

The human rights of

PERSONS WITH ALBINISM in KENYA

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ABBREVIATIONS

- AFEA: Albinism Foundation of East Africa
- ASK: Albinism Society of Kenya
- KNCHR: Kenya National Commission on Human Rights
- PWA: Person(s) with Albinism. This phrase 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.
- UTSS: Under The Same Sun

I. Executive Summary

1. Persons with albinism (PWA) in Kenya suffer terribly from pervasive myths and misconceptions about their condition. This negative public perception relegates most of them into isolation that locks them in a vicious cycle of poverty.
2. While Kenya has taken steps to improve the lives of PWA including the ongoing attempt to expressly capture albinism into its laws on disability, affirmative action and sunscreen distribution program, it remains to be seen whether these steps will be followed-through and concretized so that benefits are clearly seen in the lives of PWA.
3. Persons with albinism in the country continue to suffer from discrimination and lack of support particularly in the education system where they are often mocked for their appearance and low vision are un-accommodated. The result causes a high dropout rate amongst PWA. This in turn leaves most of them un-skilled and un-equipped for jobs and relegates them to menial jobs, including jobs that expose them to the sun and subsequently to skin cancer which is the primary killer of persons with albinism in the region of Sub Saharan Africa.
4. Lack of educational support mixed with pervasive myths and misconceptions which in turn drives stigma and discrimination against persons with albinism in the country. The effect is that their economic and social rights are greatly affected. Joblessness and extreme isolation, both self-imposed and community imposed, consign persons with albinism into a life of poverty and depravation.
5. On the extreme end of stigma and discrimination against PWA are physical attacks which seem to be met with little or no information from a follow up investigation and prosecution with the result being that perpetrators are not deterred.
6. Therefore, while Kenya has made some strides to advance the rights of PWA, there remains an extensive array of work to be done. At the very least being intensive public awareness and sensitization to humanize persons living with this obvious and immutable condition; standardizing reasonable accommodation for them at schools; and ensuring the effectiveness of the sunscreen program and affirmative action programs to ensure that many more are protected and employed indoors.

7. 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.
8. 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 and attacks.

II. Methodology

9. This report is written based on extensive research on the lives of PWA in Kenya. It is based on data gathered by UTSS and its agents on the ground. UTSS' agents have visited PWA who have been victims of attacks to interview them and their families, document their account of what happened, provide support which may include medical, psychosocial and financial support, feeding and other social support.
10. This report has also been written based on contributions from groups based in Kenya including the Albinism Foundation for East Africa, a non-governmental organization working for the advancement of persons with albinism in the country; and also from the Kenya National Commission on Human Rights, an active National Human Right Institute in Kenya.¹ Some information have also come from Albinism Society of Kenya. Contributions from these bodies are classifiable as primary sources as well as extensive research using focus group discussions and work from experts in the field.²
11. Data from the media have rarely been relied on without additional confirmation from at least one contributor to this report.
12. Limitations: Regarding records of attacks, there is no unified legal monitoring in place in Kenya to ensure that attacks are prosecuted or to make sure that cases are investigated. Local groups are often ill-equipped and underfunded and therefore unable to carry out these necessary tasks. Comprehensive and unified information is therefore scarce. The information received has been gathered here in the most comprehensive way possible.

¹ KNCHR wishes to acknowledge the contribution of Miriam Nthenge to this report.

² The most helpful data in terms of qualitative & quantitative measures came from Hannah M. Njenga, *Publics Perceptions of Albinism And Their Impact On Persons With The Condition: A Case Study Of Nairobi City* (January 2011) as cited in AFEA, Rapid Study on The Extent of Marginalisation of Women with and Affected by Albinism in Kenya. (in partnership with the Ford Foundation, Kenya). [Henceforth "Njenga Study, 2011"]

III. Albinism

13. 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.
14. The condition results in a lack of pigmentation in the skin, hair and eyes, causing vulnerability to sun exposure and bright light.
15. Skin cancer is common amongst a majority of PWA living in the region of Sub Saharan Africa including Kenya.
16. Almost all PWA are visually impaired, with the majority being classified as “legally blind.”
17. While numbers vary in North America and Europe it is estimated that 1 in every 17,000 people have some form of albinism. In Sub Saharan Africa, albinism is much more prevalent, with an estimated range of 1 in 5,000 to 1 in 15,000. However some select communities can have prevalence rates as high as 1 in 1,000.³

