# Joint Shadow Report to the Committee on the Rights of the Child: Human Rights Situation of Children with Albinism in Uganda

Ву



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#### **Executive Summary**

This shadow report, submitted by Africa Albinism Network in collaboration with organizations of persons with albinism in Uganda, including the Albinism Umbrella and Women and Children with Albinism in Uganda (WACWAU), highlights the systemic discrimination, violence, and exclusion faced by children with albinism. Despite Uganda's legal commitments under the Convention on the Rights of the Child (CRC), the Convention on the Rights of Persons with Disabilities (CRPD), and regional instruments, children with albinism remain invisible in national laws, policies, and data systems.

Children with albinism in Uganda are at risk of abandonment, bullying, ritual killings, and sexual violence, driven by stigma, myths, and a lack of public awareness. Barriers to inclusive education, essential health services (e.g., sunscreen, dermatological care, low-vision aids), and child protection persist, while the National Action Plan on Albinism (2020–2025) lacks evidence of implementation and public reporting, and child-focused frameworks fail to address their specific vulnerabilities. This report documents:

- Lack of targeted protections for children with albinism in national education and child protection policies;
- Limited access to life-saving healthcare, including sunscreen, dermatological services, and low-vision aids;
- Widespread family rejection and the absence of state-supported alternative care;
- Ongoing risks of ritual attacks and the failure to prosecute perpetrators or prevent recurrence;
- Absence of disaggregated data and inclusion in national planning.

To address these gaps, the report recommends:

- Full implementation of the National Action Plan on Albinism, with child-specific indicators;
- Development of a national child protection protocol tailored to the needs of children with disabilities including children with albinism;
- Provision of inclusive education and health services, including assistive devices and sun protection; Including inclusion of sunscreen in National List of Essential

Medicines, in alignment with the WHO Model List of Essential Medicines for Children (EMLc);

 Collection of disaggregated data to inform evidence-based policy and programming.

This report urges the Committee to call on the Government of Uganda to take immediate and concrete steps to uphold the rights of children with albinism and ensure their inclusion, safety, and dignity.

#### Introduction

This shadow report is submitted to supplement Uganda's combined third to fifth periodic report to the Committee on the Rights of the Child. It focuses specifically on the human rights situation of children with albinism in Uganda, highlighting violations and challenges faced, and providing recommendations for state action. The report draws on documented evidence, survivor testimonies, inputs from organizations of persons with albinism in Uganda, including Women and Children with Albinism in Uganda (WACWAU), Albinism Umbrella, civil society reports, and government data where available.

Children with albinism in Uganda face multiple and intersecting human rights challenges. They are subjected to discrimination and social stigma from an early age, often leading to exclusion and psychological distress.<sup>1</sup> Harmful practices such as ritual attacks, trafficking for body parts, and neglect within families and communities continue to pose serious threats to their safety and well-being.<sup>2</sup> In the education sector, children with albinism experience bullying, visual impairment-related challenges, and a lack of reasonable accommodation, which limit their effective participation and retention in school. Access to healthcare is also inadequate, especially in terms of dermatological care and low-vision services, which are critical for their protection and survival.<sup>3</sup>

While Uganda has made some progress by recognizing albinism as a form of disability under the Persons with Disabilities Act, 2020,<sup>4</sup> there is a significant gap in targeted interventions for children with albinism. The Act does not specifically mention any measures to address their unique needs or protect their rights (Government of Uganda, 2020). Moreover, there is no disaggregated data available on the number of children with

<sup>&</sup>lt;sup>1</sup>I. Ero et al, 2021 People with albinism worldwide, a human rights perspective available at chttps://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism Worldwide Report2021 EN.pdf accessed on November 12 2025 Page 14 & 55

<sup>&</sup>lt;sup>2</sup> UN Human Rights Council. (2019). Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero – A/HRC/40/62. https://docs.un.org/en/A/HRC/40/62

<sup>&</sup>lt;sup>3</sup> Albinism Umbrella, 2022 Annual Report (Albinism Umbrella 2022) available at <a href="https://albinismumbrella.org/download/albinism-umbrella-annual-report-2022/">https://albinismumbrella.org/download/albinism-umbrella-annual-report-2022/</a> accessed on 17/11/2025

<sup>&</sup>lt;sup>4</sup> Persons with Disabilities Act, 2020, Schedule 3 (Section 1) (7)

albinism in schools or benefiting from social protection, healthcare, or other government services. This lack of data further hinders the development of effective policies and monitoring progress.

Uganda adopted the National Action Plan on Albinism in 2022,<sup>5</sup> which was a welcome step toward addressing the needs of persons with albinism, including children. However, there is no publicly available report on the implementation of this Action Plan, particularly in relation to children's rights or government programs aimed at promoting and protecting the rights of children with albinism. The absence of accountability and monitoring mechanisms undermines the plan's potential impact.

