NGO REPORT of UNDER THE SAME SUN (UTSS)

Children with Albinism: Violence & Displacement

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ABBREVIATIONS

Centre(s):	See under "THS"
PWA:	Person(s) with Albinism. This is preferred to "albino" because it puts the person before his condition and does not equate him to it. "PWA" will be used throughout this report.
Shelter(s):	See under "THS"
THS:	Temporary Holding Shelters or simply "Shelter(s)." This is the phrase that has been used in some UN documents. In UTSS' previous publications we have also referred to the same with the phrase: Centers for the Internally Displaced Persons or simply "centres." Therefore, in this paper, the use of any of "THS," "shelter(s)" or "centre(s)" refers to the same thing: a place where children with albinism have been kept or have fled in the wake of attacks against them.
UTSS:	Under The Same Sun

Executive Summary

Albinism in humans is the absence of melanin or colour in any or all of the person's skin, hair and eyes. It is a world-wide genetic trait affecting all races and genders. It results in the birth of a child whose appearance is markedly pale (mostly white) compared to both parents.

In countries where the general population has dark-coloured skin, hair and eyes, PWA stand out making them easy targets of taunts, discrimination and dangerous myths.

In Tanzania and several parts of Africa, some of these myths are fatal. For example, the myth that the body parts of a PWA can, when mixed in witchcraft potions, lead to wealth, goodluck and other desirables for the end-user. Since 2007, belief in these myths has resulted in 72 documented deaths in Tanzania, and 49 survivors including victims of mutilation. Tanzania disproportionally represents over half of all 310 attacks we have recorded in 23 countries of the Africa region. Children are the majority of victims targeted and killed with roughly two-thirds of recorded murders being children. Body parts of persons with albinism trade on the black market for thousands of US dollars.[1]

Since 2012, the number of recorded killings in Tanzania seems to be on a decline. Celebration of this fact is pre-mature because attacks continue and Tanzania continues to face serious challenges in bringing safety and security to children with albinism. One key challenge, and the subject of this report, is the issue of displaced children with albinism. There are hundreds of displaced persons with albinism in Tanzania. Due to the fact that most victims of attacks are children, those who fled their homes are also mostly children.

In an attempt to protect the fleeing children and adults with albinism, the government designated certain schools as temporary holding shelters. These shelters are mostly government-run, with a few run by faith-based organizations. They were originally designed for various persons with disabilities and other special needs but have since 2007-2008, been forced to take in hundreds of children with albinism for which they were never designed and for whom they have no capacity.

The addition of children with albinism at these shelters (some as young as age 2) has caused great distress to both the original residents and also the children with albinism. Findings of the UNICEF and UTSS study of 9 shelters (see table 3) revealed appalling living conditions including gross overcrowding, health problems including disease and serious skin cancer stages visible on the children with albinism. Also there is remarkable absence of education of useful quality or one that

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[1] International Federation of Red Cross and Red Crescent Societies, (2009), *Through Albino Eyes. The Plight of albino people in Africa's Great Lakes region and a Red Cross Response, Advocacy Report,* accessed, April 6, 2014, https://www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf, at page 5 ["Red Cross Report"].

accommodates the visual disability of the children with albinism. Children with albinism are also verbally threatened and face physical and sexual abuse. Further, psychological disturbance is also visible in some children with albinism particularly those who were dumped by their parents and also those who were victims of attacks or witnessed attacks on family members with albinism. These findings of the UNICEF/UTSS study was presented to the government of Tanzania but no steps were taken to improve the conditions at these shelters.

Children with albinism have been at these shelters for nearly 7 years with little or no plan to improve their condition. Further, there is no plan of safe reunification with their families (for those who still have family ties), neither is there a plan of safe exit for those who have been abandoned there.

The shelters are not in the best interest of the children with albinism. They have effectively multiplied the human rights violations they face and will continue to do so as long as nothing is done to address the situation.

Methodology

This report is written based on:

Extensive research on the lives of PWA in Tanzania: This is conducted by our office which is based in Dar es Salaam, and Mwanza, Tanzania. We have a First Response Team that is dispatched immediately after we are informed about an attack or attempted attack against a person with albinism. Our team visits the site of the attack to interview the victim and his or her family, document their account of what happened, photograph evidence; provide support which may include medical, psychosocial and financial support to enable relocation, feeding and other social support.

The UNICEF/UTSS Study and Resulting Reports

Concerning the situation of displaced children with albinism, we have conducted an in-depth assessment of the circumstances surrounding them at 9 temporary holding shelters (shelters studied are listed at table 3 below). That assessment was done in tandem with UNICEF and experienced researchers in the field of albinism, special needs and early childhood development. The assessment resulted in two reports that provided a general overview of the situation and evidence of sexual abuse faced by these children respectively.

The resulting reports are:

- UNICEF/UTSS, *Sexual Abuse Cases Reported in Assessed Schools and Centres Hosting Internally Displaced Children with Albinism and Other Children with Disabilities,* A Report to the Ministry of Education and Vocational Training (MoEVT), May 26, 2011.

- UNICEF/UTSS, Situation Assessment of the Centres of Displaced Persons with Albinism in the Lake Zone and Tanga Regions: Findings From Under The Same Survey, 2011, October 2012.

Both of these studies are available at: http://www.underthesamesun.com/resources

Continued research on the lives of Displaced Children in Tanzania: We have visited shelters holding hundreds of displaced persons with albinism across the country. We were not only involved in the UNICEF/UTSS assessment of 9 shelters but have since discovered others (see table 4 below). We have also conducted extensive interviews with the over 300 persons with albinism – mostly children – who we have placed in our education scholarship program. Nearly all children in this program are from the centres holding displaced children. In light of government inaction, we expanded our scholarship program to help the situation as much as possible. However an NGO can only do so much and the responsibility remains and rests on Tanzania to respond to the hundreds that remain at these shelters.