Aspects of Albinism

18. The condition of albinism has several facets that expose PWA to multiple and intersecting forms of discrimination. These include:
19. **The visual aspect or “legal blindness:”** Since melanin is critical to the normal development and health of the eyes, PWA suffer from multiple eye defects due to their reduced amount of pigmentation. These include **photophobia** (inability to withstand glare and sun/light), **foveal hypoplasia** (underdevelopment of the eye’s internal surface), **nystagmus** (involuntary eye movements resulting in reduced or limited vision) amongst others. The practical effect of this is that most PWA are myopic and generally have only 20% of normal visual levels. This means that most PWA are classifiable as persons with disabilities (legally blind) and are in need of

³ See UN Preliminary Report of the United Nations High Commissioner for Human Rights, *Persons with Albinism*, 12 September 2013 [“UN Report”], at paragraph 14.

reasonable accommodation in learning institutions and place of work. Without this consideration, most quit school out of frustration due to the inability to cope.

20. **Skin cancer is the No.1 killer of PWA in Sub Saharan Africa.**
21. Most PWA will die from skin cancer 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 this basic education, most PWA die slowly from advanced skin cancer. Their lack of understanding about sun protection and their lack of education because of low vision leaves them vulnerable to working as petty traders in the sun.
22. **The colour issue:** This is one of the most dangerous aspects of albinism in Kenya. PWA are highly visible 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 in East Africa including Kenya.
23. This tragedy has recently gained the attention of the international community. It has resulted in several resolutions at the United Nations and African Union levels. It has also received support via mention in declarations and statements of international and regional bodies.⁴

⁴ Resolution 23/13, “Attacks and Discrimination Against Persons with Albinism,” 23rd Session of the United Nations Human Rights Council, June 2013 [“Resolution 23/13”]; Resolution 24/33, “Technical Cooperation for the Prevention of Attacks Against Persons With Albinism,” 24th Session of the United Nations Human Rights Council, September, 2013 [“Resolution 24/33”]; African Committee of Experts on the Rights and Welfare of the Child(ACERWC); Resolution 263, “Resolution on the Prevention of Attacks and Discrimination Against Persons With Albinism,” African Commission on Human and Peoples’ Rights, Banjul, Gambia, 05, November 2013; The Addis Ababa Declaration on Ending Discrimination and Violence Against Girls in Africa, Addis Ababa, Ethiopia, 05 November 2013. Also see joint press statement issued on 4 May 2013, “Not ghosts, but human beings ... persons with albinism,” accessed February 15, 2014, www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E. [“Joint Press Release by UN Rapporteurs”]. Specific mention has also been made in concluding observations of the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Rights of the Child and the Committee on the Elimination of Discrimination against Women (see UN Preliminary Report, at note 3 above, at para 61).

Image 1: Albinism Worldwide



IV. Albinism in Kenya

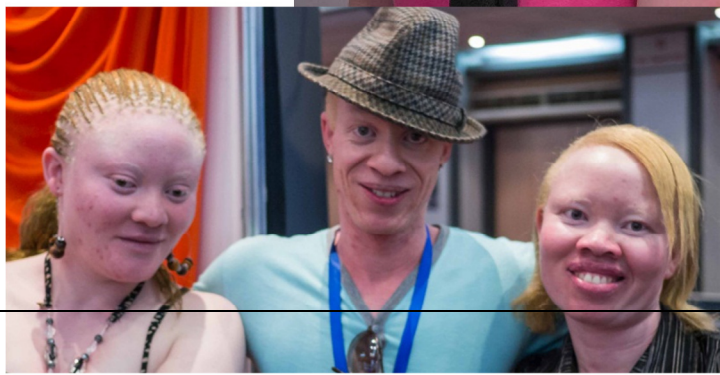
24. A PWA in Kenya pointedly stands out because nearly all others around them have a dark-pigmented skin tone. The result of this should not be underestimated because it means that PWA cannot hide even if they tried to and are therefore exposed to unusual attention and all the discrimination and stigma that comes with such attention everywhere they go.
25. There are no exact data or statistics on the number of PWA in Kenya. However, given the available range of estimates in the Africa region, the number of PWA in Kenya could be anywhere from thousands to tens of thousands.
26. Discrimination against PWA is rife and usually based on myths. Some Kenyans believe the myth that the mother of a child with albinism cheated on her husband or that the child with albinism brought a curse on the family. One study found that nearly two-thirds of children with albinism were raised by single mothers.⁵
27. There is a fundamental lack of understanding about albinism in Kenya. Myths are therefore the default school of knowledge and these myths are reinforced in the absence of adequate public awareness and education on the scientific and objective bases of the condition.
28. Like most persons with disabilities in Kenya, PWA face high challenges in receiving services within the public and private sectors. Access to basics such as education, health services and employment remains very difficult.

