

Joint Shadow Report to the Universal Periodic Review (UPR): Human Rights Situation of Persons with Albinism in Uganda

By



Africa Albinism Network (AAN)

Email: info@africaalbinismnetwork.org

Website: www.africaalbinismnetwork.org



Women and Children with Albinism in Uganda (WACWAU)

Email: womenchildrenwithalbinism@gmail.com

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Africa Albinism Network (AAN): AAN is a non-governmental organization working to promote the dignity, rights, and welfare of persons with albinism and their family members in Africa.

Women and Children with Albinism in Uganda (WACWAU) is a registered NGO aiming to serve the needs of the most vulnerable in their community. WACWAU primary beneficiaries include: Women with albinism; Children with albinism; and Parents and guardians of children with albinism. WACWAU was established in 2015 and formally registered in 2019.

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Executive Summary

The submission is based on a desk review of Uganda's UPR documents and relevant national laws and policies, including the Persons with Disabilities Act, 2020 and the National Action Plan for Persons with Albinism 2020–2025, as well as reports on albinism in Uganda. It is further informed by consultations with Uganda-based organisations of persons with albinism through interviews, focus group discussions, and questionnaire responses, including testimonies, district-level information, and evidence on implementation gaps.

The submission finds that, although Uganda has made progress by recognising albinism within the disability framework and adopting a National Action Plan, implementation remains weak. Persons with albinism continue to face stigma, harmful myths, family rejection, discrimination in education and employment, limited access to sunscreen, inadequate dermatological and skin cancer services, lack of low-vision aids, weak protection from ritual-related threats and sexual exploitation, poor official data, and limited participation in decision-making. Women and children with albinism face heightened risks, including abandonment, bullying, sexual violence, poverty, and exclusion from essential services.

The submitting organisations recommend that Uganda: renew and fully fund the National Action Plan for Persons with Albinism for 2026–2030; include sunscreen in national essential health products and provide it free through public health facilities, schools, and community systems; ensure reasonable accommodation for learners with albinism; train health workers, teachers, police, prosecutors, and social workers on albinism-related needs and protection risks; promptly investigate and prosecute attacks, sexual violence, grave desecration, and other abuses; promote employment and livelihood support for persons with albinism; and collect

safe, confidential, and disaggregated data across health, education, disability, employment, social protection, and justice systems.

Questions to the Government of Uganda

1. What concrete steps has the Government of Uganda taken to fully implement and fund the National Action Plan for Persons with Albinism (2020-2025)?
2. When does the Government of Uganda plan to renew the National Action Plan for Persons with Albinism, and will the renewed plan include a dedicated budget, measurable indicators, and participation of organisations of persons with albinism?

I. Introduction

1. This joint stakeholder submission is presented by the Africa Albinism Network (AAN), in collaboration with organisations of persons with albinism in Uganda, to contribute to Uganda's Fourth Cycle Universal Periodic Review. The report focuses specifically on the human rights situation of persons with albinism in Uganda and assesses the extent to which Uganda has implemented previous UPR recommendations relating to their protection, health, education, inclusion and equality. It draws on Uganda's UPR documents, national legal and policy frameworks, including the Persons with Disabilities Act, 2020 and the National Action Plan for Persons with Albinism 2020–2025, civil society reports; and information gathered from organisations of persons with albinism in Uganda through interviews, focus group discussions and questionnaire responses.
2. Persons with albinism in Uganda continue to face multiple and intersecting human rights challenges. They experience discrimination, stigma and social exclusion rooted in harmful myths and misconceptions about albinism. These beliefs affect their dignity, safety, family life, access to education, employment, health care and participation in community life. Children with albinism may face rejection within families, bullying in schools, lack of reasonable accommodation and poor access to low-vision support. Women and girls with albinism face additional risks of gender-based discrimination, sexual exploitation, abandonment, poverty and exclusion from maternal and reproductive health services.
3. Access to health care remains one of the most urgent concerns. Many persons with albinism lack regular and affordable access to sunscreen, protective clothing, dermatological services, skin cancer screening,

eye care and assistive devices. Sunscreen is not yet sustainably provided through Uganda's public health system, and specialised services remain limited, especially for persons living in rural and underserved communities. In education, learners with albinism continue to face barriers linked to poor vision, lack of large-print materials, inadequate teacher training, stigma, and school environments that do not protect them from harmful sun exposure.

