



Submission in response to the call for input by OHCHR on the protection of the human rights of persons living with rare diseases and their families and carers

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Contributing Organisation's Profile

The Africa Albinism Network (AAN), established in February 2021, is a consortium of organisations working to promote – through human rights advocacy – the dignity, rights, and welfare of persons with albinism and their family members in Africa. The Network aims to ensure that 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, 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.

Introduction

The AAN welcome the opportunity to contribute to the call for input by OHCHR on protecting the human rights of persons living with rare diseases

and their families and carers. This submission will provide information on the experiences of persons with albinism, their families and carers in Africa, whose voices are often underrepresented in such discussions.

Methodology

This submission is based on several reports produced by the UN Independent Expert on the enjoyment of human rights by persons with albinism, interviews and consultations carried out by the AAN in the course of its advocacy work, including surveys, workshops and meetings with scores of albinism groups across more than 20 countries in Africa.

In addition to academic articles, the submission references the following reports by the UN Independent Expert on albinism; Harmful practices and hate crimes targeting persons with albinism (A/HRC/49/52), Access to justice (A/HRC/40/62, Addressing attitudinal barriers experienced by persons with albinism (A/76/166), Albinism Worldwide (A/74/190), The rights of persons with albinism to the highest standard of health (A/HRC/37/57).

About Albinism

Albinism is a rare, non-contagious genetically inherited condition that affects people worldwide regardless of race, ethnicity or gender. The condition is characterised by total or partial lack of melanin production resulting in the absence of pigment in the affected individuals' hair, eyes,

and skin.¹ The lack of pigmentation presents various health concerns to persons with albinism ranging from visual impairment to skin-related challenges such as skin cancer. Other challenges associated with the condition include systematic and structural discrimination, stigmatisation, social exclusion, ritual attacks and killings, maiming, infanticide, banishment, and other harmful practices related to accusations of witchcraft and ritual attacks (HPAWR).²

There are two main types of albinism: oculocutaneous albinism (OCA) and ocular albinism (OA). OCA is a heterogeneous group of genetic conditions characterised by hypopigmentation of the skin, hair and eyes resulting from inadequate or no melanin production. OCA affects the skin, hair and eyes and is categorised into seven sub-types – OCA1 to OCA7.³

OCA is the most visible type of albinism seen across Africa.⁴ Individuals with OCA are strikingly different in complexion from the general African population, while OA, which affects only the eyes, is predominant among males. A mutation in the X chromosome causes OA; since males have only one X chromosome, any alteration in it causes OA. People with OCA and OA suffer from eye conditions such as nystagmus, photophobia and strabismus due to a lack of melanin. Other rare types of the condition include

¹ I Ero et al, 'People with albinism worldwide, A human rights perspective,' (2021), 12. available at https://www.ohchr.org/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf

² Human Rights Council, 'Albinism worldwide. Report of the Independent Expert on the enjoyment of human rights by persons with albinism' (2019) A/74/190

³ https://www.albinism.org/wp-content/uploads/2020/01/NOAH-What-is-Albinism_2020_low-res.pdf

⁴ Kromberg JG, Bothwell J, Kidson SH, Manga P, Kerr R, Jenkins T. TYPES OF ALBINISM IN THE BLACK SOUTHERN AFRICA POPULATION. *East Afr Med J.* 2012 Jan;89(1):20-7. PMID: 26845807.

Hermansky-Pudlak Syndrome (HPS), Chediak-Higashi Syndrome and Griscelli Syndrome. These come with multiple health complications, such as lung and bowel diseases, bruising and bleeding.

SUBMISSIONS

(i) Testimonies from persons with albinism, families and support providers;

The lived experiences and testimonies of persons with albinism, their family members and support providers in Africa have been published widely in articles, books, news publications and documentaries.⁵ However, due to widespread misunderstanding about this rare condition, most people with albinism and their families experience social isolation, stigma and discrimination from their communities.

The narratives show that many mothers of children with albinism in Africa experience stigmatising attitudes and behaviours by healthcare providers, especially at the time of birth; a lack of access to timely quality health services for their children, in particular, skin and eye care; and a lack of health-related education about the cause and care of albinism.⁶ In addition, midwives, who are often the first contact with babies with albinism, sometimes lack knowledge about albinism themselves. Below is a testimony from a single

⁵ People with albinism not ghosts but human beings (<https://albinism.ohchr.org/stories.html>); Looking inside : five South African stories of people living with albinism By Shirley Gunn, Zukiswa Puwana

⁶

mother narrating her ordeal after giving birth to a boy with albinism in the hospital.