Limitations

Since the UNICEF/UTSS reports in 2011 and 2012, no other comprehensive study has been undertaken on the situation of displaced children with albinism. That said, we have kept contact with some of the temporary holding shelters and have visited some of them in the course of our work. Aside from some improvements of space at one centre in the region of Mwanza: Mitindo primary school and plans to do the same at one centre in the region of Shinyanga: Buhangija centre, the problems identified in the UNICEF/UTSS reports have not been addressed. Children with albinism still remain at these shelters with no plan for human rights protection or a strategy to ensure that they can return home safely.

REPORT AT A GLANCE

PART I:

Albinism in Tanzania

PART II:

Substance of Report: DISPLACED CHILDREN

PART I: Albinism in Tanzania

What is Albinism?

- Albinism is a rare, non-contagious, genetically inherited condition occurring in both genders regardless of ethnicity, in all countries of the world. Both the father and mother must carry the gene for it to be passed on even if they do not have albinism themselves.
- The condition results in a lack of pigmentation in the skin, hair and eyes, causing vulnerability to sun exposure and bright light.
- Skin cancer is common amongst a majority of persons with albinism living in Tanzania. For example in the Dar es Salaam area where infrastructure is better, only 10% will live to age 30 and 2% past the age of 40 from this treatable and preventable disease.[2]
- Almost all persons with albinism are visually impaired, with the majority being classified as "legally blind."
- While numbers vary in North America and Europe it is estimated that 1 in every 17,000 people have some form of albinism.
- In Tanzania, and throughout East Africa, albinism is much more prevalent, with estimates of 1 in 2,000 people being affected.
- There are various types of albinism including:

    - **Albinism affecting the skin, hair, and eyes or oculocutaenous albinism (OCA):** This is the most common form of albinism in sub Saharan Africa and leaves its subject particularly noticeable and vulnerable in a country like Tanzania where nearly all persons have dark skin.

    - ***Albinism affecting the eyes***. This is called Ocular albinism (OA), and is relatively un-common. Most cases are recorded in males. Children with OA may have skin and hair colour that are normal but slightly lighter than those of other family members.

    - ***Albinism with HPS:*** Researchers have also identified a type of albinism that comes with additional characteristics. One of these is known as *Hermansky-Pudlak* Syndrome (HPS). In addition to having albinism, persons with HPS also have a tendency to bleed and a tendency to have lung disease. HPS is rare and we have no records of it in Tanzania so far.

- The term "person with albinism" (PWA) is generally preferred to the term "albino" because the former puts the person before the condition rather than equate him to it.

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[2] Preliminary Report of the United Nations High Commissioner for Human Rights, Persons with Albinism, 12 September 2013, available *at* www.ohchr.org ["UN Preliminary Report"], at para 12. Also see Cruz-Inigo, A., Ladizinski, B., Sethi, A., Albinism in Africa: Stigma, Slaughter and Awareness Campaigns, Dermatol Clin 29 (2011) 79–87.

Albinism Worldwide

Albinism is a non-contagious genetic condition occurring in all countries of the world. BOTH the father and mother must carry the gene for it to be passed on. Albinism is a lack of pigmentation in the hair, skin and eyes, resulting in low vision as well as vulnerability to sun exposure and bright light.

Image 1: Albinism Worldwide

Aspects of Albinism

The condition of albinism has several facets that expose persons living with it to multiple and intersecting forms of discrimination particularly in Tanzania. These include:

- **The visual aspect or "legal blindness:"** Due to the fact that melanin is critical to the normal development and health of the eyes, persons with albinism, due to their reduced amount of pigmentation suffer from multiple eye defects. These include photophobia, foveal hypoplasia, nystagmus amongst others. The practical effect of this is that most persons with albinism are myopic and have, generally speaking, only 20% of normal visual levels. This means that most persons with albinism are classifiable as persons with disabilities (legally blind) and are in need of reasonable accommodation in school, without which most drop out of school in Tanzania.

- **Skin cancer which kills most PWA in Tanzania by age 40**. The absence of melanin in the skin causes PWA to be exceptionally vulnerable to sun exposure. They need basic health education on how to protect themselves whether it is by using sunscreen - which is not affordable to most of them – or by wearing sun protective clothing. Without such education, most PWA die slowly from advanced skin cancer which they often get by working as petty traders in the sun after they failed to receive an education due to lack of accommodation for their visual impairment.

- **The colour issue:** This is one of the most dangerous aspects of albinism in Tanzania. PWA are easily noticed in a sea of dark-skinned persons and are unable to conceal this immutable aspect even if they tried. Their colouring is the crux of all myths against them and the reason why witchdoctors are hunting them to harvest their body parts in certain countries such as Tanzania.

Albinism in Tanzania

Image 2: Albinism in Tanzania

Left and right: 2 girls with albinism in Tanzania. The girl on the right is a survivor of attack (right arm mutilated)

A mother and her child with albinism in Tanzania

Prevailing and dangerous Myths

In Tanzania, there are several dangerous myths about albinism. These include the belief that body parts of PWA can bring wealth and good luck when ground into witchcraft potions; that they do not die but disappear; and that PWA are not human beings but ghosts.

