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Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development

Persons with albinism

Report of the Office of the United Nations High Commissioner for Human Rights*

Summary

This preliminary report of the Office of the United Nations High Commissioner for Human Rights on the attacks and discrimination against persons with albinism is submitted pursuant to Human Rights Council resolution 23/13 of 13 June 2013.

In some communities, erroneous beliefs and myths influenced by superstition put the security and life of persons with albinism at risk.

OHCHR has received information from various countries on cases of killings and dismembering of persons with albinism for ritual purposes. It has also collected information on the multiple and intersecting forms of discrimination persons with albinism face worldwide.

States should adopt specific measures to protect and preserve the rights to life and security of persons with albinism, as well as their right not to be subject to torture and ill-treatment, and ensure their access to adequate health care, employment, education and justice.

* Late submission.

Contents

	<i>Paragraphs</i>	<i>Page</i>
I. Introduction	1–4	3
II. Methodology	5–9	3
III. Definition	10–14	4
IV. Attacks against persons with albinism	15–63	5
A. Ritual attacks	19–32	6
B. Trade in organs, trafficking in persons and sale of children	33–42	8
C. Infanticide and abandonment of children	43–47	9
D. Measures taken by States concerned	48–59	10
E. Action by international and regional human rights mechanisms	60–63	12
V. Discrimination against persons with albinism	64–83	13
A. Main forms of discrimination	65–73	13
B. Discrimination against women and children	74–76	15
C. Areas requiring further study	77–83	15
VI. Preliminary conclusions and recommendations	84–88	17
A. To States	86	17
B. To international and regional human rights mechanisms	87	18
C. To the international community	88	18

I. Introduction

1. In its resolution 23/13, the Human Rights Council expressed concern about attacks against persons with albinism¹ and the widespread discrimination, stigma and social exclusion they suffer. The Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to submit a preliminary report at its twenty-fourth session.
2. The present report provides an overview of the most serious human rights violations faced by persons with albinism, primarily focusing on the ritual killings and attacks to which they are subjected. It also highlights the multiple forms of discrimination, stigma and social exclusion faced by persons with albinism which occur across the globe.
3. The report generates some preliminary conclusions to guide further work and address attacks and discrimination against persons with albinism. It also contains a number of recommendations to Member States and the international community aimed at ensuring the protection of the rights of persons with albinism.
4. OHCHR welcomes the adoption of resolution 23/13 by the Council, which constitutes the first global decision on this issue.

II. Methodology

5. On 17 June 2013, for the purpose of preparing the present preliminary report, OHCHR addressed a note verbale to all Permanent Missions to the United Nations Office at Geneva and to all United Nations agencies, funds and programmes to solicit: (a) detailed data disaggregated by sex and age of persons with albinism; (b) information on attacks against persons with albinism and measures taken to ensure they and their family members are effectively protected; and (c) information on any type of discrimination against persons with albinism and measures taken to combat it.
6. In addition, OHCHR requested input to the report from special procedures mandate holders, national human rights institutions, human rights mechanisms of the African Union, and various non-governmental organizations, including associations of persons with albinism.
7. OHCHR is grateful for the 38 replies received, which have informed the present preliminary report.² Written submissions were received from seven States,³ four United Nations entities,⁴ three special procedures mandate holders,⁵ the African Commission on Human and Peoples' Rights, three national human rights institutions⁶ and 20 civil society organizations.⁷

¹ The term "persons with albinism" refers to person before it mentions the condition and is preferred to the term "albino", which is often used in a derogatory way.

² The original replies are available for consultation in the files of the Secretariat.

³ Colombia, Ecuador, Guatemala, Iraq, Mauritius, Mexico and Thailand.

⁴ The Special Representative of the Secretary-General on Violence against Children, the United Nations Interregional Crime and Justice Research Institute, the Food and Agriculture Organization of the United Nations and the International Seabed Authority.

⁵ The Special Rapporteur on trafficking in persons, especially in women and children; the Special Rapporteur on extrajudicial, summary or arbitrary executions; and the Special Rapporteur on the situation of human rights in Eritrea.

⁶ The National Human Rights Commission of Mexico, the Ombudsman of Panama and the National

8. The present report contains a compilation and review of information from different sources, including those mentioned above, as well as information from OHCHR field presences. The particular focus on Africa is explained by the fact that, according to the information received, all the cases of ritual attacks against persons with albinism have occurred in African countries. The written submissions and information gathered, including from United Nations sources, refer mainly to this region.

9. The collection and verification of cases of ritual attacks is a challenge due to the secret nature of witchcraft rituals, the inability and/or fear of victims' relatives to report such incidents, as well as the limited capacity of associations of persons with albinism to monitor human rights violations.

III. Definition

10. Albinism is a rare, non-contagious, genetically inherited condition present at birth. In almost all types of albinism,⁸ both parents must carry the gene for it to be passed on, even if they do not have albinism themselves. The condition is found in both genders, regardless of ethnicity and in all countries of the world.

11. Albinism results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, almost all people with albinism are visually impaired and are prone developing skin cancer. There is no cure for the absence of melanin.

12. Many types of albinism exist: the most common form is known as oculocutaneous albinism (OCA) and affects the skin, the hair and the eyes. There are different types and subtypes of OCA, with varying degrees of melanin deficiency. The main ones are tyrosinase negative (OCA1) and tyrosinase positive (OCA2). In OCA1, there is little or no melanin production. In the more prevalent – particularly in African countries – OCA2 type, some melanin is produced, giving rise to sandy-coloured hair and light brown irises in those affected.

13. Another less common form is ocular albinism (OA), which only affects the eyes. A more rare form of albinism is known as Hermansky-Pudlak syndrome (HPS) and is accompanied by bleeding disorders and large bowel (colitis) and lung diseases.

