ACERWC
African Committee of Experts on
the Rights and Welfare of the Child

An Organ of the
African Union

# GUIDING NOTE

## ON REPORTING ON THE RIGHTS AND WELFARE OF CHILDREN WITH ALBINISM IN AFRICA

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## Acknowledgment

This Guiding Note is developed through the support of the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Muluka-Anne Miti-Drummond and in collaboration with representatives of groups of persons with albinism from around the continent.

# Guiding Note on Reporting on the Rights and Welfare of Children with Albinism in Africa

The African Committee of Experts on the Rights and Welfare of the Child (the Committee):

Recognizing the persisting violations of the human rights and fundamental freedoms of children with albinism in contravention of the African Charter on the Rights and Welfare of the Child (the African Children's Charter/Charter);

Acknowledging the measures that various African Union (AU) Member States have taken to protect, promote and fulfil the rights of children with albinism, including legislative reform; the adoption of National Action Plans; and the enactment of social protection measures, amongst others;

Recognising the various measures undertaken by the African Union through its organs and mechanisms, to address the situation of children with albinism on the continent. These include the adoption of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa; the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021 – 2031); and the Pan-African Parliament Guidelines on the Elimination of Harmful Practices Related to Accusations of Witchcraft and Ritual Attacks;

Recalling the several measures it has undertaken to address the situation of children with albinism in Africa, including conducting two fact-finding missions to investigate violations of the rights of children with albinism in the United Republic of Tanzania (2015) and the Republic of Malawi (2022); issuing Resolution 19/2022 focusing on the situation of children with albinism; holding a Day of General Discussion (DGD) on the Solutions to the Challenges faced by Children with Albinism during its 43rd Ordinary Session held from 15-25 April 2024, in Maseru, Kingdom of Lesotho; and developing an Outcome Statement on the DGD;

Taking note of the unique situation of children with albinism which is further exacerbated by multiple and intersecting forms of discrimination based on colour, disability, age, and gender in contravention of article 3 of the African Children's Charter.

Recognizing that the social and structural discrimination experienced by children with albinism is cross-cutting and impacts their ability to enjoy several human rights, including the right to survival and development (art. 5), education (art. 11), health and health services (art. 14), leisure, recreation and cultural activities (art. 12), and parental care and protection (art. 19), among others.

Noting the significance of the State Party Reporting Procedure (art. 43), which enables the Committee to discharge its duty of monitoring the implementation of the African Children's Charter at the domestic level.

Concerned about the gap in terms of state reporting on children with albinism and observing that out of the 42 State Parties that have submitted State reports to the Committee, only 12 make reference to albinism in their initial and/or periodic state reports, making it difficult for the Committee to effectively monitor the domestic implementation of Charter obligations in relation to children with albinism.[1]

Decided during its 42nd Ordinary Session, held from 08 to 17 November 2023, in Addis Ababa, Ethiopia, to develop a Guiding Note on Reporting on the Rights and Welfare of Children with Albinism in Africa to provide reporting indicators to assist States in reporting on the rights and welfare of children with albinism.

Adopted the Guiding Note during its 45th Ordinary Session held on 07-11 April in 2025 In Maseru, Lesotho.

The indicators are divided into 6 thematic areas and enable the Committee to monitor and evaluate progress periodically and proffer intervention strategies for possible adoption by States.[2] The Committee strongly urges State Parties to include the following information on children with albinism in their initial and periodic reports.

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1 State Parties that make reference to children with albinism in their initial and/or periodic reports include the Republic of Congo; the Republic of Côte d'Ivoire; the Republic of Guinea; the Republic of Kenya; the Kingdom of Lesotho; the Republic of Malawi; the Republic of Mozambique; the Republic of the Niger; the Republic of Rwanda; the Republic of South Africa; the United Republic of Tanzania; and the Republic of Zambia.

2 The indicators are guided by the UNPRPD Preconditions for Disability Inclusion, Convention on the Rights of Persons with Disabilities and the African Union's Plan of Action on Persons with Albinism.