⁵ Njenga Study, 2011, note 2 above, at.p.7. In fact, this study found that mothers who have children with albinism disproportionately (when compared to women in general in Kenya) face deep stigma, dejection, trauma and poverty all causally linked to having a child with albinism.

Images 2-5: Albinism in Kenya



People with albinism from Kenya (above and below) huddle together after a day of awareness-raising sponsored by NGOs



V. Points for commendation

29. There are ongoing efforts to amend the definition of disability in the current *Persons with Disability Act (2003)* to include persons with albinism. This will officially and legally classify PWA as persons with disabilities and oblige reasonable accommodation in key settings such as school and the workplace.
30. The government has launched a sunscreen program which provides sunscreen to all PWA in Kenya. It is not clear how this is unfolding so far although some public hospitals are reported to have sunscreen available.
31. The government established a fund to care for PWA after a collation of advocacy groups and non-governmental organizations lobbied for it and sent a delegation to parliament. The government agreed and established a fund in the supplementary budget of 2011/2012. The amount delegated, over 100 million shillings (over 1 million USD) has been renewed this financial year 2013/2014 entrenching it as recurrent expenditure.
32. Students with albinism are granted an additional 30 minutes to complete examinations. However as explained below under the section “Disability and Reasonable Accommodation”, more can be done here.
33. The constitution of Kenya provides that at least 5% of members of elected and appointed bodies should be persons with disabilities.⁶ A discussion on the reality of this practice is provided below under the section, Economic, Social and Cultural Rights. This has led to the appointment of one Member of Parliament, Hon. Isaac Mwaura, one judge of the high court, Madam Justice Mumbi Ngugi and two county assembly representatives.
34. In, 2011, in response to broad advocacy by NGOs fighting for the rights of PWA, the government of Kenya commissioned the National Council of Persons with Disability and employed at least one PWA. This Council registers PWA and has a fund allocated to them.

⁶ Article 54(2).

VI. Human Rights (HR) Issues of Persons with Albinism in Kenya:

A. Disabilities and Reasonable Accommodation

35. Due to the irregular combination of their vision impairment and barriers in society in Kenya, PWA in Kenya are persons with disabilities. In addition, due to the combination of their skin's impaired ability to produce melanin and the barriers arising from this – both health and social problems – PWA in Kenya are also person with disabilities.
36. While Kenya is extending the umbrella of persons with disability to be inclusive of PWA, the necessary outcome of reasonable accommodation is yet to be seen. Apart from a few isolated cases, PWA continue to be without reasonable accommodation in the classroom and at the workplace, leaving them ill-equipped and under-equipped for a future without poverty.
37. Reasonable accommodations for PWA are basic things that can be done to assist them to learn and work. These include placing them in front of the classroom, permitting altered uniforms so that they become sun protective clothing including long sleeved shirts and wide-brimmed hats. Also bringing an end to normalized mockery of PWA and exempting them from outdoor activities in the sunlight. A full table of other good practices for reasonable accommodation is provided in the Conclusion & Recommendations section.
38. It is commendable that Kenya has allowed students with albinism an extra 30 minutes to write examinations. This too is reasonable accommodation. Yet, this amount of extra time is not up to the standard that has been adopted elsewhere in the world including North America where students with albinism and similar visual disabilities get a total of the normal exam time plus half of the normal exam time, in other words, time-and-a-half. This type of additional time is necessary to give the student with albinism the necessary

time to accommodate their visual challenges which tend to be aggravated under periods of stress.⁷