14. The prevalence of albinism varies across the world. Reports suggest that in North America⁹ and Europe an estimated 1 in every 20,000 persons have some form of albinism.¹⁰

Human Rights Commission of Togo.

⁷ Albinism Empowerment Network (Kenya), Albinism Fellowship of Australia, Albinos Sans Frontières (Burundi), Bien-être des Albinos de Côte d'Ivoire, Confédération nationale des Albinos de Guinée, Écran Total (Cameroon), Fondation Mwimba Texas (Democratic Republic of the Congo), Association Burkinabè pour l'intégration des personnes albinos, Association des femmes albinos "Espoir" (Burundi), Association nationale des Albinos de Côte d'Ivoire, Association nationale des Albinos du Sénégal, Association nationale des Albinos du Togo, Association pour la promotion des Albinos au Cameroun, Organisation mauritanienne pour l'appui et l'insertion des Albinos, RCN Justice & Démocratie (Belgium), Association of Gambia Albinos, Witchcraft and Human Rights Information Network (WHRIN), Rotary International, Somali-Canadian Cultural Society of Edmonton and Under the Same Sun (UTSS) (Canada). The Salif Keita Global Foundation made an oral submission in a meeting with OHCHR.

⁸ The exception is one type of ocular albinism, which is passed on from mother to son.

⁹ The National Organization for Albinism and Hypopigmentation (NOHA) refers on its webpage to 1 person in 17,000 having some type of albinism in the United States of America. Available from www.albinism.org/publications/what_is_albinism.html.

Epidemiologic data on albinism from a public survey in African countries, published by the World Health Organization (WHO) in 2006, mentions that: “Epidemiologic data on albinism, such as prevalence, were available for South Africa, Zimbabwe, Tanzania and Nigeria. Prevalence as high as 1 in 1,000 were reported for selected populations in Zimbabwe and other specific ethnic groups in Southern Africa. An overall estimate of albinism prevalence ranges from 1/5,000 – 1/15,000”.¹¹ According to WHO, the estimated prevalence of albinism suggests the existence of tens of thousands of people living with albinism in Africa. OHCHR did not receive detailed data on the prevalence of albinism from any country or region.

IV. Attacks against persons with albinism

15. In some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at constant risk. These beliefs and myths are centuries old¹² and are present in cultural attitudes and practices around the world.

16. As mentioned by six special procedures mandate holders: “They are regarded as ghosts and not human beings who can be wiped off the global map. They are people living with albinism, the target of many false and harmful myths in several countries, especially in the African region”.¹³ In some countries, persons with albinism are considered to simply vanish. In other countries, they are referred to as apes and a source of money. They are seen as sorcerers, devils or persons suffering from a curse and, in some communities, it is believed that contact with them will bring bad luck, sickness or death.¹⁴

17. Other frequent myths that threaten the life and physical integrity of persons with albinism include: that sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS; that the sacrifice of persons with albinism can appease “the god of the mountain” when a volcano starts to erupt; or that pulling out the hair of a person with albinism brings good luck. It has been reported that miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold,¹⁵ and that fishermen weave the hair of persons with albinism into their nets to improve their catches.¹⁶ Civil

¹⁰ Estimates from the UTSS submission.

¹¹ Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, “Albinism in Africa as public health issue”, *BMC Public Health*, vol. 6, No. 212 (August 2006). Available from www.biomedcentral.com/1471-2458/6/212.

¹² The United Nations Children’s Fund (UNICEF) refers to the human sacrifice of a person with albinism believed to strengthen the power of the king in the Dogon cosmology and in the Bambara Kingdom. Aleksandra Cimpric, *Children Accused of Witchcraft: An anthropological study of contemporary practices in Africa* (Dakar, UNICEF, 2010), p. 28. Available from www.unicef.org/wcaro/wcaro_children-accused-of-witchcraft-in-Africa.pdf.

¹³ See joint press statement issued on 4 May 2013, “Not ghosts, but human beings ... persons with albinism”. Available from www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E.

¹⁴ Written submissions from civil society describe the various beliefs and provide examples of derogatory terms used towards persons with albinism.

¹⁵ Deborah Fahy Bryceson, Jesper Bossee Jonsson and Richard Sherrington, “Miner’s magic: artisanal mining, the albino fetish and murder in Tanzania”, *Journal of Modern African Studies*, No. 48 (2010), p. 369, cited in the UTSS submission.

¹⁶ This phenomenon was reported to occur in Lake Victoria in the United Republic of Tanzania (UTSS submission). Similar practices were reported in the submission from the Association pour la promotion des Albinos au Cameroun and WHRIN.

society organizations denounce the role the film industry plays in promoting and maintaining superstitious beliefs.¹⁷

18. This range of beliefs and superstitions leads to various forms of attacks against persons with albinism in many communities. These include ritual attacks, which usually result in death and which in some cases involve trade in organs, trafficking in persons and sale of children, infanticide and abandonment of children.

A. Ritual attacks

19. The present report considers as ritual attacks those which reportedly aim to use the body parts of persons with albinism for the purposes of witchcraft.

20. There are beliefs according to which the body parts of persons with albinism possess magical powers capable of bringing riches and power if used in potions produced by local witchdoctors. As noted in a recent report by the Special Representative of the Secretary-General on Violence against Children, persons with albinism are “perceived as a curse from the gods and a charm made from their body parts is considered to have magical powers that bring wealth, success and good luck”.¹⁸

21. Some even believe that the witchcraft ritual is more powerful if the victim screams during the amputation, so body parts are often cut from live victims, especially children. The use of children is likely linked to the pursuit of innocence which, it is believed, enhances the potency of the witchcraft ritual. Moreover, children are more vulnerable to attacks as they are easy to find and capture and do not have the physical strength to fend off attackers.