4. Uganda has made important progress by recognising albinism within the disability framework and adopting the National Action Plan for Persons with Albinism. However, implementation remains weak. There is no clearly identifiable dedicated budget for the Action Plan, limited public reporting on progress, inadequate disaggregated data, and insufficient consultation with organisations of persons with albinism. General disability programmes have not sufficiently addressed the specific needs of persons with albinism.
5. This report therefore seeks to draw attention to these gaps and urge the Government of Uganda to take concrete, measurable and time-bound steps to protect and fulfil the rights of persons with albinism. It calls for the renewal and full implementation of the National Action Plan, free and continuous access to sunscreen and skin cancer services, inclusive education, protection from violence and harmful practices, economic empowerment, reliable data collection, and meaningful participation of persons with albinism in all laws, policies, programmes and budgets affecting them.

II. Methodology

6. This submission is based on a desk review of Uganda's previous UPR documents, including the Working Group report, Uganda's addendum, the OHCHR compilation, the summary of stakeholders' submissions,

and the matrix of recommendations. It also draws on Uganda's Persons with Disabilities Act, 2020, the National Action Plan for Persons with Albinism 2020–2025, the 2019 report *Enhancing Equality and Countering Discrimination against Persons with Albinism in Uganda*, the awareness report *Just Like You: Addressing Myths and Misconceptions on Albinism*, and previous civil society reporting by AAN and Uganda-based organisations.

7. Consultations with Uganda-based organisations of persons with albinism was also carried out through interviews and Focus Group Discussions, including testimonies, district-level information, recent examples, and evidence on the current implementation status of Uganda's previous UPR recommendations and the National Action Plan for Persons with Albinism

III. Legal, Policy and Institutional Framework

8. Uganda is a party to several international and regional human rights instruments relevant to the protection of persons with albinism, including the Convention on the Rights of Persons with Disabilities, the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and the African Charter on Human and Peoples' Rights. Uganda's Constitution protects equality, dignity, freedom from discrimination, and the rights of persons with disabilities.
9. Uganda has made important progress by recognising albinism as a form of disability under the Persons with Disabilities Act, 2020. The Act prohibits discrimination in education, health services, employment, transport, access to justice, and other areas. It also provides institutional mechanisms, including the National Council for Persons

with Disabilities and local government councils for persons with disabilities.¹

10. The National Action Plan for Persons with Albinism 2020–2025 is another important step. It identifies persons with albinism as a group facing multiple and intersecting forms of discrimination and provides priority areas on awareness raising, health care, education, employment, children with albinism, women with albinism, refugees with albinism, policies and laws, accountability, safety and security.²
11. Despite these positive developments, implementation remains weak. Interview with Leaders of Albinism organisations in Uganda reveals that there is no clearly identifiable and dedicated budget for implementation of the National Action Plan, and that limited public information is available on progress achieved under the Plan. While there has been increased visibility of persons with albinism in disability discussions and some awareness activities, key areas such as sustainable sunscreen provision, specialised dermatological services, comprehensive data collection, economic empowerment and anti-stigma interventions remain inadequately implemented.

IV. Implementation of Previous UPR Recommendations

12. During Uganda’s 2022 UPR, several recommendations addressed persons with albinism directly. Uganda supported recommendation 125.73 to “increase protection for persons with albinism”; recommendation 125.74 to “strengthen measures aimed at protecting people with albinism, particularly in the field of health and education, to provide them with appropriate services”; recommendation 125.75 to “continue to promote the rights of persons living with albinism”; and

¹ Persons with Disabilities Act, 2020, provisions on non-discrimination and institutional structures.

