance Act (2019). The law gives persons with disabilities access to twenty percent of funds set aside for minority groups^v. However there have been complaints of PWA not being aware of these loans. Also that some who were able to access the loans made unsuccessful investments due to a lack of basic financial and entrepreneurial skills^{vi}.
8. The State has distributed free sunscreen lotions to PWA in some areas via the Tanzania Albinism Society and regional hospitals. However this has not been a consistent measure since it is not grounded upon specific policy. There are a lot of concerns from PWA who have not received the lotions. Plus, those that are available in cosmetic shops and pharmacies are still sold at expensive prices because of import taxes imposed on them.
9. The State allowed a visit by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism in 2017, after which several recommendations were given regarding improvement of the

situation of PWA in Tanzania.

While we commend the United Republic of Tanzania for its efforts in promoting the rights and welfare of PWA, this submission notes the following challenges:

Right to life

10. In the period of 2016 to 2020, UTSS documented 24 reported incidents including: abduction, exhumation of graves, cutting of hair and nails, attempted kidnap, attempted rape, and one mutilation of arm at elbow^{vii}. The most recent cases being:

- On November 27, 2019, there was an attempt to steal the remains from the grave of a deceased woman with albinism by the name A.J.F in Igula Village, Ilembula Ward, Wanging'ombe District in Njombe Region of Tanzania. She died of skin cancer in 2013 at the age 37. The deceased's younger brother who also has albinism expressed great fear following this incident. A police report (RB No: WANG/PE/19/2019) was then filed^{viii}.
- In June and November of 2019, a 6-year-old boy with albinism by the name of J.J.J survived 2 dangerous attempts by strangers to access him at his home in Mhongolo Mashariki Subdivision, Mhongolo Ward, Kahama District in the Shinyanga Region of Tanzania. According to Junior's mother, the first attempt was in June of 2019 by three men, and the second in November of 2019 by two men^{ix}.
- On March 25, 2018, an 8 month old baby boy with albinism by the name of Ibrahim Mwita survived abduction in Kenyaitanja Sub-village, Kewanja Village, Kyemambo Ward, Ingwe Division, Tarime District, Mara Region, Tanzania, near the Kenya border. At around 10:00 that morning Sophia Elias (26) had left her baby boy Ibrahim with their eldest daughter Maria (7) and son Amos (5) to go to the market. When she returned at around 11:00 she found her baby with patches of hair missing on his head where it had been shaved. She also noticed Ibrahim's nails, which she claims had been long, were cut. Maria told her mother that their neighbors had come over and asked if they could take little Ibrahim to their place for a while and promised to return him later. Two suspects were arrested and released on bail awaiting trial. A third one who was a witchdoctor fled the village. The victim's father who was employed by one of the relatives of the suspects got fired because he refused to withdraw the case from the court^x.

- On October 2, 2017, a 75 year old man with albinism by the name of Nassoro Mohammed Msingili survived a brutal machete attack in his home at Nyarutanga Village, Kusini sub-village, Kisaki Ward, Morogoro Rural District, Tanzania. His arm was hacked off at the elbow joint by unidentified men who broke into the house and attacked him while he was sleeping with his wife. He does not remember how it happened and he did not see the assailants. He has low vision in his right eye and lost his left eye in 1977. What he remembers was being hit on the head with a hard object and someone cutting off his left arm while he was screaming. Neighbors, including his nephews, heard the screams and came to his rescue but the attackers had already fled with his arm. The family informed the Village Executive Officer who phoned the police^{xi}.
- Temporary protection shelters for PWA have been dismantled and PWA reintegrated back into their communities. However, there are complaints from the people who were returned home about difficult access to basic needs especially food and shelter as well as extreme financial difficulty because of unpreparedness of their relatives to have them back.

Freedom from Discrimination

11. PWA still face social stigma and discrimination. For instance, A.J.W, a 24-year-old woman with albinism, and mother of three kids from Manyara region reported that she was being mistreated by her husband's family^{xii}. That her mother-in-law did not want her to marry her son because of albinism. Moreover, on several occasions, some unknown people have been locking her inside her house at night and a police report has been filed, but she still lives in fear. The matter has been referred to the social welfare office for further follow-up.
12. Similar observations were made in Mwanza and Shinyanga. In Shinyanga, one mother with albinism complained about being mistreated by her neighbors and her children being bullied. In Mwanza another woman was contemplating moving to another village due to extreme stigma she endures from her village community. Another lady was stopped from continuing with her job at a tailoring mart because her boss feared being held responsible in case something bad would happen to her. One nurse also spoke about a mother and baby that she is caring for because they were thrown out of their home by the father because the baby had albinism.

Right to Access Health Care

13. Skin cancer prevention and treatment services continue to be challenging for PWA especially in regions which have not been reached by the government and NGOs. A lack of knowledge on skin cancer prevention was observed in households where children with albinism were found wearing nothing more than a short pair of trousers while in the sun^{xiii}.
14. Deaths due to skin cancer also continue to occur^{xiv}. In the period of 2019 to 2021, the Tanzania Albinism Society recorded 26 such deaths. Statistics from other parts of Africa indicate that PWA often die early from skin cancer between the ages of 30 and 40^{xv}. This means that cancer is likely to be the leading cause of death for PWA.