22. To date, OHCHR has received information about more than 200 cases of ritual attacks against persons with albinism in 15 countries between 2000 and 2013. Owing to the secret nature of witchcraft-related rituals and the vulnerability and stigmatization of the target population, it is believed that many attacks remain undocumented and unreported.

23. The attacks are committed in particularly horrifying circumstances, severely traumatizing survivors and families of the victims. The following examples provide an idea of the nature of these attacks.

24. On 11 February 2013, a 38-year-old woman with albinism was attacked with machetes by her husband and four other men while she was sleeping, and had her left arm chopped off. Her 8-year-old daughter witnessed the attack and saw her father coming out of the bedroom carrying the arm of her mother. The woman survived the attack.

25. On 31 January 2013, a 7-year-old boy with albinism was attacked while he was asleep. The attackers slashed his forehead, right arm, left shoulder and chopped off his left arm above the elbow, using machetes. The child did not survive the attack. His grandfather, a 95-year-old man, was killed while trying to protect his grandson. The child’s father and grandmother were also attacked and survived with serious injuries.

26. In most of the cases documented, the attacks involved dismembering the victim’s limbs and resulted in death. In a few other cases, the victims were beheaded; genitals, ears, and bits of skin were removed; tongues were cut out and the eyes and the heart gouged out. Other types of attacks reported included rape for healing purposes.

¹⁷ Reference is made in the submissions from UTSS and WHRIN to the portrayal of albinism in Hollywood and Nollywood (Nigeria) movies.

¹⁸ Special Representative and Plan International, *Protecting children from harmful practices in plural legal systems with a special emphasis on Africa* (New York, 2012).

27. The information on the various cases collected by OHCHR came from multiple sources, but the level of verification varies in each case. In most cases, the information was received by national and international non-governmental organizations working for the promotion and protection of the rights of persons with albinism, gathered through field work and contacts with family members. Some cases could be confirmed through police records and court verdicts, and a few were verified by OHCHR field presences.

28. According to civil society organizations working on the issue, in countries where witchcraft is practised, the demand for human body parts tends to increase in the lead-up to and during elections, thereby generating greater risks for persons with albinism during these periods.¹⁹

29. As the body parts of persons with albinism are traded for high prices, it is reported that business people and wealthy members of society foment these ritual attacks.²⁰ It is also reported that law enforcement authorities fail to properly investigate and prosecute, and sometimes cover up, such crimes. In one of the cases reported to OHCHR, four high- and middle-ranking police officers were arrested on suspicion of accepting bribes from witchdoctors wishing to escape prosecution.²¹

30. The killing of and attacks against – including mutilation of – persons with albinism violate the right to life, the right to security of person and the prohibition of torture and ill-treatment²² as enshrined in various international human rights treaties.²³ While attacks against persons with albinism are “manifestations of the worst forms of cruel, inhuman or degrading treatment and can never be justified”,²⁴ they also could qualify as torture, both physical and mental, if the authorities fail to provide the necessary preventive and protection measures.

31. Whether any particular ritual killing or attack against persons with albinism is attributable to a State agent needs to be determined on a case-by-case basis. In addition to cases of direct liability, the State violates its obligation to ensure the right to life and the prohibition of torture and ill-treatment by failing to take appropriate measures to prevent, investigate, prosecute, punish or redress²⁵ the harm caused by the attacks on persons with

¹⁹ Submissions from Bien-être des Albinos de Côte d’Ivoire, Association nationale des Albinos de Côte d’Ivoire, Association nationale des Albinos du Sénégal and UTSS. Some cases reported in the media refer to ritual attacks during electoral periods. As an example, see “Swazi Albinos Plead for Protection Ahead of Vote”, *Daily Nation*, 24 May 2013. Available from www.nation.co.ke/News/world/Swazi-albinos-plead-for-protection-ahead-of-vote/-/1068/1861356/-/item/1/-/blp9q0z/-/index.html.

²⁰ Submissions from Special Representative on Violence against Children and UTSS submissions.

²¹ UTSS submission.

²² The generic term “ill-treatment” refers to any form of cruel, inhuman or degrading treatment or punishment in accordance with article 16 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

²³ Article 6, paragraph 1, of the International Covenant on Civil and Political Rights and article 6, paragraph 1, of the Convention on the Rights of the Child consecrate the right to life. Article 9 of the Covenant provides for the right of every person to security of person. Article 7 of the Covenant and article 37 (a) of the Convention prohibit torture and ill-treatment. See also the Convention against Torture.

²⁴ Press statement, “Not ghosts”.

²⁵ The Committee against Torture considers that the term “redress” in article 14 of the Convention encompasses the concepts of “effective remedy” and “reparation”, entailing the full scope of measures of restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition. See Committee against Torture, general comment No. 3 (2013) on implementation of article 14 by States parties, para. 2.

albinism committed by non-State actors.²⁶ The responsibility to protect and prevent is particularly relevant in cases of persons in vulnerable situations, such as persons with albinism, and in circumstances where the authorities are aware of the real and imminent danger faced by such persons and communities.

32. Measures taken by some States to address the issue of attacks and discrimination against persons with albinism are analysed in section D of the present chapter.

B. Trade in organs, trafficking in persons and sale of children

33. The killing of and attacks against persons with albinism with a view to using their body parts for ritual purposes is often related to the trade in organs and, in some cases, linked to trafficking in persons and the sale of children.

34. The secrecy surrounding witchcraft and the underground nature of its associated market make it difficult to find evidence about trafficking of persons and organs. However, the issue has been reported by organizations working with persons with albinism, as well as United Nations agencies and bodies.

