



Africa Albinism Alliance

Submission in response to call for input for report on 20th anniversary of the Durban Declaration and Programme of Action

Submission by **Africa Albinism Alliance** to the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerances.

8 August 2021

Submitting organisation:

The African Albinism Alliance, established in February 2021 is a consortium of organizations working to promote – through human rights advocacy – the dignity, rights and welfare of persons with albinism and their family members in Africa. The Alliance aims to be a professional regional entity, committed to building strong partnerships with various organizations representing persons with albinism, particularly in Africa, to ensure that the [Regional Action Plan](#) (2017-2021) and its replacement: the [African Union Plan of Action to End Attacks and other Human Rights Violations Targeting Persons with Albinism \(2021-2031\)](#) is implemented at the national level with concrete measures, including through national action plans with multi-year budgets; and that the positive effects of these measures concretely advance the enjoyment of human rights by persons with albinism in the Africa region. The Alliance is currently in its pilot phase (March 2021 – March 2023).

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Introduction:

The African Albinism Alliance appreciates the opportunity to provide the information below to the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance (Special Rapporteur on Racism) to inform her upcoming report on 20th anniversary of the Durban Declaration and Programme of Action.

Despite experiencing racial discrimination on the basis of colour, persons with albinism in Africa have not effectively benefited from the Durban Declaration and Programme of Action and the accompanying legislative, policy, programmatic frameworks at the country level that give effect to this declaration. Part of the reason for this is the lack of recognition, understanding and consensus that the discrimination experienced by persons with albinism on the basis of their colour is a manifestation of racial discrimination. The African Albinism Alliance asks the Special Rapporteur to provide guidance on the issue in her upcoming report. In addition, the organisation also

requests the Special Rapporteur to reflect on associated racial discrimination experienced by families of persons with albinism and the appropriate response.

This submission discusses persons with albinism in Africa as victims of racial discrimination; the sources, causes, forms and contemporary manifestation of such racial discrimination; the growing recognition of this racial discrimination at the international level and associated racial discrimination experienced by families of persons with albinism as an unresolved issue.

Albinism definition & Statistics in Africa

Albinism is a relatively rare, non-contagious, genetically inherited condition in which a person produces little to no melanin, resulting in little to no pigmentation, in the skin, hair and eyes. This lack of melanin often results in a pale or “white” appearance compared to other members of their family, community or ethnic group causing hypervisibility. In addition, the lack of melanin results in two congenital and permanent health conditions: visual impairment of varying degrees as well as high vulnerability to skin damage from ultraviolet rays, including skin cancer. Albinism affects people worldwide regardless of race, ethnicity or gender. Africa has one of the highest prevalence’s of persons with albinism in the world. The prevalence of persons with albinism on the continent varies from 1 person in 5,000 to 1 person in 15,000, with selected populations in Southern Africa having a prevalence of 1 person in 1,000.

Multiple and intersecting discrimination

The UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism reports show that people with albinism in Africa experience multiple and intersecting discrimination on the basis of their impairments (disability), colour gender and age.¹ Whilst there is greater recognition of the discrimination faced by persons with albinism based on their disability, in particular their visual impairment and greater access to disability protection frameworks there is still relatively little appreciation of the racial discrimination experienced by persons with albinism.

Racial discrimination against persons with albinism in Africa on the basis of colour

Persons with albinism in Africa face discrimination stemming from their unusual appearance, in particular their colouring.² Colour is a critical underlying factor at the heart of discrimination against persons with albinism on the continent. Oculocutaneous Albinism Type 2 (OCA2) is the most prevalent type of albinism on the African continent.

¹ UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Albinism Worldwide. U.N. Doc. A/74/190 (July 18, 2019)

Relebohile Phatoli, Nontembeko Bila and Eleanor Ross, “Being black in a white skin: beliefs and stereotypes around albinism at a South African University”, in African Journal of Disability, vol. 4, No. 1, (2015).

² UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism U.N. Doc. A/72/131 (14 July 2017)

This type of albinism characterised by pale or light colouring of any or all of the skin, hair and eyes make persons with albinism hyper visible in an environment where the majority of the black population have darker pigmentation. Persons with albinism therefore often appear starkly different in comparison with members of their family and their communities. Part of the challenge in grappling with this issue has been that, persons with albinism who are discriminated against on the basis of their colour, are often times the same race, descent, national and ethnic origin as those who persecute them. Discrimination against persons with albinism on the basis of colour is also linked to a state of “in-between-ness”, where persons with albinism are often perceived by their societies as not black or melanated enough, not white enough or too white. In many societies in this region persons with albinism are thus perceived and treated as outsiders of their communities.