This report seeks to draw attention to these critical gaps and to urge the Government of Uganda to take concrete steps to protect and fulfill the rights of children with albinism in line with its obligations under the Convention on the Rights of the Child and other human rights instruments.

#### **General Measures of Implementation**

Uganda has enacted several laws and policies to protect children's rights, including the Children (Amendment) Act 2016 and the National Child Policy 2020. However, these instruments lack targeted measures addressing the unique needs and vulnerabilities of children with albinism. Albinism Groups in Uganda noted that data on children with albinism are not captured in national surveys or systems like the Child Well-being Management Information System, hindering targeted planning and accountability. Uganda is a State Party to the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). The failure to disaggregate data on children with albinism contravenes Article 31 of the CRPD and Article 4 of the CRC, which both require states to implement data-driven and evidence-based policies to fulfill children's rights.

<sup>&</sup>lt;sup>5</sup> Republic of Uganda, National Action Plan for Persons with Albinism 2020–2025 (Ministry of Gender, Labour and Social Development 2020) 5–7

Available at <a href="https://albinismumbrella.org/download/the-national-action-plan-for-persons-with-albinism-2020-2025/">https://albinismumbrella.org/download/the-national-action-plan-for-persons-with-albinism-2020-2025/</a> accessed on November 11 2025

#### **General Principles**

#### Non-discrimination

Children with albinism in Uganda face systemic and pervasive discrimination rooted in myths, stigma, and misinformation. According to albinism groups in Uganda, Children with albinism are often excluded from community and school activities, face social isolation, and are vulnerable to bullying and emotional abuse<sup>6</sup>. The Equal Opportunities Commission has a mandate to protect marginalized groups, but there is no evidence of targeted interventions for children with albinism in the state party report. The state party report submitted to the Committee on the Rights of the Child indicates level.<sup>7</sup>

Reports from albinism organizations indicate that children with albinism are:

- Denied entry to private schools on commercial grounds.
- Some Schools prevent children with albinism from adapting school uniforms for sun protection (e.g., wearing hats or long sleeves).
- Refused treatment in healthcare settings due to myths about their skin condition.

Article 21 of the 1995 Constitution of Uganda guarantees equality and freedom from discrimination. Section 4(1)(j) of the Children (Amendment) Act 2016 explicitly prohibits discrimination against children. Uganda's failure to address stigma and exclusion of children with albinism violates these provisions, as well as Article 2 of the CRC.

#### Best Interests of the Child

Despite legal provisions emphasizing the best interests of the child, administrative and judicial decisions often fail to consider the specific vulnerabilities of children with albinism, especially in cases involving access to healthcare, education, and protection from violence. While it is commendable for Uganda to recognize albinism as a disability in its disability law, and children are granted exam accommodations (e.g., extra time, large font

<sup>&</sup>lt;sup>6</sup> Report by albinism groups in Uganda

<sup>&</sup>lt;sup>7</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5

papers), challenges remain. Caregivers and albinism groups providing care for children with albinism cited family neglect and societal stigma as major barriers to realizing the best interests of the child.<sup>8</sup> Reports from albinism groups also indicated that children with albinism are not allowed to wear protective clothing such as long-sleeve shirts, trousers, long skirts and wide-brimmed hats at school, denying them the maximum protection they need against the sun.<sup>9</sup>

Article 3 of the CRC requires the best interests of the child to be a primary consideration in all actions concerning children. Section 3 of the Children (Amendment) Act 2016 mirrors this obligation, yet implementation for children with albinism is inconsistent or absent.

#### Right to Life, Survival, and Development

Children with albinism in Uganda face serious and ongoing threats to their right to life and development, particularly due to the risk of ritual killings (commonly referred to as "child sacrifice"), driven by superstitions that their body parts bring wealth or spiritual power. While the government of Uganda outlines broad measures to protect children's right to life and reports progress in child survival indicators, its report does not refer whatsoever to the specific threats faced by children with albinism, despite civil society documentation of abductions, mutilations, and killings of children with albinism in past years.

Organizations of persons with albinism in Uganda, such as WACWAU and Albinism Umbrella, have confirmed that children with albinism have been abducted, attacked, or hidden away by family members in fear of ritual harm. <sup>10</sup> In some cases, fathers were reportedly involved in the abduction or abandonment of children with albinism. Although no new ritual killings of children with albinism have been officially recorded in recent years, the fear remains pervasive due to persistent beliefs in witchcraft, widespread stigma, and a lack of government protection mechanisms. Families and communities often remain silent out of fear, which contributes to underreporting and a lack of legal redress.