PREVAILING MYTHS AND TRUTHS ADVOCATED BY UTSS AND OTHER HUMAN RIGHTS DEFENDERS OF PERSONS WITH ALBINISM
MYTH: Albinism is a curse from the gods or from dead ancestors. As a result, contact with a PWA will bring bad luck, sickness or even death
TRUTH: Albinism is no more or less than a genetic condition of the human body. As such, there is nothing magical or supernatural about it. You cannot "catch" albinism – it is not a disease and it is not contagious
MYTH: People with albinism never die. They are not human - they are ghosts
TRUTH: The on-going killings in Tanzania demonstrate that PWA do die. They are NOT ghosts. Their pale skin and hair results from having very little of the substance responsible for colour known as melanin
MYTH: It is the mother's fault if a child has albinism
TRUTH: Both the mother and father must carry the gene in order for their child to have albinism
MYTH: Having sex with a woman with albinism will cure AIDS
TRUTH: No one can or has ever been cured of AIDS by having sex with a woman with albinism. Belief in this myth will only further spread the virus to others including PWA
MYTH: PWA have normal vision
TRUTH: All PWA are visually impaired to various degrees AND have a very high sensitivity to light (due to the lack of melanin). When outdoors, PWA need to wear sunglasses to protect their eyes from the sun. Many PWA are legally blind and all require special glasses or magnifiers to aid in reading and daily functioning
MYTH: A charm or potion made from the body parts of PWA has magical powers – bringing its owners wealth, success and good luck
TRUTH: No one can or has ever become rich, successful or lucky from having or using body parts of PWA
MYTH: PWA come from and live only in Tanzania
TRUTH: Albinism occurs in every race and nationality of planet earth

Table 1: Prevailing Myths against Persons with Albinism in Tanzania

These myths have formed the basis of a cultural attitude of stigma and discrimination against PWA and ultimately spurred stacks against them in Tanzania.[3]

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[3] See joint press statement issued on 4 May 2013, "Not ghosts, but human beings … persons with albinism," accessed February 15, 2014,

Attacks against PWA in Tanzania

Tanzania has the highest number of reported attacks in the region:

Country	Killed	Survivors*	Grave Robbery & others**	**TOTAL**	Most recent record
Benin	2			**2**	2012
Botswana		3		**3**	September 1998
Burkina Faso	2	6	1	**9**	August 14, 2012
Burundi	17	7	4	**28**	October 21, 2013
Cameroon	2	1	4	**7**	August 2013
Democratic Republic of Congo	7	16	4	**27**	December 2013
Egypt			1	**1**	September 16, 2011
Ghana		1		**1**	July 16, 2009
Guinea	2	4	3	**9**	June 4, 2013
Ivory Coast	6	9	6	**21**	May 30, 2013
Kenya	4	8		**12**	March 15, 2013
Malawi		2	1	**3**	July 2, 2013
Mali	2	2	4	**8**	2011
Mozambique		1	1	**2**	July 29, 2009
Namibia	1	1		**2**	May 12, 2012
Nigeria	4		4	**7**	April 2013
Rwanda			1	**1**	July 2, 2013
Senegal	3	3	1	**7**	2011
South Africa	1	1	2	**4**	February 22, 2013
Swaziland	2	7		**9**	September 2, 2013
Tanzania	72	49	18	**139**	December 15, 2013
Zambia	1			**1**	December 2011
Zimbabwe	1		1	**2**	November 29, 2012

TOTAL ATTACKS RECORDED IN AFRICA: 310
Countries affected: 23
*Includes mutilated persons and those who narrowly escaped an attack
**Also includes missing persons and successful asylum cases

Table 2: Record of Attacks

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www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E. ["Joint Press Release by UN Rapporteurs"].

The above are documented cases only. We believe, through our work at the UTSS, that historically and currently, there have been hundreds of witchcraft murders of persons with albinism in Tanzania. (This would explain the prevalent myth that PWA do not die but disappear.) Most attacks against person with albinism go unreported due to the `code of silence` and overall secretive nature of witchcraft.[4]

Also, most attacks go unreported because the body parts of PWA are sold on a black market for thousands of dollars. Specifically, a limb can be sold for thousands of US dollars and a "complete set" of organs and body parts goes for upwards of $75,000.[5] In a country where the average annual income (using GDP per capita) is roughly $2,000 US dollars per year, the only people that can afford such prices are likely the rich elite who are also better placed to bribe people into silence.[6]

A Majority of Attack Victims Are Children

Children constitute nearly 70% of all recorded attacks against persons with albinism in Tanzania. The disproportionate representation of children amongst victims is likely because:

(1) **Children are more vulnerable:** Children are easier to find and relatively easy to capture because they are often left to play outside un-supervised. Moreover, they are not always cared for by their parents because they have albinism, and do not always have the strength to physically fend off attackers.

(2) **Witchcraft values "innocence":** The use of children is also likely linked to the pursuit of their innocence. An innocent victim is generally deemed more potent in producing the intended witchcraft result. A similar use of innocence is evident in non-albinism witchcraft practices in the region.[7]

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[4] "Code of silence" is from Simon Fellows, *"Trafficking Body Parts in Mozambique and South Africa (2008),"* Human Rights League, Mozambique, http://www.scribd.com/doc/23729111/Trafficking-Body-Parts-in-Mozambique-and-South-Africa-Mozambique-Human-Rights-League , accessed August 3, 2010.

[5] Red Cross Report, at note 1

[6] Facts on GDP is from CIA World FactBook, accessed April 7, 2014, https://www.cia.gov/library/publications/the-world-factbook/geos/tz.html. On the strong likelihood of the involvement of the rich in the economy of attacks against persons with albinism, see orbiter dicta comments in *Masumbuko et al v. Tanzania* (United Republic of), Criminal Appeal No. 318, 319 & 320 of 2009 (23rd September, 2009) per Ramadhani C.J., at p.23 (second to last paragraph).

[7] UN preliminary Report, note 2 at para 21.