B. Racial [Colour] Discrimination and Related Intolerance

39. The colouring and the totality of the appearance of PWA is a key feature spurring the discrimination they face. While the Persons with Disabilities Act grant a legal identity, namely disability, it does little to protect against damaging public perception beliefs, and treatment even from family – all reactions stemming from the “white” appearance of PWA.
40. Nowhere is this more evident than in the seclusion of PWA. Seclusion is not always self-imposed; it is also frequently imposed by family and the community. In a monitoring survey conducted by KNCHR, in eight counties of Kenya between 2011-2013, it was found that PWA are often isolated within their communities mainly because of the myths associated with their appearance.⁸ Cases of some mothers abandoning a child with albinism in the hospitals or under the care of their grandmothers abound. An example of this was given in Nyeri county where a PWA narrated how her mother abandoned her so that she could get married since her mother’s prospective husband refused to marry her if she had a child with albinism. A case was also reported where a mother killed her baby with albinism after her husband convinced her to do so because the child was considered a bad omen and disgrace to the family.⁹
41. In Njenga’s 2011 study In discussing disability for example, opinions on whether or not PWAs are disabled were split between yes and no in equal measure. Due to this internal uncertainty and confusion. However respondents with albinism confirmed that they had suffered tremendously from a variety of abuse as indicated” the table below:¹⁰

⁷ See “Nystagmus” described above under Aspects of Albinism, is a condition present in albinism in which the eyes swings back and forth in a pendulum motion which results in a reduction in visual acuity. The motion is aggravated when a person is under stressful condition and this can further reduce visual acuity during the period of stress.

⁸ Study was done in line with KNCHR’s monitoring role under article 33(2) of the Convention on the Rights of Persons with Disabilities.

⁹ See full details of the story: the story of Esther MORAA below.

¹⁰ Njenga Study, 2011, note 2 above, at.p.16.

Q: ‘As a result of discrimination and marginalization, I have personally suffered from’

Table 1: Results of Marginalization –Njenga Study (2011)

Result	Frequency	%	
Name calling and branding	84	81.6	
Low self esteem	52	50.5	
Peer ridicule	36	35.0	
Identity crisis	31	29.9	
Physical violence	21	20.4	
Marital un-fulfillment	20	19.4	
Illiteracy	9	8.7	
Ill health	3	2.9	
Other			

42. The issues associated with the colouring and appearance of a PWA indicates that they are a group beyond the typical bounds of ‘disability’, yet it is a matter that is rarely discussed. One of the most helpful statements on the issue so far came from the UN Independent Expert on minority issues who stated that the problems faced by PWA such as stigma, lifelong social exclusion and discrimination, are similar to the experience faced by vulnerable racial minorities *because of their skin colour*.¹¹ Further discussion of PWA as a visible minority experiencing discrimination based on their colour remains necessary. It would not only validate their experience of discrimination based on skin colour but would also give them access to appropriate programs emanating from international instruments that protect against skin colour discrimination such as the Durban Declaration, the UN Convention on Elimination of all forms of Racial Discrimination. There are other national instruments which must be compelled to consider the issue of albinism as a new category of colour.¹²
43. The exposure of PWA to issues that go beyond mere disability, namely the human rights issues stemming out of their colouring, is a key indicator that PWA cannot easily be classified only into one of the possible legal identities they have. Other legal identities: a minority facing discrimination based on colour should be concurrently validated. Above all, their overarching identity

¹¹ See Joint Press Release by UN Rapporteurs at note 4 above.

¹² See “UN Report,” at note 3 above, at para 80. Also see relevant sections in the CERD. In particular, see Articles 1.1 and 5 of the CERD, available at OHCHR, accessed February 18, 2014, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx>. Also see UTSS Report to Advisory Committee of the UN Human Rights Council, available at: <http://www.underthesamesun.com/sites/default/files/Albinism-A%20Definition%20for%20A%20Change.pdf>

- should be that of a specific people group with particular needs that must be given special attention within national and international human rights law.
44. To that end, it is likely time for governments to adopt a national policy on albinism; one that encompasses the multiple human rights issues faced by PWA, from disability to health to colour (appearance-based) discrimination. This policy could begin by declaring PWA as a specific group with particular needs that require special attention. Such attention would include providing for them under `disability` laws even though this would not be comprehensive enough to tackle all of the unique issue related to albinism. Not only is the word ``disability`` exclusive of PWA who do not have a low vision impairment, it also excludes the major issue of discrimination and stigma they face due to the totality of their appearance.