<sup>&</sup>lt;sup>8</sup> Reports from albinism groups in Uganda

<sup>9</sup> As Above

<sup>&</sup>lt;sup>10</sup> As above

The government's report notes a rise in child sacrifice cases reported between 2007 and 2014, and the establishment of an Anti-Child Sacrifice/Human Trafficking Task Force in 2008. It also highlights the development of a National Action Plan against Child Sacrifice (2011) and the training of 2,000 police officers as first responders. However, these measures have not been extended or tailored to address the specific risk profile of children with albinism, who continue to face threats that are culturally specific and require targeted, sustained responses.

Furthermore, the Children (Amendment) Act, 2016, which prohibits rituals resulting in child sacrifice, has not been supported by implementation frameworks that identify and protect high-risk groups such as children with albinism. This absence of targeted prevention, monitoring, or rescue mechanisms leaves them particularly exposed. No guidance exists for law enforcement, schools, or local governments on how to detect, report, or prevent abduction or ritual threats involving children with albinism.

In the absence of government action, organizations of persons with albinism have stepped in to provide:

- Shelter and rescue support for children in danger;
- Psychosocial counseling for survivors and families;
- Preventive sensitization campaigns;
- Referral to safe spaces and medical services.

These life-saving interventions operate without any direct government funding or formal support, despite the state's obligations under both domestic and international law.

- Article 22(1) of the Constitution of Uganda guarantees the right to life for all persons and prohibits the death sentence for children.
- Article 6 of the Convention on the Rights of the Child (CRC) affirms the child's right to life and development to the maximum extent possible.
- Article 39 of the CRC and Article 16 of the CRPD require states to ensure protection and rehabilitation for children exposed to abuse, violence, or exploitation, including those vulnerable due to disability.

The failure to develop targeted protections for children with albinism and the continued reliance on civil society to respond to threats such as ritual attacks, amounts to a violation of Uganda's obligations under both the CRC and CRPD. While Uganda has made significant strides in reducing infant and maternal mortality and strengthening general child survival, the government has not extended the same investment or policy attention to ensuring the life and security of children who face culturally driven threats, such as children with albinism.

#### Respect for the Views of the Child

Children with albinism are frequently denied opportunities to participate in decisions affecting their lives. Cultural stigma and limited self-confidence due to discrimination restrict their ability to express themselves in schools, families, and public platforms. Article 12 of the CRC mandates that children capable of forming their views have the right to express them freely. This right is echoed in Section 4(1)(h) of the Children (Amendment) Act 2016. Lack of inclusive participation mechanisms for children with albinism infringes upon these rights.

#### **Civil Rights and Freedoms**

#### **Protection from Ritual Killings**

The Government of Uganda, in its report to the Committee on the Rights of the Child, acknowledges the ongoing problem of child sacrifice and ritual murders. It cites, for instance, a rapid assessment conducted by the Ministry of Gender, Labour and Social Development (MGLSD) in 2009, which found low reporting of child ritual murders to the police. Police crime data indicate a disturbing trend: cases of child sacrifice reportedly rose by 800% from 3 cases in 2007 to 25 in 2008, and suspected ritual murders increased from 12 in 2013 to 13 in 2014. The government itself concedes that many more cases go unreported. It further points to steps taken, such as the creation of an Anti-Child Sacrifice/Human Trafficking Task Force in 2008, the training of 2,000 police officers as first responders, the National Action Plan against Child Sacrifice (2011), and sensitization campaigns through school child rights clubs and media outlets.

However, while these efforts are commendable in principle, they fall short in addressing the specific vulnerabilities of children with albinism, who are among the groups most at risk of being targeted for ritual purposes.

Despite widespread knowledge that persons with albinism, especially children, are targeted for their body parts due to harmful beliefs in their supposed magical or spiritual properties, the government's report makes no reference whatsoever to the protection of children with albinism in its discussion on ritual killings or child sacrifice. This glaring omission is deeply concerning, as it fails to acknowledge their heightened risk and the well-documented stigma they face in Ugandan communities.

Moreover, the stigma and secrecy surrounding the killing or mutilation of children with albinism, often carried out by close family members or facilitated by community silence, means such cases are far less likely to be reported to authorities, further masking the true scale of the issue. It is therefore likely that some of the ritual killings and child sacrifice cases reported in police data may have involved children with albinism, even if not explicitly recorded as such, due to a lack of disaggregated data or misreporting.

Furthermore, while the Penal Code criminalizes murder, and the Children (Amendment) Act of 2016 outlaw rituals leading to child sacrifice, no targeted protection mechanisms exist for children with albinism. There are no safe houses, no national referral pathways, no specialized psychosocial services, and no preventive frameworks tailored to the unique threat profile they face. Civil society actors, including albinism groups and organizations, have consistently raised concerns about this lack of recognition and protection in both law and policy.

The government's report also credits civil society organizations with providing support, including reconstructive surgery and psychosocial care. While these services are vital, they underscore the state's over-reliance on NGOs to address harms that require a systemic and state-led protection response.