² National Action Plan for Persons with Albinism 2020–2025

recommendation 125.95 to “continue efforts to protect and integrate persons with albinism.”³

13. Stakeholders assess these recommendations as only partially implemented. It acknowledges positive steps, including increased recognition of persons with albinism within the disability community, inclusion of some persons with disabilities in government empowerment initiatives such as the Special Grant for Persons with Disabilities, and representation of persons with disabilities in some local government structures. However, these general disability measures have not adequately addressed the specific health, education, employment, and protection needs of persons with albinism.
14. Key barriers to full implementation include limited budget allocation, inadequate awareness about albinism among policymakers and service providers, weak monitoring and accountability mechanisms, lack of reliable data, persistent stigma and discrimination, and insufficient support to grassroots organisations of persons with albinism.

V. Equality, Non-Discrimination and Harmful Myths

15. Persons with albinism in Uganda continue to experience stigma and discrimination rooted in harmful myths, misinformation, and social exclusion. Stakeholders identify discrimination and stigma as one of the three biggest challenges facing persons with albinism. Sometimes, their own families reject children with albinism, deny them parental care and education, and expose them to insecurity because of misconceptions about albinism.
16. Stakeholders report that some children with albinism are denied admission to boarding schools because of beliefs that they may

³ Uganda UPR Matrix of Recommendations, recommendations 125.73, 125.74, 125.75 and 125.95.

frighten other children. Other harmful myths include beliefs that persons with albinism are spirits, disappear at night, emit light in darkness, or possess body parts that can bring wealth. Such beliefs undermine dignity, safety, family life, education, employment, and social inclusion.

17. Harmful myths also affect burial and bodily integrity. Interview responses revealed a case involving a deceased woman with albinism who had been breastfeeding. Some family members allegedly refused to allow her burial on ancestral land unless rituals were performed, falsely claiming that burying her without removing her breasts would cause other women in the family to die. Security personnel reportedly had to be deployed during and after the burial to prevent desecration of the grave.
18. Public awareness remains limited and uneven. Stakeholders notes that some government initiatives have provided free airtime on local radio stations to leaders of organisations of persons with albinism to raise awareness, but training in schools, health centres, police stations and local councils remain limited, non-systematic and largely led by civil society. Uganda should therefore establish a sustained, nationwide awareness programme on albinism targeting families, schools, health workers, police, law enforcers, local leaders, religious leaders, cultural leaders and the media.

VI. Right to Health: Sunscreen, Dermatological Care and Vision Support

19. Access to health care remains one of the most urgent concerns for persons with albinism in Uganda. Stakeholders identify skin cancer and limited health awareness as one of the three biggest challenges facing persons with albinism. Persons with albinism are highly vulnerable to

skin cancer due to prolonged exposure to sunlight, but many lack free sunscreen, protective clothing and adequate information on skin cancer prevention.

20. Stakeholders reports that access to sunscreen remains inconsistent and inadequate. Government provision is limited and irregular, and sunscreen is generally unavailable in most public health facilities, except in some facilities partnering with civil society organisations. Sunscreen has not been fully integrated into national supply systems as an essential health product for persons with albinism. When bought privately, it may cost between UGX 30,000 and UGX 100,000 or more, making it unaffordable for many families, especially given poverty and unemployment among persons with albinism.
21. Dermatology and skin cancer services are also limited. Stakeholders reports that specialised dermatology services are concentrated in urban areas; skin cancer screening is not routinely accessible; treatment for skin lesions and skin cancer is limited by cost, distance, inadequate specialists and delayed diagnosis; and most health workers receive little or no specialised training on albinism. Some free screening services are organised by development partners or volunteer medical personnel, but these are not systematic or continuous.
22. Harmful misconceptions among health workers further restrict access to health care. Stakeholders reports that some health workers wrongly believe that the skin of a person with albinism is transparent and that a baby can be seen through the body of a pregnant woman with albinism. Other health workers reportedly fear giving injections, intravenous drips or blood transfusions to persons with albinism because of false beliefs that they may bleed excessively or have unusually fragile bodies.

These misconceptions can delay treatment and discourage women with albinism from attending antenatal care.

23. Vision care is another major concern. Stakeholders reports that eye care services are available only to a limited extent, often through support from development partners or charitable initiatives. Only a small number of children with albinism receive magnifiers, spectacles, large-print materials or other learning aids. Some candidates with albinism receive large-print examination booklets where schools have registered them with the Uganda National Examinations Board as low-vision learners, but this is not systematic. Most teachers lack adequate training on how to support learners with low vision.