"When I first gave birth to my son (with albinism), the Doctor asked me "Why is your son like this". After some time, nurses began coming in and making a mockery of the boy. Some would ask the nurse in charge, 'we heard you had an albino child in your ward?' They will come into the ward, look at the boy, make comments and laugh. This situation got me depressed, and I did not want to breastfeed the boy."

Many women who give birth to children with albinism are often blamed for causing the condition and often face rejection and violence from their husbands. For instance, in Ghana, a mother of two children with albinism narrated that:

"When we married, everything went well until our first child was born with albinism. Then, my husband's attitude suddenly changed. He abused me at the slightest provocation. When I gave birth to the second child, also with albinism, things got worse. The abuse continued and worsened until I was hospitalised due to one such incident. He packed his belongings when I returned from the hospital, leaving me with the two children" – respondent from Ghana.

The lack of understanding of albinism has led to erroneous beliefs about the condition. For example, there is a belief in some African countries that using body parts of persons with albinism in rituals brings good luck or wealth.

One such belief is that sacrificing someone with albinism brings a bumper agriculture harvest.

'I saw a lot of people coming to the house. I heard them saying that we thank God, this year the harvest will be very plentiful, this year will have a lot of harvesting, anytime we have a person with albinism to sacrifice to the gods, we get a lot of harvests that year. So we thank God we have had one, and this one is very energetic and healthy....'⁷

Recently, the COVID-19 pandemic has created yet another dimension of stigma against persons with albinism. Reports have emerged that persons with albinism in certain parts of Africa are being accused and blamed for carrying and spreading the virus.⁸ Moreover, since the disease originated in China, anyone who looks Caucasian is believed to be a disease carrier. This has led to an upsurge of discriminatory practices against this already vulnerable group of persons. For example, a respondent who was stigmatised on three occasions due to COVID-19 narrated.

"In the first instance, I was sitting in the front seat of a minivan. There was a traffic jam, so the cars were moving slowly. A driver on a motorbike stopped next to the minivan and asked the driver why he was letting me ride in the taxi when people like me were spreading the

⁷ <http://www.myjoyonline.com/news/2015/May-1st/unwanted-how-albinos-are-killed-for-rituals-in-ghana.php>.

⁸ N Wipp, 'On the African Continent Discrimination Against Persons with Albinism is Intensifying & nbsp' JFA, Human Rights Journal, (Dec 2021) On the African continent, discrimination against people with albinism is intensifying — The jfa Human Rights Journal; Department of Women, Youth and Persons with disabilities, Deputy Minister Hlengiwe Mkhize on International Albinism Awareness Day, South African Government (13 Jun.2020) <https://www.gov.za/speeches/deputy-minister-hlengiwe-mkhize-international-albinism-awareness-day-13-jun-2020-0000>

virus. He became confrontational and demanded to know where I was from and kept shouting that I should go back and stop spreading the virus. In another incident, I went into a supermarket to get some groceries while sanitising my hands. A guy walked up to me and asked in a local language if I was Chinese. I replied that I was not in the vernacular. He said if I had been, he would have prevented me from going into the shops because Chinese people are spreading the virus. Finally, I had instances when I was walking down the street and had people call me Mr Coronavirus man."

(ii) Key human rights challenges and barriers relevant to persons living with albinism, their families and support providers;

- **Multiple and Intersecting Discrimination experienced by people with albinism**

Persons with albinism experience multiple and intersecting forms of discrimination, stigma and societal prejudices based on their skin colour, visual impairment, disability (arising from skin and eyes), age, gender, socio-economic and other status. These forms of discrimination have devastating and lifelong effects on all aspects of their lives, including access to health, education, employment, safety and security, and social interactions.

Due to their complexion, their body parts are erroneously believed to have magical powers resulting in them being murdered, their body parts being mutilated, and graves desecrated for ritual purposes.⁹ These harmful practices violate their rights to life, security and safety. Women and girls with albinism are at high risk of rights violations because of their gender and age. The belief that having sex with a woman or a girl with albinism cures HIV/AIDS or brings wealth exposes them to sexual assaults and the danger of contracting sexually transmitted infections.

The experience of intersectional discrimination for many people with albinism results in a vicious cycle of human rights violations. A child with albinism is at risk of infanticide, abandonment, or having their limbs or other body parts hacked off for ritual purposes. If they survive these harmful practices, they face lifelong stigma, discrimination and social exclusion. Lack of support and reasonable accommodation for their vision impairment, bullying, name calling and stigma become barriers to accessing education. Consequently, the child may drop out of school without qualification to get employment indoors and engage in outdoor menial jobs. In addition, repeated sun exposure without sunscreen and protective clothing is likely to lead to skin cancer. Access to skin cancer screening and treatment is often limited.