In light of these realities, Uganda is failing to meet its obligations under:

- Article 19 of the Convention on the Rights of the Child (CRC), to protect children from all forms of violence.
- Article 5 of the African Charter on the Rights and Welfare of the Child, to ensure the survival and development of the child to the maximum extent possible.
- Article 23 of the CRC, which guarantees the rights of children with disabilities (including those with albinism, as recognized under Uganda's Disability Act) to special protection and support.

Given Uganda's acknowledgment that child sacrifice remains a persistent and underreported threat, and considering the known targeting of persons with albinism in East Africa, it is urgent that the government explicitly includes children with albinism in its anti-ritual killing frameworks, collects disaggregated data, and ensures adequate protection mechanisms tailored to this population.

#### **Violence Against Children**

Children with albinism in Uganda face a distinct and heightened risk of violence due to their condition. This includes:

- Targeted attacks linked to harmful myths that body parts of persons with albinism bring wealth or power;
- Bullying and social isolation in schools, often by both peers and teachers;
- Rejection within the family, especially by fathers who deny paternity or blame mothers;
- Neglect in public services, particularly due to the lack of reasonable accommodations in schools and healthcare settings;
- Sexual violence against girls with albinism, rooted in the dangerous belief that sex with them cures diseases like HIV/AIDS.

These forms of violence constitute grave violations of Article 19 of the CRC, Articles 16 and 17 of the African Charter on the Rights and Welfare of the Child, and Uganda's Domestic Violence Act (2010). However, they are absent from the government's narrative on violence against children in its state to report to the Committee.

While the state lists various legal and policy initiatives, such as the Children (Amendment) Act (2016), the Domestic Violence Act (2010), and the National Action Plan for Ending Violence Against Children (2020), none of these specifically recognize or address the unique vulnerabilities of children with albinism. There are no tailored protection protocols, no survivor support programs, and no prevention measures aimed at ending violence based on albinism.

The government highlights the National Child Helpline, violence surveys (such as VACS), and sensitization campaigns. Yet these measures remain generalized and fail to respond to the lived realities of children with albinism, who often do not report abuse due to stigma, fear of disbelief, or normalization of violence within their families and communities.

The state report cites high levels of physical and sexual violence, with 44% of girls and 59% of boys aged 13–17 reporting physical violence, and 35% of females and 17% of males experiencing sexual violence before age 18.<sup>11</sup> However, it fails to disaggregate this data by disability status or recognize the compounded vulnerabilities of girls with albinism. Survivors and advocacy organizations report that girls with albinism are especially targeted for sexual assault due to superstitions, yet the government provides no data, policy, or response framework to address this issue.

The government acknowledges a rise in ritual and child sacrifice cases, citing police data that show an 800% increase in such cases between 2007 and 2008, and further incidents in 2014 and beyond. While it reports creating an Anti-Child Sacrifice Task Force and adopting a National Action Plan against Child Sacrifice (2011), it fails to recognize that children with albinism are prime targets for such crimes. It also concedes that many ritual killings go unreported, which aligns with findings from the Ministry of Gender's 2009 rapid assessment on child sacrifice.

<sup>&</sup>lt;sup>11</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 para 56

<sup>&</sup>lt;sup>12</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 para 29

<sup>&</sup>lt;sup>13</sup> Violence against children in Uganda findings from a national survey 2015

Given the secrecy, cultural complicity, and fear of retaliation surrounding the murder of children with albinism, it is highly plausible that several unreported cases of child sacrifice involved children with albinism. Yet, the state report does not acknowledge this possibility or indicate steps taken to investigate or prevent such crimes against this group.

While the government notes that schools are sites of violence, citing a 2012 Ministry of Education study showing that 81% of children aged 10–18 experienced violence at school.<sup>14</sup> it again fails to discuss the unique challenges faced by children with albinism, such as:

- Bullying linked to their appearance or vision impairment;
- Failure to provide assistive devices or seating accommodations;
- Verbal and physical abuse by teachers who believe they bring bad luck.

This lack of adaptation constitutes systemic neglect, a silent yet persistent form of violence that leads to poor learning outcomes, school dropouts, and lifelong inequality.

The government highlights trafficking trends, including child trafficking for labor, sexual exploitation, and even transnational trafficking. However, there is no recognition that children with albinism, due to poverty, stigma, and their perceived "value" in witchcraft practices, may be trafficked internally or across borders. Uganda's failure to include albinism-related vulnerability in anti-trafficking measures represents a critical gap in the national child protection system.

Uganda has made progress in building a general child protection framework. However, it has systematically failed to acknowledge, record, and respond to the specific forms of violence faced by children with albinism. These children continue to suffer in silence, invisibility, and exclusion.