Government Response to the Attacks

Temporary Holding Shelters ("Shelters" or "THS")

The initial response of several (mostly local) government officials to the widespread attacks against persons with albinism, particularly children, was to move these victims into temporary holding shelters (THS). At these shelters, - discussed below – the children with albinism are further abused and made worse off than their initial positions. This report, as it will show, is a cry for help for the children who have virtually been abandoned at these shelters. They are the lost group in the cheer about an apparent reduction in records of attacks against persons with albinism in Tanzania. It is noteworthy that Tanzania does not adequately discuss this issue in its report.

Tanzania`s State Party Report: OUR RESPONSE

On the issue of albinism, the most comprehensive statement made by Tanzania in its State Party report is as follows (at paragraph 119):[8]

> Towards this end, the result of Tanzania survey provide sound and validated evidence to inform the development of guidelines and regulations associated with implementation of the Law of the Child Act. In addition, *the campaign on violence against women, children and people with albinism was conducted throughout the country with the support of Mobile Cinema, TV and Radio Programmes and community sensitization. Similarly, those who were involved in the killings were sued and some were accordingly sentenced. As a result, at a short period of time the act of killing albino was minimized to a large extent. Furthermore, a boarding school specific for albino children has been established in Misungwi District to provide safer and friendly environment for children with albinism to study.*
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> [Italics /Emphasis Added]

Our Response

1. **No evidence of the stated campaign**. We have not seen any government led public awareness campaign on albinism. We call on Tanzania to provide specific examples of the stated campaigns.

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[8] Tanzania's 3rd, 4th & 5th Reports on the Implementation of the Convention on the Rights of the Child (CRC) 2005 – 2011. Submitted to the United Nations Committee on the Rights of the Child by Ministry of Community Development, Gender and Children (Mainland) and Ministry of Social Welfare, Youth, Women and Children Development (Zanzibar), January 2012, ["State Party Report"].

Public awareness in Tanzania has been largely executed by NGOs. For example, UTSS has initiated, organized and conducted public awareness in schools, communities, government departments and at faith-based institutions via electronic, print media and interactive seminars.

Tanzania needs to actively take ownership of this project or provide support to NGOs that are struggling to provide the same but have limited means.

2. **Impunity remains:** there are only 5 known convictions out of 139 attacks – including murders, mutilations, and grave robberies.[9]

   In Tanzania, the state prosecutes and therefore the victims rely heavily on the state to bring their matter forward. However, in Tanzania, the state has, case after case, failed to do so and in some cases attempted to do so without preparing the surviving victims to testify or informing him or her of the process.

   Prosecution in Tanzania is also dogged by the secret nature of witchcraft such that witnesses refuse to give evidence in court due to fear of reprisal from witchdoctors and other witchcraft practitioners and consumers.

   Further, incidents of government and police corruption have been reported. Local Tanzanian media have reported that some members of the Tanzanian police and other government officials have been involved in the trafficking of human body parts from those with albinism and have benefited financially from the proceeds of this grisly crime.

   Law enforcement and legal officers are largely ignorant and unaware about the genetic condition of albinism because they have been raised in a culture where they believe PWA are ghosts, that they do not die but simply vanish; that they are substandard, unequal human beings who are considered bad luck or insignificant. Take for example the case of Mariam Stafford, a victim that lost both arms in an attack. Mariam`s testimony that she saw and heard her perpetrator and that she could identify him was dismissed on the grounds that a person with albinism could not see well. While true, a person with albinism can see enough in certain conditions to accurately identify a victim. Particularly one that was known to her in the past as was the case here.

3. **Skin Cancer Treatment is Inaccessible to Most PWA**: There are 3 hospitals designated by government where PWA could get medical services such as chemotherapy and liquid nitrogen treatment for skin cancer. Still PWA have to incur significant transport and accommodation costs while visiting these hospitals in Dar es Salaam and Moshi. As a result PWA still die at epidemic rates from skin cancer when they ought not to.

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[9] Details available via UTSS

4. **Local Sunscreen Production:** The government needs to support projects such as local sunscreen production. UTSS and other NGO have committed themselves financially for production of sun cream locally in Tanzania – the first of its kind. The resulting cream, called **KiliSun** is distributed to several communities in eastern, north-western and north-eastern Tanzania

   The project needs the support of government as soon as possible if it is to be sustained. We wish to remind Tanzania that it is the responsibility of the government to care for its citizens with albinism and reliance on NGOs is inadequate and not sustainable.

5. **Misungwi District Boarding School**

   Tanzania states that this boarding school is specifically for children with albinism and provides a safe and friendly environment for them to study.

   The boarding school to which they refer is Mtindo Primary School in Misungwi District (``Mitindo``). Mitindo does not do what has been claimed.

   Mitindo boarding school became a government designated centre for persons with albinism since 2007 when the reports about the killings of persons with albinism became common. Mitindo quickly became overcrowded with appalling conditions. With the help of donors, the government has constructed additional buildings including extra washrooms, dormitories and a computer laboratory. Yet, the school has a shortage of desks, teachers, including special needs education teachers, additional matron and caregivers, teachers' tables, dining room tables and chairs, desks, recreation room and facilities. Aside from these materials, there is a lack of understanding about albinism and the systemic discrimination and abuse faced by the children.

   Some NGOs have helped to improve it – but only slightly and there is much left to be done. UTSS did its part by taking 66 students out of there and placing them on its education scholarship program. We had initially aimed to take only 50 children for primary school education level from the Lake Zone but tripled that number due to the dire straits that the children in shelters such as Mitindo face.[10] Mitindo remains a cry for help from the government of Tanzania.

   Further, the idea of presenting Mitindo as a successful way of handling children with albinism (paragraph 119 of State Party Report) directly contradicts

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[10] When we started taking displaced children into our education scholarship programme in April 2010, we had allocated only 50 places for the lower education level. But because of overcrowding in all the 9 shelters studied as well as requests from parents who were fleeing their villages to save their children from the atrocities, we were forced to increase that number to 150. This included 66 from Mitindo, and others (see shelters at Table 3), namely Buhangija, Bukumbi, Mugeza, Pongwe and the rest from their home villages and police stations where they were kept for their safety.