VII. Right to Education

24. Children with albinism have the right to quality, inclusive, and safe education. However, stakeholders report that although many children with albinism are enrolled in school, retention remains a challenge. Key barriers include poor vision, stigma and discrimination, lack of assistive devices, poverty, inadequate learning accommodations, bullying, isolation, and negative stereotypes.
25. Reasonable accommodation remains inconsistent. Most schools provide limited accommodations, except where civil society organisations of persons with albinism have conducted awareness activities. Some learners are allowed to sit near the front of the class, but this is not consistently practised. Large print materials are generally unavailable. Most school uniforms are not adapted to protect children with albinism from the sun, and some schools refuse to adjust uniforms to allow protective clothing. Hats, long-sleeved uniforms and sunscreen are allowed only in some schools, often where civil society sensitisation has taken place.

26. Uganda should require schools to provide reasonable accommodation for learners with albinism, including front-row seating, large-print materials, low-vision aids, extra time in examinations, permission to wear wide-brimmed hats and long-sleeved uniforms, shaded spaces during outdoor activities, and anti-bullying measures. Teacher training institutions should include albinism-specific content inclusive education curricula.

VIII. Protection from Violence, Harmful Practices and Insecurity

27. Persons with albinism in Uganda continue to face protection risks linked to harmful myths, ritual-related beliefs, and social exclusion. Stakeholders report that, although cases of attacks may have decreased, threats and fears associated with harmful beliefs continue to persist. There have been reports since 2022 of threats, attempted exploitation, and grave violations linked to harmful myths, although many cases remain underreported.
28. Children with albinism are particularly vulnerable because they depend on adults for protection. Women and girls with albinism also face exposure to sexual violence and exploitation. Stakeholders report harmful beliefs that sexual intercourse with a person with albinism can bring wealth or cure chronic illnesses. Such myths contribute to sexual exploitation and abuse, particularly against women and girls with albinism, resulting in unwanted pregnancies, single motherhood, sexually transmitted infections, and HIV/AIDS.
29. Reporting and justice responses remain inconsistent. Interview participants note that some cases are reported to the police, but many remain unreported due to fear, stigma, a lack of trust in institutions, institutional ignorance about albinism, and negative attitudes of some

officials. Responses by police, prosecutors, and courts vary, with some cases investigated, and others delayed or inadequately followed up.

30. Uganda should strengthen community awareness, law enforcement, survivor support services, protection mechanisms for women and children with albinism, and faster prosecution of offenders. Police, prosecutors, social workers, teachers, health workers, and local leaders should be trained to identify and respond to risks faced by persons with albinism, including harmful practices, ritual-related threats, sexual exploitation, neglect, abandonment, and grave desecration.

IX. Women, Girls and Caregivers

31. Women and girls with albinism face multiple and intersecting forms of discrimination based on gender, disability, appearance, poverty, and harmful myths. Stakeholders report that women and girls with albinism are particularly vulnerable to sexual exploitation, abuse, and gender-based violence, especially due to economic hardship and misconceptions about albinism.
32. Women with albinism may also face stigma in maternal health services. False beliefs among some health workers discourage women with albinism from attending antenatal care. Mothers of children with albinism may experience blame, rejection, and poverty, while the children themselves may lack parental affection, protection, sunscreen, reading glasses, protective clothing, and personal safety.
33. Uganda should ensure that women and girls with albinism are explicitly included in gender-based violence prevention, sexual and reproductive health services, livelihood programmes, legal aid, psychosocial support, social protection, and access-to-justice initiatives. Special attention should be given to single mothers, girls at

risk of abuse, women in rural areas, and caregivers of children with albinism.