#### **Family Environment and Alternative Care**

Children with albinism in Uganda are frequently subjected to family rejection and abandonment, particularly in rural areas. Fathers often deny paternity or distance

<sup>&</sup>lt;sup>14</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 para 62

themselves from the child due to deep-rooted stigma and myths surrounding albinism. Many children with albinism are raised solely by their mothers or grandmothers, living in single-parent or female-headed households that struggle to meet basic needs. These caregivers often lack financial resources and receive no targeted support from the state.

The Children (Amendment) Act, 2016, under Sections 6 and 42B, requires the state to preserve the child's family environment and to provide alternative care when family support is unavailable. Similarly, Article 20 of the Convention on the Rights of the Child (CRC) obliges Uganda to ensure that children deprived of a family environment receive special protection and assistance, including foster care, adoption, or other appropriate community-based alternatives.

However, the government's report to the Committee does not mention any specific measures to protect or support children with albinism under these legal obligations. It lists general child protection efforts, such as the National Child Helpline, district-level child protection units, and interventions against violence, but fails to acknowledge the structural challenges faced by children with albinism within their families. The government also reports efforts to address harmful cultural practices (para. 67), but again, does not consider the impact of stigma and discrimination related to albinism on family dynamics and abandonment.

Reports from organizations of persons with albinism in Uganda, including Women and Children with Albinism in Uganda (WACWAU) and Albinism Umbrella, confirm that family abandonment is a widespread and recurring issue, especially in remote districts where traditional beliefs about albinism remain strong. These organizations regularly intervene to support affected children and caregivers through:

- Psychosocial counseling to children and mothers facing isolation and trauma;
- Provision of protective gear such as sunscreen, sun hats, and long-sleeve clothing to mitigate the health impacts of albinism;
- Menstrual hygiene support for adolescent girls with albinism;
- Economic empowerment initiatives for single mothers and grandmothers raising children with albinism.

These essential services are being provided almost entirely by civil society with no sustained support or partnership from the state. The lack of a dedicated foster care system or community-based alternative care models for children with albinism amounts to systemic discrimination, as it excludes a vulnerable population from state protection mechanisms available to other children.

Despite Uganda's legal obligations under the CRC and domestic law, the omission of children with albinism in state-supported care programs reflects a failure to implement inclusive child welfare policies. The state has not developed guidance, training, or targeted interventions for social workers, child protection officers, or foster care agencies to respond to the specific vulnerabilities of children with albinism.

#### Disability, Basic Health, and Welfare

Children with albinism in Uganda face severe and unique health risks stemming from their genetic condition, including:

- Extreme sensitivity to sunlight due to melanin deficiency, leading to a heightened risk of skin cancer;
- Visual impairments, which impact learning, mobility, and participation in school;
- Lack of access to specialized health care, such as dermatological services and low-vision support.

Despite these well-documented vulnerabilities, the Government of Uganda's state report made no mention of children with albinism as a distinct group with health-related needs, nor does it identify any targeted programs or policies to meet their medical, rehabilitative, or preventive care requirements. This omission is concerning and represents a significant gap in the national health response for children with disabilities.

Unlike some other disabilities mentioned in the report, albinism is not addressed at all under the sections on disability, healthcare, or vulnerable children. Although the persons with disability act explicitly make provision for sunscreen to be distributed to persons with

albinism at no cost or at a subsidized rate.<sup>15</sup> However, there is no mention of sunscreen provision as an essential health product, despite the fact that consistent access to high-SPF sunscreen is the most basic and effective protection against ultraviolet-induced skin cancer. Uganda does not include sunscreen on its essential medicines or health products list, and sunscreens remain unaffordable and unavailable in public health facilities, especially in rural areas.

Likewise, access to dermatologists is extremely limited. Most skin cancer services are provided only in private or tertiary facilities, which are geographically and financially inaccessible to many families of children with albinism. Moreover, no public screening or early detection programs exist for this high-risk group.

The state report refers broadly to maternal and child health gains, budgetary commitments to the health sector, and immunization program. However, these achievements do not reach children with albinism in any specific way, and their invisibility in national health strategies further entrenches their marginalization.

In the absence of state-led interventions, albinism-focused organizations are filling the gap by providing:

- Sunscreen and protective clothing (wide-brimmedm hats, long sleeves);
- Psychosocial support to children facing stigma and bullying;
- Menstrual hygiene kits for girls with albinism;
- Counseling and empowerment for caregivers, especially single mothers and grandmothers raising children rejected by their fathers.

While the government celebrates its partnerships with NGOs in the broader disability and child protection space, it does not recognize or support the specialized services provided by albinism groups, nor does it allocate funding to scale these efforts.

<sup>16</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 para 135 -145

<sup>&</sup>lt;sup>15</sup> Persons with Disabilities Act, 2020, Act 3 of 2020. Article 7(7) states, The Government shall provide persons with albinism with skin protective creams and persons with disabilities with assistive devices at no cost or subsidized prices.