The manifestations of discrimination against people with albinism on the basis of colour include harmful practices and violence, consisting of, but not limited to, physical attacks, mutilation and trafficking in body parts reported in 27 countries in sub-Saharan Africa. This has been fuelled and perpetuated by widespread and long-term ignorance about albinism which gave birth to various erroneous beliefs in the region about what albinism is and how a person has the condition. Recently there have been calls for the crimes against people with albinism to be considered a hate crime on the basis of color.³In a number of cases this colour discrimination has created barriers to the full enjoyment of the right to health, education, and work, as well challenges in accessing social services for persons with albinism. Women and girls with albinism are vulnerable to sexual abuse.⁴

The racial discrimination has had a tremendous effect on the inclusion and participation of persons with albinism in all spheres of their societies. In some cases, it has led to persons with albinism being rejected and abandoned by their families; normalized isolation, alienation, marginalisation from the rest of society and customary banishment by communities.

Special Procedures

The Special Rapporteur on Racism, together with other Rapporteurs, issued a Statement on the attacks against people with albinism. In the Statement, the SR on Minorities stated:

“People living with albinism do not fall under the internationally accepted definition of minorities,” she said. “However, their stigma, the lifelong social

³ Report of the UNIE at para 75: <https://undocs.org/A/HRC/46/32>

⁴ UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. Albinism Worldwide. U.N. Doc. A/74/190 (July 18, 2019)

exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour.”⁵

The SR on racism added:

““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”, the UN Special Rapporteur on racism, Mutuma Rutere added. “It must be ensured that people living with albinism enjoy their human rights without distinction and have the same opportunities as anyone else.”

Judicial Decisions

In the few cases of attacks against people with albinism that have been prosecuted, in which perpetrators have testified to seeking people with albinism for their “colour”, “complexion” or being “albino” or having albinism.⁶

Committee on the Elimination of all Forms of Racial Discrimination on albinism & racism

The Committee on the Elimination of all Forms of Racial Discrimination has recognised that persons with albinism face racial discrimination and stigmatization on the ground of colour (see [CERD/C/ZAF/CO/4-8](#), paras. 20–21). The Committee has expressed concern at the “discrimination and stigmatization faced by persons with albinism, on the basis of their colour” and has subsequently recommended the implementation of effective measures to protect persons with albinism in action plans and other measures taken to implement the **Durban Declaration and Programme of Action**.

The Committees view that persons with albinism, who are discriminated against on the basis of their colour, even if they are often of the same race, descent, national and ethnic origin as those who oppress them, face a manifestation of racial discrimination is consistent with article 1 of the International Convention on the Elimination of All Forms of Racial Discrimination explanation of racial discrimination. Racial discrimination is described in article 1 as a distinction and an exclusion, restriction or preference based on, inter alia, colour which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of human rights and fundamental freedoms in the political, economic, social, cultural fields or any other field of public life on an equal footing with others. The grounds for discrimination listed do not need to be combined, and discrimination based on any one of these triggers not only the applicability of the Convention, but also all the instruments applicable in the efforts to combat racial discrimination.⁷

⁵ <https://newsarchive.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E>

⁶ See Judgement in the case of Thandizile Mpunzi at para 10. Also see The Judgement in the case of an 17 month old infant murdered in Nigeria, the High Court of Justice, Delta State. Case 0/80/2000. see pp 8-12 in particular

⁷ See 1 above

Associated racial discrimination experienced by families of persons with albinism

Associated racial discrimination experienced by families of persons with albinism is often not addressed or considered in the implementation of the DDPA. The racial discrimination toward persons with albinism sometimes extends to those associated with them; in particular, their immediate family members. The Independent Expert on albinism in her report on women and children impacted by albinism (A/HRC/43/42) noted that family member of children with albinism, especially mothers, are also subjected to discrimination, stigma, isolation, and ostracism because of their association with a person with albinism. Mothers of children with albinism are often blamed for 'causing' the condition in their children.

An ongoing study on mothering and albinism in Africa (<https://motheringandalbinism.com/>) has revealed that fueled by superstitious beliefs about albinism, mothers of children with albinism face discrimination along a continuum of severity, from verbal insults, to reduced or hindered access to education and health and other social services for their child and themselves, social exclusion, intimate partner violence, loss of employment opportunities and abandonment. This discrimination starts at the birth of an infant with albinism and continues across the life span of the child and mother with albinism. The discrimination is often based on the colouring of their child with albinism. There is need for greater protection of families experiencing this.

Conclusion

For the DDPA to continue to be relevant for fighting racial injustice and inequality it has to be inclusive. Individuals and groups of persons with albinism and their families who are or have been negatively affected by, subjected to, or targets of racial discrimination should equally benefit from the DDPA. There is need for greater recognition of the racial discrimination experienced by this perceptible minority at the United Nations, and at the regional, national and local levels.