35. A 2010 UNICEF anthropological study of contemporary practices in Africa mentioned that the body parts of persons with albinism were commercially traded.²⁷ In November 2009, in its concluding observations on the Democratic Republic of the Congo, the Committee on Economic, Social and Cultural Rights expressed deep concern that persons with albinism had been killed and their organs used or trafficked for witchcraft ceremonies (E/C.12/COD/CO/4, para. 19).

36. The demand for the body parts of persons with albinism appears to be sustained by the high prices that some are willing to pay to obtain them. A 2009 report of the International Federation of Red Cross and Red Crescent Societies noted that the market for body parts of persons with albinism was “generated by big-money buyers who use them as talismans to bring luck and above all wealth” and that, according to senior police officers in Dar es Salaam, “a complete set of albino body parts – including all four limbs, genitals, ears, tongue and nose – was fetching the equivalent of 75,000 US dollars”.²⁸

37. There are concerns that the market is an incentive for the desecration of graves and subsequent robbery of body parts. To date, OHCHR has received reliable information on 19 cases of grave robberies in two countries. The cases were reported by organizations working with persons with albinism, through contacts with family members. Some cases were confirmed by police records.

38. Associations of persons with albinism have alleged that the body parts of persons with albinism are traded across borders between some countries in Africa and that, in some cases, the trade in organs is linked to trafficking in persons. However, data are scarce on the subject and difficult to verify.

39. In the review of the third periodic report of Kenya submitted to it in 2012, the Human Rights Committee expressed concern at continuing reports of trafficking in persons

²⁶ See Human Rights Committee, general comment No. 6 (1982) on the right to life, paras. 3 and 5, and general comment No. 7 (1982) on the prohibition of torture or cruel, inhuman or degrading treatment or punishment, para. 1.

²⁷ Cimpric, *Children Accused*, p. 28.

²⁸ *Through Albino Eyes: The plight of albino people in Africa's Great Lakes region and a Red Cross response* (Geneva, 2009), p. 5. Available from www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf.

for labour, sexual exploitation and body parts, particularly of persons with albinism (CCPR/C/KEN/CO/3, para. 17). In 2010, a court in the United Republic of Tanzania sentenced a national from another country for kidnapping and trafficking in persons, for trying to sell a man with albinism for US\$ 250,000.²⁹ The arrest of a man crossing the border with the Democratic Republic of the Congo, carrying the head of a child with albinism in his suitcase, was mentioned in a UNICEF report.³⁰ Other cases of cross-border trade and trafficking in persons were reported to OHCHR by multiple sources.

40. In relation to the sale of children, the Special Representative on Violence against Children has noted that: “In some cases, acts of violence and killings have been committed by members of the family, and children have been known to have been ‘sold’ by their families to outsiders. The absence of adequate registration of vital statistics, such as information on birth and death, further enhances the likelihood of cases going unreported and failing to be investigated”.³¹

41. In its review of the United Republic of Tanzania under the Optional Protocol on the sale of children, child prostitution and child pornography, the Committee on the Rights of the Child expressed its deep concern about reports of the sale of children for ritual purposes, including ritual killings of children with albinism (CRC/C/OPSC/TZA/CO/1, paras. 20 and 21).

42. While article 3 (a) of the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime, refers to trafficking in person for the purposes of exploitation, including removal of organs, it does not apply to cases of trade in organs.

C. Infanticide and abandonment of children

43. As mentioned by the Special Representative on Violence against Children, “children with albinism are at high risk of abandonment, discrimination and exclusion as a result of the appearance of their skin, and due to disability factors such as impaired eyesight and high susceptibility to skin cancer and other health risks associated with albinism”.³²

44. Harmful traditional practices of infanticide of children with albinism have been reported in a few East African tribes.³³ Written submissions received by OHCHR from civil society organizations in African countries refer to persistent beliefs that children with albinism are a potential source of misfortune and/or the proof of unfaithful wives. As a result, sporadic instances of infanticide still occur and the abandonment of children seems to be a common practice.³⁴

²⁹ UTSS submission and court verdict.

³⁰ Cimpric, *Children Accused*, p. 28.

³¹ Special Representative’s submission.

³² Ibid.

³³ The Sukuma tribe traditionally killed their babies with albinism as soon as they were born. Over time, the child with albinism was spared from the infanticide and allowed to grow to adulthood but would be buried alive with the Sukuma Chief when the latter died. In the Chagga tribe, newborns with albinism were traditionally left in the forests to die. In the Digo and Maasai tribes, newborn children with albinism were killed after a trial by ordeal. See *Children with Albinism in Africa: Murder, Mutilation and Violence*, report submitted to the Special Representative on Violence against Children by UTSS (2012).

³⁴ Most of the submissions from civil society refer to the abandonment of children. Submissions from Albinos Sans Frontières, Bien-être des Albinos de Côte d’Ivoire, the Association nationale des Albinos du Sénégal and the Association pour la promotion des Albinos au Cameroun refer to

45. The documentation of these cases is difficult as, like in other births considered as “abnormal”, the death of a child considered a curse is perceived as a beneficial act for the family and the community. Thus, the killing is often done in secret and the birth is often unreported.³⁵ In some cases, a midwife assists in killing the child, announcing that the child is stillborn and burying the child immediately, without the parents seeing it.³⁶

46. As mentioned earlier, the general absence of adequate registration of births and deaths of persons with albinism hinders the reporting and investigation of cases of infanticide. A few such cases have been reported to OHCHR by different sources.