C. Economic Social and Cultural Rights:

Education

45. Families frequently neglect the education of children with albinism as they believe their education is a waste of resources.¹³ These same families tend to hide their children from society, viewing them as a source of shame.
46. Even when families take their child(ren) with albinism to school, they are sometimes turned away due to the myths and misconceptions held by the school. For example, the vision impairment of PWA has led to the assumption that they are all blind. This has frequently resulted in such children being enrolled in special schools for the blind and forced to learn braille instead of being integrated into regular schools and taught to read and write.
47. In some cases, their inability to see the blackboard, owing to significant vision impairment, forces them to drop out of school. Although simple changes and reasonable accommodative practices in the classroom such as placing students in front of the class or photocopying teachers' notes may be effective for PWA, this is rarely done.
48. Due to the absence of reasonable accommodation, PWA tend to drop out of school earlier than normal and consequently have low education levels and do not have all the necessary social or economic tools to live productive lives.
49. This is a fundamental issue that ought to be addressed, taking into account the correlation between education and acquisition of employment. Lack of

¹³ UN Preliminary Report, para 68.

proper education and skills has left many PWA living in abject poverty and having to depend on their relatives for sustenance.

Social Issues: Name-Calling and Bullying that Dehumanize in the Public Sphere

50. Persons with albinism in Kenya, both in schools and on the streets, often suffer from teasing and bullying from classmates. Some of these names are used by teachers and other people in authority causing grave demoralization and psychosocial issues in children and students as a whole.¹⁴
51. These names are often deeply derogatory and dehumanizing which have been normalized in society and in every walk of life. Names used include “*dili*” which means a monetary deal that can be earned from ritual killing or “*Zeru Zeru*” which refers to mystical or ghostlike beings. Another common term is “*mzungu*” which is a name typically used to refer to Caucasians. All of these names show a lack of understanding about albinism and a perception of PWA as lesser beings.
52. The effect of name-calling should not be under-estimated as it is pervasive across Kenya and are commonplace in most tiers of society.¹⁵ As stated by a Kenyan woman with albinism:

“People just see you on the street [and say] ‘its that albino!’ instead of thinking ‘that is Jayne’...[because] they don’t see us like a person [sic] ; ... I’ve been a victim of discrimination, I have been a victim of not getting resources, and , I’ve been a victim of ignorance ...You are called money or walking bank notes.”¹⁶
53. Even the rare PWA who has managed to beat the odds and become a contributing member of society has not been spared from publicly accepted derision. For example, Lady Justice Judge Mumbi Ngugi, woman with albinism, which the government of Kenya commendably appointed as Justice of the High Court was derided in public by a politician who attacked the fact that she had albinism.
54. A member of parliament with albinism appointed relatively recently, Hon. Isaac Mwaura, was also mocked by a fellow member of parliament. The words

¹⁴ Njenga Study, 2011, note 2 above, at.p.14.

¹⁵ See note 16 below.

¹⁶ See On Beauty Webisode: Jayne Waithera, YouTube, accessed May 28, 2014, <http://www.youtube.com/watch?v=aFfU8czbUoE>

- of contempt were directed at Hon Mwaura's sun protective clothing, making a statement to the effect that Mr. Mwaura was a cowboy who wore a funny hat.
55. These incidents – even directed against the few PWA who have broken out of the mould of poverty and seclusion– shows a clear indication of low awareness about albinism in Kenya and the amount of public awareness work that remains to be done.
56. There is also the erroneous belief that albinism is contagious. The effect of this belief is that PWA are often not afforded the social physical contact that is given to those without the condition.
57. In public settings, PWA must constantly endure the awkward gawks and stares of those around them. This is likely linked to the myths and misconceptions about them and the fundamental lack of knowledge about their condition. This, amongst other social factors mentioned above, means that PWA tend to prefer a private life rather than engaging with the public. A private life of self-seclusion guarantees less public abuse but often consigns PWA to isolation, a failure to integrate into their society and poverty.

Employment

58. While the constitution of Kenya enshrines affirmative action by providing that at least 5% of elected and appointed bodies are persons with disabilities, this has not been realized.¹⁷ In most cases, PWA tend to be passed over for persons with other types of disabilities as most employers, government included, do not regard them as properly belonging to the category of persons with disabilities.
59. Persons with albinism also suffer double discrimination in the field of employment as employers assume that their capacity to deliver within the workplace is below par. Sometimes they may also be subject to conditions that are hostile to their condition such as working directly under the hot sun or bright light which puts them at risk of skin cancer and /or further eye impairment.¹⁸

Health

60. The government has launched a free sunscreen program which provides sunscreen to all PWA in Kenya. This is highly commendable because skin cancer is the number one killer of PWA in the Sub Saharan Africa region.

¹⁷ Article 54(2).

¹⁸ Njenga Study, 2011, note 2 above, at p.11.

Sunscreen distribution could reverse this trend. Yet, information about the program is sparse and whether the program has officially taken effect is unclear at this point.