The exclusion of children with albinism from national health policies and services violates:

- Article 23 of the Convention on the Rights of the Child (CRC), which guarantees children with disabilities the right to special care and assistance;
- Article 24 of the CRC, which ensures every child's right to the highest attainable standard of health;
- Articles 25 and 26 of the Convention on the Rights of Persons with Disabilities (CRPD), which call for equal access to health care and habilitation services without discrimination;
- Section 9 of the Children (Amendment) Act, 2016, which mandates the state to uphold the rights of children with special needs or disabilities without discrimination.

The government's failure to name albinism in its disability policy implementation and lack of specific budgetary or programmatic focus for this population results in de facto exclusion. This omission constitutes systemic discrimination and undermines Uganda's commitments under both national and international law.

#### **Education, Leisure, and Cultural Activities**

Uganda's state report outlines a wide range of initiatives to promote inclusive education through Universal Primary and Secondary Education, the Special Needs and Inclusive Education Implementation Strategy (2012–2017), and teacher training programs through Kyambogo University and Primary Teachers' Colleges. While commendable in scope, none of these programs specifically address the unique educational needs of children with albinism, who face both disability-related and social barriers in accessing and succeeding in school.

Children with albinism commonly experience:

- Low vision requiring assistive devices such as magnifiers and prescription glasses;
- Lack of adapted learning materials, such as large print or high-contrast text;

<sup>&</sup>lt;sup>17</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 para 118, 123, and -176

- Refusal or failure to accommodate front-row seating, despite its importance for low vision learners;
- Bullying and discrimination from peers and even teachers, often linked to superstitions or myths about albinism;
- Sun sensitivity, which is exacerbated by a lack of shaded spaces in schools, affecting participation in outdoor classes, play, sports, or assembly;
- Exclusion from boarding schools, either due to stigma, rejection by caregivers, or infrastructure that fails to accommodate their needs (e.g., sun protection, adequate lighting).

The government report refers to ongoing efforts to improve special needs education, construction of disability-sensitive infrastructure, and support for out-of-school children through alternative education programs. However, children with albinism are not mentioned once in these sections, despite the fact that their visual impairments and health vulnerabilities qualify them for special needs support under both international law and Uganda's own policy frameworks.

Although the Education Act (2008) and related policies support inclusive education, they do not explicitly recognize children with albinism or their specific challenges. This omission results in inconsistent application of reasonable accommodations, such as:

- Extra time during exams;
- Provision of large-font examination papers;
- Use of assistive technologies.

Civil society organizations such as WACWAU and Albinism Umbrella have reported that while some children with albinism receive such accommodations, they are not systematically implemented, especially in rural areas. These inconsistencies contribute to higher dropout rates, low literacy outcomes, and limited transitions to secondary education among children with albinism.

<sup>&</sup>lt;sup>18</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 para 117-120 and 186-189

Furthermore, the lack of government-financed assistive devices, including glasses and magnifiers, forces families and NGOs to cover the cost. For many families already experiencing poverty and stigma, this is not feasible. This deepens educational inequality and violates the rights of children with albinism to equitable access and participation in education.

Despite Uganda's efforts to support education through donor-supported projects, capitation grants, and bursaries, there is no data disaggregated by type of disability or by condition such as albinism. Without disaggregated data, the educational exclusion of children with albinism remains invisible in policy planning and resource allocation.

Uganda's failure to provide inclusive education tailored to the needs of children with albinism violates:

- Article 28 of the Convention on the Rights of the Child (CRC) the right to education without discrimination;
- Article 24 of the Convention on the Rights of Persons with Disabilities (CRPD) –
   the right to inclusive education with reasonable accommodation;
- Article 30 of the CRPD, which recognizes the right of children with disabilities to participate in cultural life and recreation on an equal basis;
- The Children (Amendment) Act 2016, which mandates non-discrimination and equal access to education for children with disabilities.

Furthermore, Uganda's Education Act (2008) should be revised to explicitly include children with albinism within the Special Needs Education framework to ensure consistent provision of services and monitoring of outcomes.

#### **Special Protection Measures**

Children with albinism in Uganda are exposed to unique and heightened vulnerabilities due to persistent discrimination, harmful cultural beliefs, and systemic neglect. They face risks of abandonment, physical attacks, trafficking, sexual violence, exclusion from services, and stigma within their families and communities. These risks demand targeted protection measures under Article 39 of the CRC, which obligates states to take all appropriate measures to promote physical and psychological recovery and social

reintegration of child victims of any form of neglect, exploitation, or abuse. This obligation is reinforced by the CRPD, particularly Articles 7, 16, and 31, which require appropriate legal, policy, and data measures to protect children with disabilities from violence and abuse.