47. Article 6 of the Convention on the Rights of the Child consecrates as an inherent right of the child the right to life, survival and development and article 19, paragraph 1, requests States parties to take all appropriate measures to protect the child from all forms of physical or mental violence. States parties are obliged to protect all children from infanticide and abandonment, and should take steps towards the abolition of practices which put the life of children under threat, including through the adoption of appropriate criminal legislation.³⁷

D. Measures taken by States concerned

48. The State’s obligations to take the necessary measures to prevent attacks and discrimination against persons with albinism are particularly critical due to the vulnerable situation of this group. These measures include the appropriate criminalization of such acts, their investigation and the prosecution of perpetrators. They also include preventive measures to protect persons with albinism and measures to ensure the access of survivors and their families to effective remedies, redress and rehabilitation, including health care, shelters and other services.

1. Legal response and impunity

49. In its resolution 23/13, the Human Rights Council expressed concern about the impunity associated with attacks against persons with albinism.

50. Very little information was available as to the legal status of the cases of ritual attacks recounted to OHCHR. While some investigation and prosecution seems to take place, sentencing appears to be extremely rare: of the 72 murders of people with albinism documented in the United Republic of Tanzania since 2000, only five cases are known to have resulted in successful prosecutions.³⁸ While noting the State party’s commitment to prevent, investigate and prosecute cases of mutilation and killing of persons with albinism, the Human Rights Committee expressed concern about the high number of reported incidents in the United Republic of Tanzania and the limited number of court cases and slow proceedings in this regard (CCPR/C/TZA/CO/4, para. 15). In relation to four reported cases in 2013 in the country, the Attorney General’s Chambers informed OHCHR that a significant number of suspects had been apprehended and charged and that a special task

infanticide.

³⁵ Cimpric, *Children Accused*, p. 26.

³⁶ UTSS submission.

³⁷ See also Committee on the Rights of the Child, general comment No. 13 (2011) on the right of the child to freedom from all forms of violence and Human Rights Committee, general comment No. 6, para. 5.

³⁸ See press release, “Pillay condemns ‘abhorrent’ attacks on people with albinism in Tanzania”, 5 March 2013. Available from www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=13074&LangID=E.

force was assisting law enforcement authorities in the investigation and prosecution of these cases.³⁹

51. From the information gathered from OHCHR in Burundi, since 2008 11 people have been arrested in relation to attacks against persons with albinism, of whom six escaped and one was convicted. In 2010, in the Democratic Republic of the Congo, two persons were sentenced for the murder of a person with albinism. According to available information from Côte d'Ivoire and Nigeria, two cases have resulted in convictions in each country.

52. The monitoring of court proceedings concerning these crimes by civil society actors is very rare, and associations of persons with albinism often lack the financial means and expertise to conduct legal monitoring activities.

53. According to information received by OHCHR, persons with albinism face significant difficulties in having their cases brought to justice for the following reasons: the fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses owing to the ostracism they face within their community and, frequently, the involvement of family and community members in the attacks; the lack of awareness of legal rights; the lack of financial resources; the inadequate capacity of the judicial system to address such cases; the lack of legal aid and adequate legal representation; and the lack of knowledge of or confidence in the law enforcement and justice systems.

54. As noted by the Special Representative on Violence against Children, "The human rights violations committed against children with albinism are of the highest severity. Discrimination, harassment and violence, including cases of mutilation and murder, are often met with passivity and are rarely reported, as they take place in remote areas and because such children are perceived as bringing bad luck and being a source of shame to even their own families and communities ... Mutilation and murders of children with albinism are mostly met by social silence and indifference".⁴⁰

55. The information available to OHCHR indicates that access by persons with albinism to justice, remedies and redress is extremely limited. The right of victims of human right violations to claim redress and reparation is enshrined in most universal⁴¹ and regional human rights instruments.⁴² Under this right, States not only have the duty to provide redress for the harm suffered but also need to guarantee equal and effective access to justice.⁴³ Reparations should be proportional to the gravity of the violation and the harm suffered and could take the form of restitution, compensation, rehabilitation, satisfaction, and guarantees of non-repetition.⁴⁴

56. Further work is required in collecting legal data, including the analysis of criminal laws in the countries concerned. This should be done in close cooperation with Member States.

³⁹ Correspondence received from the Permanent Mission of the United Republic of Tanzania, 21 March 2013.

⁴⁰ Special Representative's submission.

⁴¹ Universal Declaration of Human Rights, art. 8; Covenant on Civil and Political Rights, art. 2; International Convention on the Elimination of All Forms of Racial Discrimination, art. 6; Convention against Torture, art. 14; Convention on the Rights of the Child, art. 39.

⁴² African Charter on Human and Peoples' Rights, art. 7; American Convention on Human Rights, art. 25; Convention for the Protection of Human Rights and Fundamental Freedoms, art. 13.

⁴³ See Committee against Torture, general comment No. 3, para. 5.

⁴⁴ See Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of the International Humanitarian Law, paras. 18–23.

2. Preventive measures

57. OHCHR received examples of a number of preventive measures taken by those States in which the highest number of attacks on and killings of persons with albinism have been reported. These measures include the public condemnation of attacks and killings; the appointment of a person with albinism as Member of Parliament or Cabinet; the banning of witchdoctor licences; public awareness-raising campaigns and the provision of temporary shelter to persons under the threat of attacks.

58. While the effectiveness of these measures is to be evaluated, concerns were expressed in relation to poor living conditions in temporary shelters, particularly the sanitary conditions, overcrowding and food.⁴⁵ There is also concern that these shelters reinforce the marginalization of persons with albinism and keep children separated from their families.

59. It was reported that important initiatives are under way, such as the instruction to register disaggregated data on persons with albinism in the United Republic of Tanzania and the elaboration of a national policy to promote and protect the rights of persons with albinism in Burundi.