D. Torture and other Cruel Inhuman and Degrading Treatment

61. Twelve attacks have been documented against PWA in Kenya. Some of them qualify as torture given the extreme pain inflicted on the victim and the intent of the perpetrator. These attacks are discriminatory, witchcraft based beliefs that the body parts of a PWA can bring wealth and good luck when used as potion and amulets.¹⁹

62. These following are reported/documented cases only.

Table 2: Record of Attacks

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		3	1	4	March 2014
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

¹⁹ Definition taken from article 1 of the *Convention Against Torture* and the assistive document for interpretation: *Interpretation of Torture in the Light of the Practice and Jurisprudence of International Bodies*, OHCHR, at p.3 http://www.ohchr.org/Documents/Issues/Torture/UNVFVT/Interpretation_torture_2011_EN.pdf, Accessed May 21, 2014.

South Africa	1	1	2	4	February 22, 2013
Swaziland	2	7		9	September 2, 2013
Tanzania	73	48	18	139	May 13, 2014
Zambia	1			1	December 2011
Zimbabwe	1		1	2	November 29, 2012

TOTAL ATTACKS RECORDED IN AFRICA: 311

Countries affected: 23

*Includes mutilated survivors and those traumatized while escaping attack

**Also includes missing persons, grave robberies and successful asylum cases

60. Most attacks against PWA go unreported due to the `code of silence` and overall secretive nature of witchcraft.²⁰
61. 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 body parts goes for upwards of \$75,000.²¹ In a country where the average annual income (using GDP per capita) is roughly \$1,800 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.²²

Narrative of Murdered Victims

62. We have records of the following PWA murdered for their body parts in Kenya (Except where a case was widely reported in the media and has effectively become a matter of public record, their surname has been deleted for protect them from reprisal). Most of these cases were confirmed by UTSS’ agents on the ground in Kenya.
 - a. **ESTHER MORAA:** On August 2, 2010, a 4 month old baby girl with albinism by the name of Esther Moraa was killed by her mother, Sara Kemunto Nyabuto, age 23, at Bokimweri sub location in Nyamache district, Kenya. The father was threatening divorce and had convinced her to kill the baby since she was born with albinism, hence a bad omen and a disgrace to the family. The mother has been sentenced to serve one year in

²⁰ “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.

²¹ International Federation of Red Cross and Red Crescent Societies, Through Albino Eyes (Advocacy Report), IFRC, accessed May 27, 2014, <http://www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf>

²² 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).

jail in a Gucha court by Ogembo Resident Magistrate Richard Koech saying “the accused killed her child for being an albino.”²³

- b. **MARGARET K.:** In January of 2008 a woman friend came knocking at Margaret's door and when she opened it three men abducted her. Her body was found the following morning with her legs, genitals, breasts and hands removed.²⁴
- c. **JOYCE M.:** On Sunday, March 4th, 2012 Joyce`s mother took her daughter Joyce to church for the evening prayers. The pastor was having individual prayers with his congregation therefore he asked that all children be taken out of the church to play outside. After prayers Mrs. Muzungu couldn't find Joyce. She approached the pastor to enquire on the whereabouts of Joyce since he is the one who ordered all children to be taken out of the church. The pastors responded by telling her to be patient and wait for Joyce by the rock outside the church and keep praying. The evening became darker Joyce`s mother couldn't wait any longer, she went to the neighborhood looking for Joyce but there was no success. On Monday the Pastor called Joyce`s mother stating he has Joyce and they should meet on Thursday afternoon so as to reunite her with Joyce. That Thursday afternoon all the villagers gathered at the church. Instead of the Pastor coming he sent his assistant, which provoked the villagers to beat him. The Pastor sought police protection which triggered the villagers to burn down the church. Up to today Joyce has never been found. The pastor relocated to another place.²⁵

63. **Narrative of Survivors of Attacks & Attempts of Attacks**

We have records of the following persons with albinism attacked with the aim of using their body parts. They survived the attack:

- a. **UNKNOWN:** On March 15, 2013, a 7 year old boy with albinism in Embu, Kenya managed to escape relatives who tried to sell him for ritual purposes. He was kidnapped by his uncle together with other relatives who attempted to take off to an unknown destination where they were to meet the buyers. The boy said that the kidnappers threw him out of the window of a moving vehicle when he screamed.²⁶
- b. **UNKNOWN:** On August 16, 2011 a near death experience occurred for a girl with albinism when her father was caught in the act and charged with human trafficking. The arrest revealed that he was in the process of selling

²³ Also see "Woman kills albino child to avoid bad omen," Standard Digital, August 25, 2010, accessed June 26, 2013, <http://www.standardmedia.co.ke/?articleID=2000016790&pageNo=1>

²⁴ Agent of Under The Same Sun in Kenya who visited and interviewed survivors of the victim (July, 2013).