However, the Government of Uganda's state report makes no reference to children with albinism under its extensive section on "Special Protection Measures." While the report details significant efforts targeting children in street situations, child labour, refugee and conflict-affected children, and those in the justice system, 19 children with albinism are absent despite facing similarly grave and in some cases, more complex forms of vulnerability.

There is no national child protection strategy or protocol specifically tailored to the needs of children with albinism. Neither the National Orphans and Vulnerable Children Policy nor the Alternative Care Framework cited in the report mentions albinism or addresses the abandonment and neglect of children with albinism by their families, particularly the well-documented rejection by fathers, which often leaves children to be raised solely by mothers or grandmothers. This lack of recognition in policy and programming constitutes a serious protection gap.

In practice, civil society organizations such as WACWAU and Albinism Umbrella have reported widespread instances of abandonment, especially in rural areas, where stigma is entrenched. Children with albinism are often excluded from community support systems, and there are no state-supported foster care systems or community-based alternatives in place to guarantee their right to a secure and loving family environment, as required under Article 20 of the CRC.

While the government report outlines the role of Probation Officers, Child and Family Protection Units, and Justice for Children Coordinators, there is no evidence that these actors receive any training on the rights and risks specific to children with albinism. In the absence of sensitization, law enforcement officers, community leaders, and social

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<sup>&</sup>lt;sup>19</sup> Committee on the Rights of the Child. Combined third to fifth periodic reports submitted by Uganda under article 44 of the Convention, due in 2011. Date received: 12 May 2021] CRC/C/UGA/3-5 paras. 203–258

workers may fail to identify abuse or threats against children with albinism or worse, may be complicit in discriminatory attitudes or neglectful responses.

Furthermore, while the report highlights the establishment of Remand Homes, Rehabilitation Centres, and Legal Aid Centres for children in contact with the law, there is no indication that any of these facilities or services are equipped to accommodate children with albinism, especially with respect to:

- Sunlight-sensitive infrastructure,
- Provision of sunscreen or protective gear,
- Psychosocial support addressing stigma, or
- Visual aids and communication accommodations.

A cross-cutting failure in the state report is the absence of disaggregated data on children with disabilities, particularly children with albinism. Without such data, the government cannot effectively plan, budget, or monitor interventions that are responsive to their specific needs. This data invisibility violates Article 31 of the CRPD, which requires the collection of appropriate disability-disaggregated data to formulate and implement policies aimed at enforcing the Convention.

While the government cites monitoring frameworks such as the Justice for Children programme and mentions the creation of child-friendly spaces, there is no accountability mechanism to ensure children with albinism are protected or included in these efforts.

Uganda has made commendable efforts to strengthen child protection systems for certain groups, but the total exclusion of children with albinism from these frameworks amounts to systemic neglect. Their specific vulnerabilities are overlooked in:

- National child protection strategies;
- Training of police and justice actors;
- Family reintegration and foster care initiatives;
- Data collection and disaggregation;
- Infrastructure and services in protection institutions.

This exclusion violates Uganda's obligations under:

Articles 20 and 39 of the CRC;

- Articles 7, 16, 23, and 31 of the CRPD;
- The Children (Amendment) Act 2016, which guarantees protection for all children in vulnerable situations.

#### Recommendations

To effectively address the systemic discrimination and human rights violations faced by children with albinism in Uganda, and to uphold its obligations under the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities, and the African Charter on the Rights and Welfare of the Child, the Government of Uganda should urgently take the following actions:

#### 1. Ensure Access to Sun Protection as a Life-Saving Health Intervention

The Committee should recommend that the Government of Uganda:

- Add sunscreen to the National Essential Medicines and Health Products
   List, in compliance with the Persons with Disabilities Act (2020), which
   recognizes sunscreen as an assistive product, and in alignment with the WHO
   decision to include sunscreen on the Model List of Essential Medicines for
   Children (EMLc).
- Ensure free or subsidized provision of high-SPF (≥50) sunscreen for all
  children with albinism through public health facilities, schools, and community
  health workers, prioritizing rural and high-sun-exposure districts.
- Establish routine skin cancer prevention and early detection services, including dermatological screenings at primary health facilities and regional referral hospitals.
- Develop and fund a national sun-safety campaign targeting caregivers, teachers, health workers, and community leaders, emphasizing prevention of skin cancer among children with albinism.
- Train health workers under the Ministry of Health on albinism-specific clinical guidance, including dermatology, visual impairment, psychosocial support, and referral pathways.