E. Action by international and regional human rights mechanisms

60. Overall, the human rights situation of persons with albinism has received little attention from Member States, the international community and human rights advocates. International and regional human right mechanisms have only sporadically raised the issue.

61. Specific mention of the situation of persons with albinism has been made in a few concluding observations from the Human Rights Committee,⁴⁶ the Committee on Economic, Social and Cultural Rights,⁴⁷ the Committee on the Rights of the Child⁴⁸ and the Committee on the Elimination of Discrimination against Women.⁴⁹

62. On 4 May 2013, a joint press statement was issued by six United Nations special procedures mandate holders, highlighting the gravity of attacks against persons with albinism and the profound discrimination they face.⁵⁰ The then Special Rapporteur on extrajudicial, summary or arbitrary executions included a brief reference to the killings of persons with albinism in his 2009 report (A/HRC/11/2, para. 49), as did the current Special Rapporteur in his oral statement at the twenty-third session of the Human Rights Council.⁵¹ As part of the universal periodic review, recommendations were made to the Governments of Burundi,⁵² Uganda⁵³ and the United Republic of Tanzania⁵⁴ and to take preventive and protection actions to address attacks and discrimination against persons with albinism.

⁴⁵ According to information gathered by OHCHR in Burundi, persons with albinism used to be accommodated in police stations and houses near communes. In the United Republic of Tanzania, they are sheltered in boarding schools for children with special needs.

⁴⁶ CCPR/C/TZA/CO/4, para. 15, and CCPR/C/KEN/CO/3, para. 17.

⁴⁷ E/C.12/COD/CO/4, para. 19, and E/C.12/TZA/CO/1-3, para. 5.

⁴⁸ CRC/C/OPSC/TZA/CO/1, paras. 20 and 21; CRC/C/BDI/CO/2, paras. 33 and 34; and CRC/C/GNB/CO/2-4, paras. 28 and 29.

⁴⁹ A/63/38, paras. 142 and 143.

⁵⁰ Press statement, "Not ghosts".

⁵¹ Opening remarks by Christoph Heyns, 30 May 2013.

⁵² A/HRC/10/71, para. 80.5, and A/HRC/23/9, paras. 126.31 and 126.84.

⁵³ A/HRC/19/16, para. 111.35.

⁵⁴ A/HRC/19/4, paras. 85.33–35 and 85.39–42.

63. In its thirty-fourth activity report submitted to the African Union Assembly of Heads of State and Government, the African Commission on Human and Peoples' Rights identified the situation of persons with albinism in Kenya and the United Republic of Tanzania as a matter of concern, highlighting some initiatives taken by the concerned States, such as the provision of free sunscreen and education campaigns.⁵⁵

V. Discrimination against persons with albinism

64. The right to equality and non-discrimination is enshrined in the Universal Declaration of Human Rights (art. 2) and is at the core of the main international human rights treaties⁵⁶ and regional human rights instruments.⁵⁷ The Universal Declaration and the two Covenants refer to discrimination on the basis of "colour" and the open-ended category "other status".

A. Main forms of discrimination

65. Structural discrimination against and marginalization and social exclusion of persons with albinism have been reported as a global phenomenon. According to submissions received by OHCHR, persons with albinism have difficulties getting the health care they require and accessing education, employment, legal protection and redress. This situation is compounded by deeply entrenched societal prejudices against and stereotypes of persons with albinism.

66. The following testimony illustrates the nature and scope of discrimination suffered by persons with albinism throughout their lifetime:

I have never known happiness in my life, and every time I think about my future tears flow in my eyes, I wonder if I would be happy one day? I still remember my difficult childhood, my father has always rejected me because I am an "albino". One day he told my brothers that I represented the devil, that I was not his daughter. He refused to send me to school. My maternal uncle enrolled me in a public school where I studied until third grade. Teachers and students made fun of me because I could not see the class-board. I could not endure all these insults, so I dropped out of school. This is how I found myself on the street, helpless. When I tried to sell some goods on the market nobody wanted to buy what I was selling. I was raped by a man and have a 15-month-old child. I feel desperate and lost.⁵⁸

67. As noted by the Independent Expert on minority issues, "one of the major challenges for people living with albinism is that they are often rejected and abandoned by their own families under the societies' pressure".⁵⁹

⁵⁵ African Commission on Human and Peoples' Rights submission.

⁵⁶ Covenant on Civil and Political Rights, art. 2; Covenant on Economic, Social and Cultural Rights, art. 2; Convention on the Rights of the Child, art. 2; International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, art. 7; and Convention on the Rights of Persons with Disabilities, art. 5. The Convention on the Elimination of All Forms of Racial Discrimination prohibits discrimination on the ground of race and the Convention on the Elimination of All Forms of Discrimination against Women on the ground of gender.

⁵⁷ African Charter on Human and Peoples' Rights, arts. 2 and 3, and American Convention on Human Rights, art. 24.

⁵⁸ Albinos Sans Frontières submission.

⁵⁹ Press statement, "Not ghosts".

68. As noted earlier, children with albinism are at high risk of abandonment, and women giving birth to children with albinism are often repudiated by their husband and families. Families frequently neglect the education of children with albinism as they believe their education is a waste of resources. Those who attend school often suffer from teasing and bullying from classmates. In some cases, their inability to see the blackboard, owing to significant vision impairment, forces them to drop out of school.⁶⁰ As a result, many have low education levels and do not have all the necessary social or economic tools to live productive lives. This marginalization can be a contributing factor to a shorter life expectancy than for other members of the same society.