Tanzania's later statement in the same report that it is committed to integrating children with disabilities and not institutionalizing them.[11]

Displaced Children: The killings against PWA may have reduced but its effects, including the displacement of hundreds of children with the condition remains unaddressed. (The issue of these displaced children is taken up below).

Good Practices & Points for Commendation

Tanzania in tandem with some civil society groups have taken up the issue of PWA at some limited but commendable levels. These include the following:

- **Adoption of a GUIDE Concerning Reasonable Accommodation of Persons with Albinism**: In 2013, in conjunction with civil society such as our NGO, UTSS, the Ministry of Education and Vocational Training adopted a Guide for the care and reasonable accommodation of children with albinism in schools. This Guide, largely written by UTSS, gives direction and illustrations on how to care for a person with albinism. It is aimed at teachers, parents and caregivers. It was adopted into the curricula of teachers in training and has been distributed to all relevant medical and educational institutions. We look forward to its implementation.

- **Appointed a member of parliament with albinism**: In 2008, the president of Tanzania, appointed a member of parliament, Hon Alshaymaa Kwegyir who is still active in that body. Ms. Kwegyir has come to symbolize what Tanzania wishes to show to the world concerning its relationship with persons with albinism. While Ms. Kwegyir is a symbolical improvement, she remains a government appointee and hence limited in the amount of practical change she can advocate for on-behalf of persons with albinism.

- **Appointment of one person with albinism in the constitution review process**: It appears that in its on-going constitutional review, Tanzania has involved at least one person with albinism from the Tanzania Albino Society to represent the views of persons with albinism in the process.

- **A Reduction in Number of Reported Attacks:** This is perhaps the most important step that we see in Tanzania. Although this victory is greatly attributable to the agitation of civil society groups at the national and international level, it is also commendable that some high ranking government officials, particularly the Prime Minister, Mr. Peter Pinda, spoke on the issue on several occasions. That said, we remain concerned that due to the secretive nature of witchcraft, some ongoing attacks may remain

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[11] Paragraph 203 of State Party Report, at note 8.

unreported. However we are erring on the side of hope that the reduction in reported attacks is a true reflection of the situation.

PART II: SUBSTANCE OF NGO REPORT

Displaced Children

Introduction

Since 2007, hundreds of children with albinism fled their homes in Tanzania in the wake of attacks against them. The genetic condition of albinism had left them visible and vulnerable to attacks by witchdoctors peddling the myth that their body parts can bring wealth and good luck when mixed into potions. Indeed out of 139 attacks recorded in Tanzania to date, a majority are children.

Today, while recorded attacks seem to be on the decline in Tanzania, the issue of children who have been displaced due to the attack and are currently living in temporary holding shelters is rarely discussed.

What are the Temporary Holding Shelters? (THS or “Shelter(s)”)

Shelters are mostly boarding schools, most located in the Lake Zone region of north-western Tanzania. They are a mixture of government-owned and faith based organizations designated by government for children with various disabilities or conditions warranting some level of special care.

These shelters were not designed to absorb hundreds of children with albinism fleeing their homes. However this is what they have done in the past 6 years and continue to do. The situation is now untenable at most of these shelters particularly for children with albinism, some of whom are as young as 2 years old.

Children at the shelters were placed there either by government officials or by their families in the wake of attacks against persons with albinism in the country and the simultaneous absence of adequate protection for them at their homes.

Image 3: Location of known centres holding displaced children with albinism in Tanzania as of 2014 (indicated with black stars).

Table 3: 9 Shelters Studied by UNICEF/UTSS (2011-2012)

	2011-2012	
Centres (across 6 Regions)*	**CWA Interviewed**	**Total No. of Students including PWA**
Buhangija	121	775
Kabanga	73	724
Mugeza	74	549
Pongwe	32	864
Furaha	49	92
Mitindo	99	1,147
Kitengule	52	256
Bukumbi	10	356
Missionaries of Charity	20	134

**These are from the following regions: Kagera, Kigoma, Mwanza, Shinyanga, Tabora & Tanga*

The UNICEF/UTSS reports generated from this study, listed below, were submitted to the Ministry of Education and Vocational Training, the Ministry of Health and Social Welfare and the Prime Minister's Office, Regional Authority and Local Government. That said, no recommendation arising from the study has been comprehensively applied or implemented by the government.

- UNICEF/UTSS, *Sexual Abuse Cases Reported in Assessed Schools and Centres Hosting Internally Displaced Children with Albinism and Other Children with Disabilities,* A Report to the Ministry of Education and Vocational Training (MoEVT), May 26, 2011.

- UNICEF/UTSS, Situation Assessment of the Centres of Displaced Persons with Albinism in the Lake Zone and Tanga Regions: Findings From Under The Same Survey, 2011, October 2012.