Right to Education

15. Students with albinism face challenges in school including bullying, and inadequate reasonable accommodation for their low vision, and vulnerability to skin cancer. According to findings and experiences by Tanzania Albinism Society, melanin deficiency causes complex visual impairment, one of the factors that contribute to denial to accessing quality inclusive education, school drop-outs and/or poor academic performance^{xvi}. In some schools, teachers have been reluctant to admit students with albinism on the premise that they wouldn't know how to care for them^{xvii}.
16. Safety concerns also hinder PWA from properly participating in school. One mother from Mungula village, Kahama Township in Shinyanga region said that their family had to move from Kirogo village to this new home after their ten year old daughter with albinism was chased by unidentified people while on her way from school back in 2019^{xviii}. Also, C.V.M a 24 year old student with albinism was forced to move from Wanging'ombe secondary school in Njombe region to another school in Tabora region after he was attacked in 2019 by unidentified men who stabbed him with a sharp object as he was walking back to class from the restroom^{xix}.

Access to Justice

17. About 30 cases involving violence against PWA have been quashed on grounds of insufficient evidence. Moreover victims of this violence are yet to be compensated for the injuries they incurred from the violence^{xx}.

18. Questions to the Government of Tanzania

- To what extent does the State budget cater for promoting the welfare of PWA regarding protection from harmful practices, provision of low-vision assistive devices, as well as skin cancer prevention?
- To what extent is the government cooperating with civil society in the development of a national action plan on PWA human rights promotion?
- What rehabilitation support is the government providing for PWA who lost their body parts from attacks? Can they be compensated?
- How many PWA who were living in the temporary shelters have been safely reintegrated back into their communities. Has this information been made accessible to relevant stakeholders?
- When will statistics of PWA be updated?
- Will the review of the Persons with Disabilities Act address PWA issues?

19. Recommendations to the Government of Tanzania

Right to life

- Sensitize communities on raising alarm and immediately reporting attacks against PWA to the police.
- Ensure whistleblowers of such violence with security and anonymity.
- Include as beneficiaries in the Tanzania Social Action Fund (TASAF), PWA who formerly resided in temporary protection shelters.

Freedom from Discrimination

- Conduct nationwide public awareness raising campaign particularly in Southern Regions.

Right to Access Health Care

- Subsidize costs for accessing optometry, skin cancer prevention and treatment services for PWA, and train more dermatologists and optometrists.
- Train nurses and midwives on albinism on counseling parents at birth of babies with albinism. This will reduce chances of rejection and abandonment of such mothers and their babies.

Right to Education

- Expressly allocate funds for providing assistive devices to students with albinism particularly the unaffordable ones like eye glasses and magnifying lenses.
- Endorse and disseminate the revised draft guidelines for teachers and educators of children with albinism that were developed by CSOs in collaboration with the government.

Access to Justice

- Conduct thorough investigation of attacks against people with albinism.
- Provide victims of attacks and their dependents with full medical care for injuries sustained, psychiatric counseling, monetary compensation and, reallocation to safer areas of residence where necessary.

Legislative, Policy and Administrative Measures

- Endorse the draft national action plan on PWA developed in consultation with CSOs.
- Review the draft Person with Disabilities Act to expressly include issues of PWA in consultation and cooperation with relevant stakeholders.
- Collect accurate population and needs assessment data on PWA make the data easily available to stakeholders.

- Continue cooperating 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.

ⁱ 2012 Population and Housing Census: Disability Mimeograph, at page 12,

https://www.nbs.go.tz/nbs/takwimu/census2012/DISABILITY_MONOGRAPH.zip

ⁱⁱ European Commission, “Protecting people with albinism in Tanzania”, July 2020 https://ec.europa.eu/international-partnerships/stories/protecting-people-albinism-tanzania_en

ⁱⁱⁱ Under The Same Sun, <https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf> , 2020.

^{iv} In the case of LimiLuchoma (case no. MTO/1IR/76/2015)7.

^v The Local Government Finance Act, CAP 290, R.E 2019, at Section 37A.

^{vi} Tanzania Albinism Society.

^{vii} UTSS <https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf> 2020.

^{viii} Source: UTSS resource person in Mbeya; Wanging’ombe Social Welfare Officer (SWO); Igula Village Executive Officer (VEO); Wanging’ombe District Development Director (DED); the deceased’s mother; the deceased’s brother; and Wanging’ombe OCD.

^{ix} Source: the child’s father, the child’s mother, Village Executive Officer Mhongolo, SWO Kahama District, and TAS Chairman Kahama District.

^x Source: A journalist who reported the abduction in the Tanzania Daima Newspaper on March 30, 2018; the victim’s mother; village Chairperson.

^{xi} Source: UTSS interviews with the victim in hospital, as well as hospital staff, police and investigating the scene of the attack.

^{xii} Source: Information gathered by UTSS in January 2020 during a team visit to the woman’s home.

^{xiii} Tanzania Albinism Society, “The 2019 Baseline Survey on Socio-economic Status on Persons with Albinism and their Households in the Lake Zone, December 2019, at page 143 & 144.

^{xiv} Tanzania Albinism Society.

^{xv} Note i, at para 54.

^{xvi} Tanzania Albinism Society, “The 2019 Baseline Survey on Socio-economic Status on Persons with Albinism and their Households in the Lake Zone, December 2019, at page 129.

^{xvii} Tanzania Albinism Society and Under the Same Sun.

^{xviii} Mrs. BHM, the child’s teacher at her current school. Info received through UTSS toll-free hotline.

^{xix} UTSS interview with C.V.M (the victim) – Kazima Secondary School, Wanging’ombe District Development Director (DED), and Victim’s mother.

^{xx} See UNCRPD communications CRPD/C/18/D/22/2014, CRPD/C/20/D/23/2014 and CRPD/C/22/D/24/2014