⁹ Various cases of attacks against people with albinism prosecuted in Malawi, Zambia, South Africa and Tanzania have all confirmed that the complexion of people with albinism was a rare feature targeted by proponents of witchcraft and ritual attacks.

Living with a rare condition like albinism intersects with colour, disability, health, and other situations where human rights violations occur. This leads people with albinism to endure discrimination similar to racialised groups.¹⁰

In other cases, societal pressure coupled with belief systems leads to rejection or ex-communication of mothers of children with albinism. For example, in Uganda, clan members usually influence husbands to abandon their children with albinism. Even if the man really wants to remain with his family, when the family members tell him, "We shall all die if you remain with that woman, " they leave their families.

- **Harmful practices**

The UN Independent Expert on albinism, in her recent report to the Human Right Council, defined harmful practices as 'persistent practices and behaviours that are grounded in discrimination based on sex, gender, age and other grounds, as well as multiple and/or intersecting forms of discrimination that often involve violence and cause physical and/psychological harm or suffering.'¹¹ These harmful practices targeting persons with albinism, including ritual murder, mutilation of body parts and grave desecrations for ritual purposes, violate the fundamental human rights of these individuals, such as rights to life and security.

¹⁰ https://tbinternet.ohchr.org/Treaties/CERD/Shared%20Documents/KEN/INT_CERD_NGO_KEN_27123_E.pdf

Also see <https://www.ohchr.org/en/press-releases/2013/05/not-ghosts-human-beings-persons-albinism>

¹¹ A/HRC/49/56

These harmful practices result from wrong belief systems that associate the body parts or the existence of persons with albinism with supernatural powers with the possibility of bringing good or bad omens. For instance, as of March 2022, these misconceptions have caused over 800 reported attacks in 28 countries across the African region since 2006.¹² Examples of testimonies received from persons with albinism and their families:¹³

"I learnt from a family of five children – that they were having sleepless nights because bad people wanted to steal these children and sacrifice them and get body parts." Respondent from Uganda

"It has been reported that miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold and that fishermen weave the hair of persons with albinism into their nets to improve their catches." Respondent from Tanzania¹⁴

- **Access to Health**

Access to adequate health care is paramount to persons with albinism because of their skin and eye conditions. For example, people with albinism are highly susceptible to skin cancer after prolonged sun exposure due to lacking melanin. Various reports state that most people with albinism in Africa (80 per cent on average) die of skin cancer by age 40.¹⁵

¹² https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf

¹³ Ero (N 1) above

¹⁴ Ero (N 1) above

¹⁵ The rights of persons with albinism to the highest standard of health ([A/HRC/37/57](#))

Similarly, melanin deficiency impact how persons with albinism can see. This means that people with albinism have low vision of varying degrees, with the possibility of further deterioration with age.

These conditions require regular healthcare services, especially for early detection and prevention of skin cancer. However, access to health for persons with albinism remains significantly low due to a lack of appropriate healthcare facilities and trained personnel. In addition, access to sunscreen lotion in most African countries remains a significant challenge. Most significantly, the government's unwillingness to add sunscreen to essential drugs and its scarcity leads to a high number of skin cancer cases. These factors can result in a lower lifespan. Here are a few testimonies from the field.¹⁶

"The costs of health care services are very high for the people with albinism in our country. The cost of consultation, skin care products and other related care are inaccessible. There is no health insurance for people with albinism. There are no early medical interventions. This is why many cases of skin cancer are detected every year. The situation in rural and remote areas is even more critical. Because the specialists (dermatologists and ophthalmologists) can only be found in some urban centres." Respondent from Burkina

¹⁶ Ero (N 1) above

"Access to health care is minimal for [people with albinism]. There is only one dermatologist in the province of Nampula. He works only in the central hospital in the city of Nampula. The health professionals in other districts are under-trained in albinism, its causes, and how to detect and treat skin problems due to sun exposure. When a [person with albinism] visits a health professional for reasons outside of the problems associated with albinism, most doctors do not address the issue and, if they do, often are relating misinformation about the condition. We have found that many parents are afraid to take their child [with albinism] to the doctor because they feel they will be blamed for causing albinism." Respondent from Mozambique

"Mainstream hospitals and clinics do not understand the condition. Often people with albinism do not get adequate medical care because the hospitals and clinics are not user-friendly. How can one serve a person they are afraid of because they think by just getting into close contact with them, they too will give birth to a child with albinism? The myths themselves hinder services." Respondent from Zimbabwe