Table 4: 23 More Shelters Discovered since the UNICEF/UTSS report[12]

- These 23 more shelters discovered are listed as follows (**without highlights**)
- The 9 highlighted are the ones that were studied by the UNICEF/UTSS
- TOTAL known shelters = 32

N0	School	District	Region
1	Makalala	Mafinga	Iringa
2	Mugeza Mseto	Bukoba Rural	Kagera
3	Furaha	Tabora Urban	Tabora
4	Kizega	Kiomboi	Singida
5	Kateshi	Hanang	Manyara
6	Longido	Longido	Arusha
7	Buigiri	Dodoma	Dodoma
8	Ikungi	Ikungi	Singida
9	Uhuru Mchanganyiko	Ilala	Dar es Salaam
10	Buhangija	Shinyanga Urban	Shinyanga
11	Kabanga	Kasulu	Kigoma
12	Luhila	Songea	Ruvuma
13	Malangali	Sumbawanga	Rukwa
14	Mwisenge	Musoma	Mara
15	Maziyungu	Kilosa	Morogoro
16	Masasi	Masasi	Mtwara
17	Hombolo	Dodoma Rural	Dodoma
18	Irente	Lushoto	Tanga
19	Pongwe	Tanga	Tanga
20	Mitindo	Misungwi	Mwanza
21	Same	Same	Kilimanjaro
22	Katumba II	Tukuyu	Mbeya
23	Azimio	Mpanda	Katavi
24	Nyangao	Lindi	Lindi
25	Mwaya	Kilolo	Iringa
26	Ilembula	Wanging'ombe	Njombe
27	Patandi	Arusha	Arusha
29	Nengo	Kibondo	Kigoma
30	Kitengule	Karagwe	Mugeza
31	Bukumbi	Misungwi	Mwanza
32	Missionaries of Charity	Tabora	Tabora

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[12] This list was obtained from the Ministry of Education and Vocational Training. Letter from MoEVT available upon request from UTSS.

Child Rights Violations at the Shelters

The conditions at these shelters have created an avenue for gross human rights abuse of the children with albinism who reside there. These violations as they relate to the rights of children under the UN *Convention on the Rights of a Child* are detailed below under thematic clusters.

CLUSTER: Violence against Children

- **abuse and neglect, including physical and psychological recovery and social reintegration (arts. 19 and 39)**
- **right not to be subjected to torture or other cruel, inhuman or degrading treatment or punishment, including corporal punishment (arts. 37(a) and 28(2))**

Governmental Neglect: The shelters are not temporary

The THS are not "temporary" as they were originally intended. Since 2007, these shelters have become de facto long-term holding places for children with albinism who are unable or unwilling to return home for fear that it is still not safe for them to do so. The government has no plan of safe exit for these children including:

- Ensuring that the children with albinism are returned to their home safely
- Ensuring that their homes are in fact safe
- Providing adequate facilities and care while the children with albinism are at the shelters

Security Risk

These shelters are not particularly safe for children with albinism. While there have been no record of murders and mutilations at these centres, no one is monitoring them comprehensively – and therefore it cannot be said conclusively that the children are safe. Moreover, when one considers attacks to include physical and sexual violence, then these children are far from safe as discovered by the UNICEF/UTSS study.

Further, security infrastructure and staff are weak and ill-equipped. There are weak doors, no locks, lighting and un-trained guards. The absence of potable water on-site also means that children with albinism often have to go long distances through bushes to find water without security. Sometimes they are sent on errands by staff without due regard to their security. The insecurity at these centres is made worse by overcrowding and mixed ages of residents including a mixture of adults and children at several shelters.

Separation of Children With Albinism From Their Families.

The shelters have become dumping grounds for parents who wish to rid themselves of the difficulty of raising a child with albinism**.** In a society where children with albinism are already seen as a curse, bad luck, a "ghost and not human," the opportunity to legitimately abandon a child with albinism is very attractive.[13] Most of the children with albinism at these centres are effectively dumped or abandoned there by family and other relatives. They are not visited and in a significant number of cases, the children have not seen their parents since they were left there. What is worse is the inaccessibility of these centres including the terrible road conditions which in addition to the remote locations of most of these centres facilitates the separation of children from their families.

Institutionalization

Tanzania's new law on disability: *Persons with Disabilities Act* (2010) provides that every person with disability ought to be assisted by his local government authority, relatives, disability organisations, civil society or any other person to live as independently as possible and be integrated in the community. It also provides that a person with disability is <u>not forced</u> to live in an institution or in a particular living arrangement <u>including settlement for persons in need of special protection.</u>[14]

Yet, children with albinism have been forced, due to circumstances of attacks, to live in these institutionalized settings that are likely to compound the challenges they face. As aptly stated by a CRPD researcher in the Africa region:

> Children who …may themselves have disabling illnesses, …are… at a high risk of <u>acquiring newly disabling conditions</u> when they are housed in congregate settings with <u>sub-standard care and limited stimulation."</u>[15]

Given the history of these children, some of whom are survivors of attacks or witnessed attacks against their siblings and relatives, they have arrived at the centres already scarred and traumatized by fear. Unfortunately for them, and as discovered by the UNICEF/UTSS study, the children at these shelters are further subject to various forms of abuse: physical, psychological and sexual. This, in addition to the fact that the shelter provides sub-standard care and limited stimulation meaning that the children are more likely to be worse off than when they first arrived at the shelters. It also means that they ought to be de-institutionalized as quickly and as safely as possible to mitigate the damage done, support independent living, and facilitate societal integration as best as possible.

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[13] See press release: "Not Ghost but Humans,"

[14] Underlining eemphasis Added. Act accessed on April 3, 2014, http://www.tanzania.go.tz/egov_uploads/documents/The_Persons_with_Disabilities_Act,_2010_%28Act_No_sw.pdf.

[15] Janet Lord and Michael Ashley Stein, "Prospects and Practices for CRPD Implementation in Africa.

Physical Abuse

The UNICEF/UTSS study found that corporeal punishment was a norm at these shelters. Nearly all children with albinism are physically punished mostly through flogging. Oftentimes the punishments, the children report, were baseless and without rationale. This punishment also includes keeping them outside in the sun which is life-threatening to them. The children are exposed to the sun without protection – neither sun cream nor the more accessible sun-protection was given to them.

Verbal Abuse and Threats

Nearly all children with albinism reported verbal abuse and threats of a kind that is particular to them. These included statements such as:

- "[They] will take us to our village to be slaughtered."
- "Do this ….otherwise, we will return you to your village for attack."