69. The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health noted that “people living with albinism often do not receive the necessary special attention, health care or treatment that corresponds to their health needs”.⁶¹ Many cannot, for example, afford simple remedies, such as sun cream, that would protect them from the elevated risk of developing skin cancer.

70. Without effective and affordable access to justice, persons with albinism are denied the possibility of claiming their rights and contesting the abuses or human rights violations to which they are exposed.⁶²

71. All these forms of discrimination are interrelated, and the principle of the indivisibility and interdependence of human rights should be highlighted.⁶³ The right to education of persons with albinism, for instance, is adversely affected due to the vision impairment they suffer. A poor education, in turn, affects the right to an adequate standard of living, consigning many persons with albinism to poverty.

72. The right to work is provided for in article 6 of the International Covenant on Economic, Social and Cultural Rights, which thus prohibits discrimination in access to and maintenance of employment, including on the basis of colour and on the ground of “other status”. It also prohibits denying or limiting equal access to decent work to all persons, especially disadvantaged and marginalized individuals and groups.⁶⁴ Reference is also made to the ILO Convention No. 111 (1958) concerning Discrimination in Respect of Employment and Occupation. The right of everyone to the enjoyment of the highest attainable standard of physical and mental health is recognized by article 12, paragraph 1, of the Covenant. According to the Committee on Economic, Social and Cultural Rights, “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds”.⁶⁵ Article 26 of the International Covenant on Civil and Political Rights, article 5 of the International Convention on the Elimination of

⁶⁰ The Special Rapporteur on the right to education has referred to dropout rates of children with albinism and ways to reduce them (press statement, “Not ghosts”). All the written submissions received from civil society referred to discrimination in education and/or incessant bullying and name-calling.

⁶¹ See press statement, “Not ghosts”.

⁶² See paragraphs 49–56 of the present report describing the challenges persons with albinism face in accessing justice.

⁶³ See for instance, Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) on the right to the highest attainable standard of health, paragraph 3, referring to how the right to health is closely related to and dependent upon the realization of other human rights, including the rights to food, work, education, human dignity, life, non-discrimination and the prohibition against torture.

⁶⁴ *Ibid.*, general comment No. 18 (2005) on the right to work, paragraphs 12 (b) (i) and 23.

⁶⁵ General comment No. 14, paragraph 12 (b).

All Forms of Racial Discrimination and article 15 of the Convention on the Elimination of All Forms of Discrimination against Women similarly enshrine the right of everyone to equality before the law.

73. The right to freedom from discrimination would require that States ensure that persons with albinism are afforded equal protection under the law and in practice.⁶⁶ States are obliged to ensure that their laws, policies and practices address the specific needs of persons with albinism.

B. Discrimination against women and children

74. Women and children with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination. In addition, children are particularly targeted for ritual killings (see para. 21 above) and women with albinism are sometimes victims of sexual violence.⁶⁷

75. The Committee on the Elimination of Discrimination against Women has referred to women with albinism as a group of women in a vulnerable situation, meaning that they are at risk of being victims of multiple discrimination.⁶⁸ According to the Special Rapporteur on violence against women, its causes and consequences, violence against women is deeply rooted in multiple layers of discrimination and inequality. As these layers of discrimination intersect, violence against women intensifies. Addressing systematic discrimination and marginalization is crucial to ending violence against women (see A/HRC/17/26). In her 2012 report to the Council, the Special Rapporteur included witchcraft-related killings under gender-related killings (A/HRC/20/16, paras. 14 and 16).

76. The Committee on the Rights of the Child has also expressed serious concerns at reports of killings of and attacks against children with albinism, addressing this issue under the right to equality and non-discrimination (art. 2 of the Convention), among other rights. In the case of Burundi, the Committee expressed concern in its concluding observations that “de facto discrimination of children prevails [in the country] and is tolerated in the State party vis-à-vis ... albino children” (CRC/C/BDI/CO/2, paras. 29 and 30). The Committee encouraged the State party to review legislative instruments and adopt a comprehensive strategy, including awareness-raising, to eliminate discrimination on any grounds and against all vulnerable groups, particularly children with albinism (ibid.).

C. Areas requiring further study

77. Further analysis and consultations are required to determine the category into which persons with albinism may fall and the basis for discrimination against them. In some of the written submissions received from associations working with persons with albinism they are considered persons with disabilities.⁶⁹ Others refer to discrimination on the ground of skin colour.⁷⁰

⁶⁶ Human Rights Committee, general comment No. 18 (1989) on non-discrimination, paras. 1,5 and 10.

⁶⁷ Submissions from Albinos Sans Frontières, Bien-être des Albinos de Côte d’Ivoire, Confédération nationale des Albinos de Guinée, Association des femmes albinos “Espoir”, Écran Totale and UTSS.

⁶⁸ In its concluding observations on the United Republic of Tanzania, the Committee expressed concern at reports that women and girls with albinism had been targeted in ritual killings, recommending that the State party protect them (A/63/38, paras. 142–143). See also Committee on the Elimination of Discrimination against Women, general comments Nos. 12, 19 and 28.

⁶⁹ Albinism Fellowship of Australia, Association nationale des Albinos du Sénégal, Association of

78. Under the Convention on the Rights of Persons with Disabilities, persons with albinism could be considered persons with disabilities. According to article 1 of the Convention, persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. However, the Committee on the Rights of Persons with Disabilities has not dealt with the issue so far. According to the information received, some national legislation recognizes albinism and associated visual impairment as a disability.⁷¹ Additional review of national legislation on disability needs to be conducted. Moreover, consultations with persons with albinism are required on the issue of self-identification.

79. With regard to disabilities, the Durban Declaration and Programme of Action urges States and international and regional organizations to address the situation of persons with disabilities who are also subject to racism, racial discrimination, xenophobia and related intolerance; and to take necessary measures to ensure their full enjoyment of all human rights (para. 57).