"The emphasis on a curative approach to health has undermined early detection and preventive measures required of cancer, especially through community health education and information. [People with albinism] therefore are denied the right to vital information that could keep them alive." Respondent from Kenya¹⁷

¹⁷ Ero (N 1) above

"In the DRC, these challenges [to access to health] are compounded by many other problems, including instability armed conflicts, extreme poverty, displaced populations, the absence of specialists in dermatology and the lack of basic training in dermatology for dermatologists, health professionals in general, the lack of access to sun protection or dermatological drugs in the country, and lack of support organisations for the dermatology or albinism." Respondent from the Democratic Republic of the Congo

- **Access to Education**

Education is both a human right in itself and an indispensable means of realising other human rights.¹⁸ However, access to education for persons with albinism remains significantly challenging. Several factors, including lack of reasonable accommodation, social stigma, discrimination, poverty, lack of appropriate infrastructure and personnel trained on disability support, superstition and myths surrounding albinism, contribute to low school attendance and the high dropout rate among persons with albinism.¹⁹ Furthermore, in the absence of reasonable accommodation measures, for example, large print textbooks and the provision of assistive devices and technology, students with albinism struggle to reach their full academic potential.²⁰

¹⁸ CESCR, *General Comment 13 on the Right to Education (Art 13)* p1

¹⁹ Ero (N 1) above

²⁰ Ero (N 1) above

Aside from teachers' lack of awareness of the needs of students with albinism and, at times, their unwillingness to accommodate these needs, children with albinism in schools also face discrimination, bullying and labelling by their peers and teachers alike. Often other students refuse to play with children with albinism on their parents' instruction or based on pre-existing prejudices and misconceptions associated with the condition. For instance, in Ghana, a class teacher who was pregnant made a student with albinism in her class sit at the back of the class even though he could not see the blackboard from there because of the belief that being in close contact with him (student with albinism) would cause her to give birth to a child with albinism.²¹ The combined effects of these factors lead to high school dropout rates, low academic performance, and repetition of classes among persons with albinism reducing their chances of an adequate standard of living and participation in political, social, economic and cultural life in their communities.

The situation is even worse in remote and rural areas generally due to a lack of adequate infrastructure such as classroom blocks, teaching and learning material and assistive devices. In addition, large class sizes mean students with special learning needs in mainstream schools receive no individualised support from teachers.²²

- **Rights to work and an adequate standard of living**

²¹ Adonai StudiosGH, "my colour" (albinism documentary 2020, Thisability Episode 10' (2020), Available at <https://www.youtube.com/watch?v=alu2g30CQKs&t=12s> (accessed 10 November 2021)

²² Addressing Attitudinal Barriers experienced by persons with albinism (A/76/166)

Many challenges hinder access to employment for persons with albinism in Africa, including discrimination, lack of qualification due to low education attainment, stigma, marginalisation and lack of reasonable accommodation at workplaces. As a result of these factors, persons with albinism remain unemployed or work in low-paying jobs under hazardous working conditions. Here are some testimonies from respondents:

"Challenges in accessing education lead to the myth that people with albinism are not intelligent. Hence, most companies are not keen to employ people with albinism. Coupled with the general myths surrounding the whole condition, no one is willing to work side by side with a person with albinism." Respondent from Zimbabwe

"My situation was not all that bad, there is no job I can't do, but some people, on looking at our bodies, think we [persons with albinism] are too weak to work." Respondent from Uganda

"Many employers shun engaging persons with albinism to work in their company for the reason that they do not have the capacity to perform and also, they may scare away potential customers." Respondent from Ghana

"The low level of education among persons with albinism in the large north and the prevailing poverty has made them accept small jobs without real qualifications. In addition, there is also discrimination in hiring due to prejudices and the need to adapt the workstation; a PWA that works on a computer needs to place the magnifying glass or zoom

in strongly to see the writings displayed there." Respondent from Cameroon.

"The private sector is still reluctant to employ people with albinism on the pretext that they would not be effective because of their fragile condition. As a result, there are very few initiatives giving the opportunity for people with albinism to benefit from activities generating income." Respondent from Cote D'Ivoire.

- **Access to Justice**

Accessing justice remains a significant challenge for persons with albinism in Africa when their rights are violated due to several factors, including lack of access to information on their rights and recourse, structural and legal barriers, and socio-economic and cultural factors. Due to their low vision, which significantly impacts their education in countries with little to no reasonable accommodation in the classroom, persons with albinism find it challenging to access information about their rights and legal procedures. Similarly, their access to justice is affected by socio-economic and cultural factors such as poverty, stigma, discrimination, lack of family support and the fear of reprisal attacks.²³ Below are some testimonies from persons with albinism regarding access to justice.