The gravity of such normalized threats should not be underestimated where, as in this case, the children are meant to feel safer than at their homes. Further, such statements are traumatic on survivors of and witnesses of attacks who are also residents at these shelters.

Psychological Disturbance

There is evidence of psychological disturbance in some of the children with albinism at these centres. These include persistent rocking in the seating position back and forth, not speaking, inability to walk in children past the walking age, grieving from children who witnessed attacks or survived them. There is no psychosocial support for the mental state of these children with albinism. Rather they are left to cope with their mental health on their own in an environment that is likely to make it worse.

Gross over-crowding[16]

The THS were not designed to accommodate the current numbers of children with albinism. Some were designed for one quarter of their current numbers. This means the infrastructure and amenities needed are not present and this seriously contributes to the issue of security because overcrowding reduces the control of staff at the shelters. It also contributes to the spread of other diseases to which children with albinism who already – in most cases, have certain stages of skin cancer - become more vulnerable.

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[16] The problem of overcrowding is particular only to those 9 centres studied in the UNICEF/UTSS report and identified at Table 3. Fortunately, this also means that the problem of overcrowding may be easily dealt with since it is not in a majority of the cases.

Image 5: Overcrowding

Tents provided by the Red Cross in collaboration with UTSS to combat overcrowding at Buhangija School, Shinyanga Tanzania

Understaffing

The quality and quantity of staff at the THS are directly correlated to the health and well-being of children with albinism living there. The lack of staff in terms of numbers (a quantitative issue of capacity) and their lack of awareness about albinism (a qualitative issue of capacity) are foreseeably linked to well-being and preservation of life of the children with albinism. Staff at these centres are generally unaware, incapable or unwilling to take the extra steps needed to protect the children with albinism e.g. from sun damage. Most staff at the THS are overwhelmed by the level of work that the unplanned addition of children with albinism has placed on them and the lack of support - adequate wages and human resource - from officials of the state to enable them to effectively carry out their duties.

CLUSTER: Disability, basic health and welfare

- **survival and development (art. 6(2))**
- **health and health services, in particular primary health care (art. 24)**

No Primary Health Care: Re: Skin Cancer.

Melanin, the skin's natural pigment, generally protects persons from sun damage and eventual skin cancer. Without melanin, persons with albinism are particularly vulnerable to skin cancer than those with melanin. Children with albinism are particularly vulnerable in tropical or sunny climates where playing outside is the norm. Children with albinism at shelters in Tanzania are further vulnerable to sun damage and eventual skin cancer because they are without their parents or primary caregiver who should receive basic health education on their behalf. With the absence of knowledgeable staff at the shelters, skin cancer at various stages is visible on most children with albinism at these centres. Most Tanzanians believe these cancerous lesions are simply sores that are a normal part of albinism.

Even where we have gone to these centres to teach staff how to care for the skin of children with albinism, the results are rarely positive because the staff is a high turnover rate because they are over-worked, dis-incentivized and unable to cope with the number of children with albinism needing attention.

If immediate care and action is not taken on the issue, these centres will be contributing on a large scale to the rapid increase of skin cancer in the children and will rear a generation of children that will almost certainly suffer from that disease and face fatality from it if something is not done immediately.

It is not enough to claim that persons with albinism in Tanzania generally have access to skin cancer treatment in Dar es Salaam and in Moshi. Not everyone lives in or near these cities and not everyone can afford it. In fact most persons with albinism in Tanzania live in poverty not unrelated to their genetic condition. More importantly, having these skin cancer centres means nothing to the children who are at the shelters who receive no care, are under the supervision of persons who have no training on skin health, are unable to care for themselves and have no one referring them to medical practitioners who would give them life-saving cancer treatments.

Image 2: Skin Cancer

Children as young as 3 at Buhangija Shelter in Shinyanga region showing visible signs of extensive sun damage that lead to skin cancer. Some also show skin disease due to unhygienic conditions at the shelter.

Braille Forced on the Children

A number of the shelters, particularly Mitindo in Mwanza and Malangali Primary School in Rukwa, force the children with albinism to learn Braille. This is highly problematic given that a majority of children with albinism have enough residual vision to cope using large print and low vision devices. The imposition of Braille on children with albinism is also problematic because it:

- underutilizes the child with albinism' s potential such that they are barely getting sufficient education to equip them for a life that is already difficult for them;
- Ill prepares the child with albinism for integrated work in society. A child with albinism who knows only Braille and cannot visually read or write (while having sufficient vision to do so) will have difficulty finding employment. This will be an obstacle in his or her path of finding work indoors.

CLUSTER: Special Protection Measures

- **children belonging to a minority or an indigenous group (art. 30) ·**
- **sexual exploitation and sexual abuse (art. 34)**

Stigma

Nearly every child with albinism who participated in the UNICEF/UTSS study complained of stigma from everyone at their respective shelters. The stigma came from both staff and fellow students, including students with other disabilities. The prevailing attitude towards persons with albinism is that they are sub-human. Myths as well as name-calling peculiar to their condition are alive and utilized at the shelters

Sexual abuse

A separate report on sexual abuse was generated by the UNICEF/UTSS study. The report draws a graphic image of findings of various level of sexual abuse of children with albinism. A good number of these abuses are student-on-student abuse. This is a strong indicator of the incapacity of staff at the shelters to bring security, order and above all human rights protection to children with albinism.

CLUSTER: Non Discrimination and the Best Interest of the Child

- **Non Discrimination (art.2)**
- **The Temporary Holding Shelters are not in the best interests of the child (art.3)**

Discrimination facilitated by the THS:

These THS facilitate familial discrimination against children with albinism and are likely to enhance the discrimination that the children will face once they are in society at large. All the issues discussed above reflect this: namely the THS legitimately permits dumping of children with albinism who were not wanted in the first place, the children are not provided the education they need or the accommodation that they require to succeed as persons with low vision. They are also likely to develop deadly skin cancer and to emerge from the centres with more trauma than they had when they first arrived. These factors together are likely to hinder the development – in health and employment – of the PWA, which will reinforce general myth that they are of no good and are less human.