## 2. 1. Amend the Education Act to Recognize Albinism Under Special Needs Education

Uganda's Education Act (2008) does not explicitly address the unique educational barriers faced by children with albinism, including low vision, high sensitivity to ultraviolet exposure, and discrimination within school environments. To ensure equitable and inclusive education, the Act should be amended to:

- Explicitly recognize albinism within the definition of "special needs" to guarantee tailored support for learners with albinism.
- Mandate the provision of appropriate low-vision assistive devices, including magnifiers, prescription glasses, and high-contrast learning tools.
- Require schools to provide front-row seating, large-print or high-contrast learning materials, and other accommodations that facilitate effective learning for children with low vision.
- Introduce guidelines for sun-safe school environments, including shaded play areas, covered walkways, and minimal exposure to direct sunlight during outdoor activities.
- Require the integration of training modules on teaching learners with albinism in all teacher training institutions, with a focus on inclusive pedagogical approaches.
- Mandate the inclusion of protective clothing within the official school uniform for learners with albinism, such as wide-brim hats, long-sleeved shirts, and trousers or long skirts, to reduce harmful UV exposure during school hours.
- Introduce clear examination guidelines for learners with albinism and other visual impairments, including the provision of large-print examination papers, extended time allocations, and low-vision assistive devices during assessments.

# 3. Fully Implement the National Action Plan on Albinism (2020-2025), with Specific Child-Focused Measures

Although the Government adopted a National Action Plan on Albinism in 2022, there is no evidence of its implementation or reporting. The Government should review and renew the Plan for the period 2025–2030, ensuring its full operationalization through. The Plan should be operationalized with:

- A dedicated budget line and a results-based monitoring and evaluation framework;
- Specific indicators addressing the needs of children with albinism in health, education, and protection sectors;
- Inter-ministerial coordination among the Ministries of Gender, Health, and Education;
- Active and sustained involvement of organizations of persons with albinism in implementation and monitoring.

### 4. Amend the Persons with Disabilities Act (2020) to Include Provisions Specific to Albinism

Although albinism is recognized as a form of disability, the law does not provide targeted protections or entitlements for children and persons with albinism. The Act should be amended to:

- Clearly recognize the distinct medical, educational, and social protection needs of persons with albinism;
- Mandate the inclusion of sunscreen on the National Essential Medicines and Health Products List;
- Require the state to provide free dermatological care and visual aids for persons with albinism including regular skin and eye screening particularly in rural areas;
- Promote public awareness campaigns to counter myths and harmful practices related to albinism.

#### 5. Establish a National Child Protection Protocol for Children with Albinism

Children with albinism in Uganda face specific threats, including abandonment, rejection, trafficking, ritual attacks, and sexual violence. The government should:

 Develop and adopt a national child protection protocol specifically tailored to children with albinism;

- Train child protection workers, social workers, police, and teachers on the unique risks faced by children with albinism;
- Create clear referral and response pathways for cases of violence or neglect involving children with albinism;
- Collaborate with organizations of persons with albinism to deliver these interventions effectively.

## 6. Ensure Disaggregated Data Collection and Monitoring on Children with Albinism

The lack of disaggregated data on children with albinism leads to their invisibility in national planning and service delivery. The government should:

- Mandate the collection of data disaggregated by condition, age, gender, and disability in all relevant sectors;
- Include albinism-specific indicators in national surveys such as the Uganda
   Demographic and Health Survey and the Violence Against Children Survey;
- Use this data to inform inclusive budgeting, policy development, and periodic reporting under the CRC and CRPD.

#### Conclusion

Children with albinism in Uganda continue to face systemic discrimination, violence, and exclusion. Despite existing laws, implementation remains poor. The Government of Uganda must urgently adopt targeted and inclusive policies to protect and fulfill the rights of children with albinism, in line with its commitments under the CRC and CRPD. Inputs from organizations of persons with albinism in Uganda underscore the pressing need for coordinated state-led action.

#### LIST OF REFERENCES

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- 6. Violence Against Children Survey (VACS), Violence Against Children in Uganda: Findings From the National Survey 2015 (Government of Uganda/UNICEF 2015).
- 7. Reports from albinism groups in Uganda (various submissions on file with the author).

#### LIST OF LEGAL FRAMEWORKS

#### **National Legislation**

- 1. Persons with Disabilities Act 2020, Act 3 of 2020 (Uganda), Schedule 3 (s 1(7)).
- 2. Persons with Disabilities Act 2020, Act 3 of 2020 (Uganda) s 7(7).

#### **International & Regional Legal Frameworks**

- 3. Convention on the Rights of the Child (CRC), adopted 20 November 1989, entered into force on 2 September 1990.
- 4. Convention on the Rights of Persons with Disabilities (CRPD), adopted 13 December 2006, entered into force 3 May 2008.
- 5. African Charter on Human and Peoples' Rights, adopted 27 June 1981, entered into force 21 October 1986.
- 6. African Charter on the Rights and Welfare of the Child, adopted 11 July 1990, entered into force 29 November 1999.
- 7. African Union Plan of Action on Albinism in Africa (2021–2031).