²⁵ Agent of Under The Same Sun in Kenya who visited and interviewed survivors of the victim (July, 2013).

²⁶ See, "7 Year Old Escapes Deathly Ritual," Citizen News, March 15, 2013, accessed June 26, 2013, <http://www.citizennews.co.ke/news/2012/local/item/8667-7-year-old-escapes-deathly-ritual>.

his daughter to a Tanzanian buyer for an undisclosed amount of money. This case was still before the courts on the date of the newspaper report.²⁷

- c. **ROBINSON MUKWHANA:** Robinson used to work as a night guard at a shop in Kitale town and his best friend Nathan Mutai had promised to look for a better paying job for him in Nairobi. On 12th August 2010 Nathan tricked Robinson that he got the job and they had to travel to Nairobi but instead brought him to the border between Kenya and Tanzania. Robinson had never travelled outside Kitale therefore he couldn't question the direction on which they were heading. Robinson had no travelling documents but Nathan facilitated through corrupt ways for him to cross into Tanzania. Nathan booked Robinson into a lodge/motel in Mwanza. The following morning Nathan left the lodge/motel to meet with the purported new employer of Robinson. By chance Nathan was dealing with Tanzanian undercover police officers. After Nathan had negotiated the price for Robinson with the three gentlemen, they insisted on seeing what they were buying. That's when Nathan took them to Robinson. When they reached Robinson's room Nathan was arrested and taken to police custody. Nathan was taken to court and sentenced to serve in Jail for a time not known to Robinson. Robinson was taken back to Kenya a free man but psychologically disturbed. "How it is my best friend would organize to sell me? Who can I trust?" Those were his last words to us. He still has hopes of pursuing his studies and becoming an independent PWA.²⁸
- d. **BETTYLYN A.:** In the year 2008 Betty was two years old and used to love playing with umbrellas. One day in a market a stranger enticed her with an umbrella and due to her love of umbrellas she followed the stranger. Before she could leave the market with the stranger, a neighbor who knew her took Betty back to her mother. This incident caused her mother to take Betty to school earlier than the recommended age for her safety

In 2011 while Betty was leaving home to school with other children, they noticed some men trailing them. The kids reported the incident to the school management. When her mother heard of the occurrence she decided to move to another secretive place.

In a third incident in September of 2012 Betty was playing with other kids when a car with tinted windows parked outside their residence. They started sending passing-by kids to call for them the "Mzungu." One of the kids who was sent instead of calling Betty went and called Betty's Mom. When the occupants of the car saw Betty's Mom approaching, the car sped

²⁷ See, "Child Traffickers on the Prowl," The Standard, August 17, 2011, accessed June 26, 2013, https://www.standardmedia.co.ke/?articleID=2000040932&story_title=child-traffickers-on-the-prowl&pageNo=1

²⁸ Source: UTSS Agent, Kenya, July 2013. See also: "Kenyan arrested by Tanzania police over 'albino sale'," BBC News, August 17, 2010, accessed June 26, 2013, <http://www.bbc.co.uk/news/world-africa-11001791>).

off before she could check the number plate. She moved to another residential area and enrolled Betty for boarding school.²⁹

- e. **HENNERINAH BEATRICE:** Beatrice runs a small business by the roadside near her home. One evening in March 2012 while walking home from her business with a friend, they noticed a car stopped abruptly in front of them and started reversing in their direction. Beatrice ran into the cassava plantation and two men jumped out of the vehicle and ran after her. They didn't bother with Beatrice's friend and when she realized they were in pursuit of Beatrice she ran towards her home and informed neighbors. The neighbors were able to chase of the men in the car. Beatrice meantime ran to a friend's house who welcomed her in and they called for support from the neighbors.³⁰

E. Impunity

- 64. Very little information is available as to the legal status of the above cases. The monitoring of court proceedings concerning these crimes by civil society actors is very rare, and associations of PWA often lack the financial means and expertise to conduct legal monitoring activities.³¹
- 65. Aside from the widely published case of Robinson Mukhwana in 2010 very little is known on the legal proceedings that should have occurred in every reported attack and murder.
- 66. The impact of Impunity is twofold. First, it creates no deterrence for possible perpetrators: without adequate prosecution, perpetrators have incentive to continue attacks and have no fear or deterrence that the weight of justice will be exercised against them after attacking a PWA.
- 67. Second, it increases insecurity and fear amongst PWA. Without prosecution, PWA are unable to live without fear, including fear of entering proper relationships which they need to build an adequate social ring of protection and support.