Not in the Best Interest of the Child:

While it may be argued that the THS were set up as an emergency response to the crisis of attacks against PWA, particularly children, the THS are not in the best interest of the child. The UNICEF/UTSS study revealed gross child rights violations at the THS including physical and sexual abuse detailed above.

The principle of the best interest of the child is enshrined in both Tanzania's *Law of the Child Act* and the *Zanzibar Children's Act* but are not implemented at the THS. It is not enough to claim that the THS were necessary for the protection of the children who are under attack or to protect children who have since been abandoned at the shelters. One human rights violation cannot be treated with another.

Conclusions & Recommendations

The UNICEF/UTSS studies which this report heavily relies on, made some useful recommendations to the government of Tanzania. We re-iterate them here and call upon the government of Tanzania to start taking further action on them. Support from civil society such as UTSS is readily available including a necessary consultation phase that would be needed to decipher and plan the ways to tackle this multifaceted issue.

Recommendations

Census: The government must immediately conduct a proper census on the residents at these shelters. Indeed, this is the only way to monitor the progress and welfare of the children with albinism at these centres. Census data must be stored in secure ways that prevent their usage by perpetrators of attacks. Support from international bodies such as UNICEF could be enlisted for this undertaking and safe storage.

Security: Infrastructure needs to be improved in all shelters. These include installing proper doors with locks, trained guards, installing adequate lighting and providing potable water on-site.

Expand living space: While some shelters such as Mitindo have expanded their space and some such as Buhangija are in the process of acquiring more dormitories, a large amount of work is needed at these and other shelters. This could be either relocation of children with albinism back to their families or if their security cannot be guaranteed, the immediate provision of adequate facilities for them at the current shelters. These facilities should ensure that the families of children can come and reside with them at the shelters so that the children are not severed from their much needed familial environment.

Family Reunification: The government ought to immediately enlist the services of experienced agencies such as the Red Cross, UNHCR and UNICEF in ensuring that children with albinism at these shelters are returned to their homes as soon as possible with the proper pre-assessment of their security and safety. If such pre-assessment concludes that it is not safe to return the children to their homes, then government ought to immediately facilitate regular visitation by families, expand living space at these shelters and begin to carry out other recommendations presented here.

Psychosocial: There is a need to involve trained psychologists and social workers in the well-being of children with albinism who have particularly been through the trauma of attacks. Overall support is also necessary for all children with albinism who have been forced to live at THS knowing that their body parts are being hunted for sale.

Staff Capacity Building:

Three key areas of staff capacity need to be addressed:

Incentives / Better Wages

It is evident that staff caring for children with albinism at these shelters are neither incentivized nor trained. They need better compensation and support to encourage them to care for these most vulnerable in society. Further, if they are to care for children with albinism without contributing to their abuse, they must be trained on the basics of how to prevent and handle abuse: psychological, physical and sexual, the basics of health such as skin cancer prevention and the basics of low vision as it pertains to children with albinism. Again UTSS is willing to cooperate with the government in ensuring that this training takes place. However, without proper incentives to staff, there will be rapid staff turnover which will lead to a waste of training. Therefore the most effective first step from government must be incentivizing staff.

Skin Cancer Training

Staff has little to no background knowledge about skin cancer and its deadly impact on children with albinism. There has to be on-going training and monitoring to ensure that all staff has the basics of sun protection for children with albinism. Staff also needs to be trained on treating sun burn and making referrals of skin cancer or its precursors to the correct health authorities and to ensure follow-up. Skin cancer prevention does not need expensive solutions such as sunscreen. Basic health information can be effectively implemented by staff such as sun avoidance as well as the use of sun-protective clothing: wide-brimmed hats and long-sleeved clothing can save lives.

Low Vision Training

Staff needs to be aware of the low vision status of children with albinism and respond to them accordingly. This includes avoiding the use of braille as a teaching tool unless in the few exceptional cases. It also means teaching using more verbal techniques and making basic changes such as writing with large print on the chalkboard. Low vision training will also ensure that staff is better prepared to articulate their request for support from authorities including making particular requests for chalkboard, low vision devices, and tinted sunglasses.

Social Welfare Workers

There is a high need for trained and well-resourced social service workers who should be familiar with albinism and supplement the efforts of permanent staff. These workers would need to attend the shelters frequently to record the circumstances and hear the grievances of the children and record them. Active social work at these centres is essential for monitoring and eventually disbanding these shelters for the purposes of holding displaced children with albinism. They would also be needed for reuniting them with their families.

Sexual Abuse:

We call on the government of Tanzania to immediately conduct a follow-up visit to these shelters, with the view of investigating further the incidences and allegations of sexual abuse and come up with concrete and workable solutions to address them.

Evaluation and Monitoring:

Tanzania itself recognizes the need for evaluation and monitoring as discussed in its Report.[17]Evaluation and on-going monitoring is crucial for government decision making but appears to be lacking. It is this lack of evaluation and monitoring that has resulted in all the problems identified so far. It is probably the same reason why Tanzania may still believe that these shelters were the best reaction to the situation of attacks. Yet, nearly 7 years is a long time to keep children in a “temporary” situation. If it is true that Tanzania is “safer” today for children with albinism than 7 years ago, as is often claimed by officials, then why have children not been re-located safely to their families? Why have the shelters not been de-commissioned as “shelters” for fleeing persons with albinism?

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[17] See para 105 of State Party Report, at note 8.