X. Employment and Livelihood

34. Stakeholders identify unemployment as one of the biggest challenges facing persons with albinism. Many persons with albinism who complete education still face significant barriers to employment due to discrimination, negative stereotypes, and assumptions about their capabilities.
35. Stakeholders report that persons with albinism experience exclusion during recruitment, workplace stigma, lack of reasonable accommodation, and limited nomination to executive or leadership posts. Some persons with albinism are included in government livelihood programmes, but participation remains limited. Many women with albinism continue to face economic vulnerability, while only a small proportion of youth with albinism benefit from skills training or business support.
36. Uganda should promote economic empowerment of persons with albinism through affirmative action, vocational training, entrepreneurship support, access to capital, employment opportunities, market linkages, and targeted inclusion in government livelihood programmes, including the Special Grant for Persons with Disabilities and other national poverty reduction initiatives.

XI. Data Collection and Visibility

37. A major barrier to effective implementation is the lack of reliable, disaggregated data on persons with albinism. Stakeholders report that official data collection remains limited and fragmented. While the previous census in Uganda reportedly considered persons with

albinism, inclusion in census, health, education, disability, and social protection data systems remains inconsistent and does not always generate reliable, disaggregated data.

38. Some leaders of albinism organizations in Uganda maintain their own beneficiary records; for instance, WACWAU reports that it knows approximately 2,800 persons with albinism while directly reaching and supporting approximately 230. However, civil society data cannot replace official national data. The lack of official data leads to poor planning, inadequate budgeting, exclusion from services, limited policy development, and difficulty monitoring progress.
39. Uganda should collect safe, confidential, and disaggregated data on persons with albinism, including population statistics, education outcomes, health status, employment levels, access to social protection, and incidents of discrimination and violence. Data collection should be rights-based, voluntary, confidential, and developed in consultation with organisations of persons with albinism.

XII. Participation and Accountability

40. The meaningful participation of persons with albinism and their representative organisations is essential. Stakeholders report that consultation by the government occurs occasionally but should be more regular and meaningful. Representation exists in some disability councils, national committees, and local government structures but remains inadequate. The participation of children, women, and youth with albinism is particularly limited.
41. Uganda should establish regular consultation mechanisms, ensure dedicated representation of persons with albinism, build the capacity of organisations of persons with albinism, provide adequate funding for participation, and include them at all levels of decision-making.

Accountability also requires public reporting on implementation of the National Action Plan, including budgets, activities, districts reached, persons supported, and progress against indicators.

XIII. Recommendations

We, the above organisations representing persons with albinism, jointly recommend that Uganda:

42. Renew and fully implement the National Action Plan for Persons with Albinism for the period 2026–2030, with a dedicated budget line, public annual progress reports, measurable indicators, and clear responsibilities for relevant ministries and local governments.
43. Include sunscreen in Uganda’s essential health products or national supply system and make it available through public health facilities, schools, and community health systems, and train health workers on albinism-related health needs, including skin cancer prevention, low vision, maternal health, psychosocial support, and referral pathways.
44. Require all schools to provide reasonable accommodation for learners with albinism, including front-row seating, large-print materials, low-vision aids, extra examination time, and sun-safe school environments, and integrate albinism into teacher training curricula and continuous professional development programmes.
45. Train police, prosecutors, social workers, teachers, health workers, and local leaders on harmful practices, ritual-related threats, sexual exploitation, neglect, abandonment, and grave desecration affecting persons with albinism.
46. Ensure prompt registration, investigation, and prosecution of attacks, threats, trafficking, mutilation, sexual violence, grave desecration, and other abuses against persons with albinism.

47. Promote employment and economic empowerment of persons with albinism through affirmative action, skills development, entrepreneurship support, access to capital, market linkages, and targeted inclusion in livelihood programmes.
48. Collect and publish safe, confidential, and disaggregated data on persons with albinism across health, education, disability, employment, social protection, and justice systems.

XIII. Conclusion

Uganda has made important normative progress by recognising albinism as a disability and adopting a National Action Plan for Persons with Albinism. However, persons with albinism continue to face serious barriers to equality, health, education, safety, social protection, and participation. The next UPR cycle provides an important opportunity for Uganda to move from recognition to implementation.

The Government should take concrete, measurable, and time-bound steps to ensure that persons with albinism are protected from discrimination and violence, provided with essential health and education services, included in national data and budgeting systems, and meaningfully represented in decisions that affect their lives. The rights of persons with albinism must not remain aspirational; they must be made real in homes, schools, health facilities, communities, and public institutions across Uganda.