80. Similarly, the Committee on the Elimination of Racial Discrimination has not yet examined the issue of discrimination on the basis of colour with respect to persons with albinism.

81. The Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance, referring to people living with albinism, has noted that: “Regardless of whether one has a lighter or a darker skin compared to the majority population in a country or a community, everyone is entitled to the same rights, dignity and treatment ... [and] the same opportunities as anyone else.” On the other hand, the Independent Expert on minority issues has stated that: “People living with albinism do not fall under the internationally accepted definition of minorities ... However, their stigma, the lifelong social exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour”.⁷²

82. The Durban Declaration and Programme of Action, while not addressing specifically the situation faced by persons with albinism, recognizes that racism, racial discrimination, xenophobia and related intolerance occur on the grounds of race, colour, descent or national or ethnic origin, and that victims can suffer multiple or aggravated forms of discrimination based on other related grounds (including “other status”). It notes that these practices may be aggravated by inequitable distribution of wealth, marginalization and social exclusion.

83. Organizations working with persons with albinism advocate for considering them as a group requiring special attention, as the discrimination and attacks they are exposed to are mainly rooted in erroneous beliefs and myths that must be addressed.⁷³

Gambia Albinos and UTSS.

⁷⁰ Confédération nationale des Albinos de Guinée, Association des Femmes albinos “Espoir”, Association nationale des Albinos du Sénégal, Organisation mauritanienne pour l’appui et l’insertion des Albinos and UTSS.

⁷¹ For instance, the amended version of the Persons with Disabilities Act in Kenya recognizes albinism as a disability. Discrimination laws in Australia protect the rights of people with disabilities, including albinism (Albinism Fellowship of Australia submission). In Canada and the United States, persons with albinism are considered “legally blind” and thus as persons with disabilities according to domestic legislation (UTSS submission).

⁷² Press statement, “Not ghosts”. The list of types of minorities included in the 1992 Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities is not open-ended.

⁷³ Albinos Sans Frontières and UTSS submissions. According to UNICEF, in order to understand the

VI. Preliminary conclusions and recommendations

84. OHCHR expresses its grave concern at the severity of the human rights violations committed against persons with albinism in many countries, including at the multiple and intersecting forms of discrimination they, and particularly children and women, face. Persons with albinism have the right to start living without fear of being killed or dismembered and without facing discrimination.⁷⁴

85. OHCHR recommends the following actions.⁷⁵

A. To States

86. It is recommended that they:

(a) Address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating superstition and stigma vis-à-vis albinism, including through education and awareness-raising campaigns;

(b) 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;

(c) Take the necessary legislative measures to criminalize harmful practices;⁷⁵

(d) Evaluate and address the needs of persons with albinism, including through a census of the population and the mandatory registration of birth and death of persons with albinism;⁷⁵

(e) Increase efforts to put an end to the various forms of crimes affecting persons with albinism, strengthen the legal response to such crimes and bring perpetrators to justice, through prompt and impartial investigations;

(f) Guarantee the victims' right to justice and redress, and provide medical, psychosocial and legal support to victims of attacks;

(g) Adopt firm measures and policies to address the multiple and intersecting forms of discrimination affecting persons with albinism, including by ensuring they have adequate access to health care, social services, employment and education;

(h) Adopt a comprehensive strategy to eradicate violence and discriminatory practices affecting persons with albinism;

(i) Develop national institutional mechanisms for the protection and promotion of rights of persons with albinism,⁷⁵ including by ensuring that national human rights institutions effectively address the human rights situation of persons with albinism;

particular character of ritual killings of person with albinism, it is essential to analyse the types of representations associated with these harmful practices and which are linked to the belief that persons with albinism possess magical characteristics. Cimpric, *Children Accused*, p. 28.

⁷⁴ See press release, "Pillay condemns 'abhorrent' attacks".

⁷⁵ The present recommendation is part of a set of recommendations resulting from the international expert's consultation on the protection from harmful practices in plural legal systems (Special Representative and Plan International, *Protecting children from harmful practices in plural legal systems with a special emphasis on Africa*).

(j) Support civil society organizations working for the promotion and protection of rights of persons with albinism;

(k) Integrate the situation of persons with albinism into human rights national action plans or action plans to combat discrimination.

B. To international and regional human rights mechanisms

87. It is recommended that:

(a) The United Nations treaty bodies conduct a more systematic review of the situation of persons with albinism when assessing compliance of States parties with their international obligations arising from the relevant treaty provisions;

(b) The relevant mechanism of the Human Rights Council requests a follow-up study on the human rights situation of persons with albinism;

(c) The special procedures of the Human Rights Council – particularly the mandates on extrajudicial, summary or arbitrary executions; on torture and other cruel, inhuman or degrading treatment; on racism; on health; on education; on violence against women; and on trafficking in persons, especially women and children – pay greater attention to human rights violations committed against persons with albinism during their country visits, and consider the submission of thematic reports on the situation of persons with albinism, as relevant;

(d) The Durban follow-up mechanism specifically address the situation of persons with albinism during a relevant session;

(e) African Union mechanisms pay further attention to human rights violations committed against persons with albinism, including by seeking effective means to combat discrimination and violence against them.

C. To the international community

88. It is recommended that it:

(a) Provide financial assistance for the development of technical cooperation activities aimed at supporting measures to prevent and combat discrimination and attacks against persons with albinism, and at providing assistance to the victims and their family members;

(b) Strengthen international, regional and bilateral cooperation for the prevention of cross-border crimes affecting persons with albinism, notably trafficking in persons, child trafficking and organ trafficking.⁷⁵