²⁹ UTSS Agent, Kenya, July 2013.

³⁰ UTSS Agent, Kenya, July 2013.

³¹ UN Report, at note 3 above, at para 20.

VII. Conclusion & Recommendations ³²

68. Kenya has taken commendable strides in protecting PWA, particularly the ongoing efforts to extend the identity of persons with disabilities to PWA. Yet a lot more needs to be done. The government needs to accelerate programs that have been announced such as the affirmative action in the constitution and the sunscreen program. The government should also consider a census to make its announced programs more effective and to ensure that all services gets to all PWA, especially those in rural areas.
69. The government also needs to take concrete steps in the following areas:³³

a. Disability and Reasonable Accommodation

1. Promote and normalize the following basic reasonable accommodations for PWA. This can be comprehensively packaged in a national policy for PWA.
2. Reasonable accommodation for PWA may include at minimum:

Table 3: Reasonable Accommodation

FOR	REASONABLE ACCOMODATION	NOTES
Visual Impairment	Sit student close to the board: front and centre.	May not work for all persons with albinism as visual level varies. Talk to student
	Provide texts or reading material in large font if possible	
	Teacher ought to dictate as they write on the board	
	Print in large clear sentences when writing on the board	
	Teachers ought to photocopy their notes for the student either in advance or immediately after class	
	Teachers can facilitate a peer-mechanism whereby a good student with good notes can borrow his or her notes for the PWA to copy or transcribe	
	Permit PWA to use visual aids such as monocular for long distance viewing	
	Provide extra time during exams using the common standard of	

³² UN Report, at note 3 above, at para 86.

³³ All of these recommendations were repeatedly alluded to or expressly stated by all contributors to this report. They were also highlighted in the Njenga Study, 2011, see note 2 above at pp 23-24.

SKIN	ordinary exam time + half of ordinary exam time	
	Patently dealing with the student with respect and abstaining from name-calling	
	REASONABLE ACCOMODATION	NOTES
	Exempt students from outdoor activities in the sunshine	
	Permit altered school uniforms e.g.: long sleeve shirts and , long trousers, and the use of wide-brimmed hats and sunglasses (even indoors)	
	Provide sun protection cream at little or no cost	
	Provide visual aids such as monocular for long distance vision at little or no cost	

b. Colour Discrimination

1. Consider adopting a national policy on albinism; one that encompasses the multiple human rights issues faced by PWA from disability to health to colour (appearance-based) discrimination. This policy could begin by declaring PWA as a specific group with particular needs that require special attention. Such attention would include providing for them under `disability` laws, health policies including sunscreen, anti-discrimination laws based on skin tone or colour and so on.

c. Economic, Social and Cultural Rights

1. Awareness-Raising: Government should intensify awareness-raising campaigns to educate the public on albinism as a way of curbing prejudice and use of derogatory language against them
2. Education: Train teachers and social welfare workers on dealing with children with albinism in the classroom, and support NGOs that provide such training services
3. Employment: Enforce the constitutionally-protected affirmative action for PWA as persons with disability.
4. Healthcare: Government, particularly the Ministry of Health, should ensure and facilitate programs to enhance health for PWA and prevent early death due to skin cancer. These include :
 - i. ensuring that the announced sunscreen program is effective;
 - ii. supporting initiatives for producing sun protection cream locally;
 - iii. permitting free skin cancer treatments at all hospitals across the country;
 - iv. providing free or low cost visual aids so that PWA can be accommodated in their classrooms.

d. Torture and Other Cruel Inhuman and Degrading Treatment

1. Adopt positive and specific measures to protect and preserve the rights to life, to security of person and not to be subject to torture or ill-treatment;

e. Impunity

1. Increase efforts to put an end to the various forms of crimes affecting PWA, strengthen the legal response to such crimes and bring perpetrators to justice through prompt and impartial investigations; and
2. Guarantee the victims' right to justice and redress, and provide medical, psychosocial and legal support to victims of attacks.