²³ Access to justice (A/HRC/40/62)

"The access to information with regards to rights is a challenge as most documents are written in English and generally complex, yet most [persons with albinism] are not educated." Respondent from Eswatini

"The main challenge is the bureaucratic nature of the justice system. It is a long process and can be very exhausting, emotionally draining, and embarrassing, especially for people with albinism who are victims of rape and other attacks. Which is why most of the cases they decide not to report." Respondents from Zimbabwe.

"Delayed justice is justice denied": many murder cases involving the killing of persons with albinism have not been prosecuted to the end in law courts." Respondent from Tanzania.

"Women whose spouses were involved in attacks against their child with albinism often face actual threats of reprisal after testifying against their husbands in investigations of cases of attacks. Reprisal often comes from both the family of her husband and the community at large." Respondents from Kenya.

(iii). The burden of rare diseases in developing countries, particularly in Africa and Asia, preferably with information disaggregated by age, sex, gender, race, ethnicity, socio-economic status and any other relevant factors.

The prevalence of persons with albinism varies from region to region, with Africa recording the highest prevalence with an average of one in 5 000 to one in 15 000 persons and pockets of one in 1,000 in certain communities.

Despite the relatively high prevalence of albinism in the region, few studies provide insight into the burden of albinism in Africa, which are adequately disaggregated.²⁴ Official data has been compiled in only five Member States: Malawi,²⁵ Namibia,²⁶ Kenya,²⁷ Sierra Leone²⁸ and the United Republic of Tanzania.²⁹ In Europe and North America, the prevalence of albinism is estimated to be between one in 17 000 to one in 20 000 persons, with newer studies establishing a higher prevalence in parts of Ireland and the Netherlands, among others.

(iv). Research currently underway on rare diseases, including specific diseases being researched, obstacles experienced by researchers, and interventions which would help address these obstacles.

The AAN does not focus on scientific research on albinism but the human right and relevant social science research and approaches. That said, we support more scientific research where possible and find the links below useful for the question above.

1. <https://www.nih.gov/news-events/news-releases/nih-researchers-develop-first-stem-cell-model-albinism-study-related-eye-conditions#:~:text=Researchers%20at%20the%20National%20Eye,the%20National%20Institutes%20of%20Health.>

²⁴ 1. <https://ojrd.biomedcentral.com/articles/10.1186/s13023-018-0894-3>

2. <https://pubmed.ncbi.nlm.nih.gov/16916463/>

²⁵ Malawi Government, '2018 population and Housing Census, Disability Report' (National Statistical Office 2020) 20.

²⁶ Namibia 2011 Census, 'Disability Report' (Namibia Statistics Agency 2016).

²⁷ Kenyan National Bureau of Statistics (KNBS), '2019 Kenya population and housing census, Volume IV; Distribution of population by socio-economic characteristics' (2019) 9.

²⁸ FM Conteh and L Braima, 'Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra

²⁹ United Republic of Tanzania, 'Disability Monograph' (National Bureau of Statistics 2016).

2. <https://www.nih.gov/news-events/news-releases/nitisinone-increases-melanin-people-albinism>

(v) Challenges to the development of therapies and treatments for rare diseases;

No Comments. We leave this to organisations taking a scientific approach to albinism

(vi) Examples of promising practices, together with the criteria used in evaluating them as such where possible, on how to better protect the rights of persons living with rare diseases and their families and carers, including in resource-poor settings.

Through her work, the former UN Independent Expert on the enjoyment of human rights by persons with albinism Ms Ikponwosa Ero has identified and documented best practices used by states and Civil Society to protect the rights of persons with albinism. See the link for more details. <https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/A-75-170-Addendum.pdf>

Key best practices

- a. Put sunscreen on the list of essential medicines (globally at WHO and also nationally) because sunscreen is essential to the right to life for people with albinism
- b. Count people with albinism in the census under disability as advised by the Washington group on disability statistics

- c. Include people with albinism in surveys and other statistics processes outside of national censuses³⁰
- d. Concrete measures to ensure that people with albinism are protected in larger groups, such as groups of people with disabilities or people with rare conditions. Leaving no one behind should be a cross-cutting principle inter and intra group, especially when the right to life and security are at stake.
- e. Development of national action plans on albinism and with a budget. Adopting a national action plan in line with the African Union plan of action to end attacks and other human rights violations against persons with albinism in Africa³¹ is a crucial policy measure to ensure that states take responsibility for protecting and promoting the rights of persons with albinism.

³⁰ <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/>

³¹ <https://actiononalbinism.org/en/page/sfj6gs7s8kid5f6c6zyhw7b9>