## 1. Equality and non-discrimination

Societal barriers, including prejudice and discrimination limit the full and effective participation of persons with albinism in society. Moreover, the impairments associated with albinism, such as visual impairment and lack of melanin in the hair, skin and eyes expose children with albinism to additional level of exclusion. Therefore, albinism fits into the parameters of disability enunciated in preamble paragraph (e) of the Convention on the Rights of Persons with Disabilities and article 1 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Person with Disabilities in Africa (African Disability Protocol) which state that disability results from the interaction between persons with impairment and environmental and attitudinal barriers. The jurisprudence of the Committee on the Rights of Persons with Disabilities clearly indicates that albinism is considered a type of disability.[3] In addition, the Protocol on the Rights of Persons with Disabilities in Africa makes reference to albinism in its preamble thus clearly recognizing the condition as falling within the framework of disability. However, at the domestic level, albinism is not always understood as a type of disability which excludes children from albinism from legal protection and special measures protection. Therefore, State Parties must provide information on whether the efforts to disseminate the African Children's Charter also include highlighting that albinism is a type of disability. In addition to recognition of albinism as disability, legislative and administrative frameworks should be put in place to address the social barriers and exclusion of children with albinism at all levels. Special protection of measures that respond to the specific needs of children with albinism should be provided at community level, in education institutions, health care facilities and all other sectors to ensure inclusion.

In this regard, the following indicators should guide State Parties when reporting on measures undertaken concerning the right to equality and non-discrimination:

- Number of children with albinism: Has the State Party taken steps to systematically collect demographic data on children with albinism? (Yes/No. Explain). If so, how many children with albinism does the State Party have? How recent are these statistics?

- Recognition of albinism as a disability: Does the State Party recognize albinism as a type of disability in its national laws and policies and does it ensure equal access to disability services by children with albinism? (Yes/No. Explain).

- Anti-discrimination legislation and policies: Has the State Party enacted

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[3] X v United Republic of Tanzania, Communication 22/2014, CRPD Committee (18 August 2017) UN Doc CRPD/C/18/D/22/2014 (2017).

specific anti-discrimination laws and policies for children with albinism? (Yes/ No. Explain).

- Intersectional discrimination: How many cases of intersectional discrimination affecting children with albinism (e.g., based on gender and age) have been reported and addressed? (Number of cases. Explain).

- Anti-discrimination initiatives in schools and communities: How many schools and community centers, in both rural and urban areas, have implemented anti-discrimination programs specifically targeting stigma and stereotypes against children with albinism? (Number of schools/communities).

- Public awareness campaigns: How many national awareness campaigns target reducing stigma and discrimination against children with albinism? (Number of campaigns. Explain).

## 2. Service delivery and protection of specific rights

This section is divided into specific service and key rights areas to capture comprehensive details on various support mechanisms provided for children with albinism.

### a. Health and healthcare services

Research indicates that children with albinism in Africa generally have poorer health outcomes compared to children without albinism. Children with albinism lack access to health and health care services in contravention of article 14 of the African Children's Charter due to poor quality health services, particularly in rural areas, high cost of health services, discrimination, lack of support for eye care services and skin cancer prevention.[4] Moreover, there is a scarcity of medical practitioners specializing in eye care (ophthalmologists) and skin cancer prevention (dermatologists) and treatment (oncologists). These specialist services needed by children with albinism because of their condition are often difficult to access in light of the high demand for these services in public hospitals and their high cost in the private sector.

In this regard, the following indicators should guide State Parties when reporting on measures undertaken concerning the right to health and healthcare services:

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[4] Ebenezer Durojaye and Satang Nabaneh, 'Human rights and access to healthcare for persons with albinism in Africa' (2019) 7 African Disability Rights Yearbook 35, 50-55.

- Provision of skin and eye protection products: How many children with albinism have received free or subsidized sunscreen lotions, other skin protection products and eye protection products, such as sunglasses, during the reporting period? (Number of beneficiaries. Explain).

- Healthcare facilities offering specialized services: How many national healthcare facilities provide free or subsidized specialized dermatological and ophthalmological services for children with albinism? (Number of facilities).

- Number of specialists: How many dermatologists and ophthalmologists work at these facilities? (Number of specialists)

- Training of specialists: What steps have been taken to increase the number of specialists, including dermatologists, ophthalmologists and oncologists? (Explain)

- Training of health care service providers: What steps is the State Party taking to train existing health care service providers including nurses, midwives and doctors on the health needs of children with albinism (Explain).

- Cancer screening and treatment: How many children with albinism have received cancer screening and treatment services? (Number of children screened and treated).

- Inclusion of albinism in health policies: Are health policies inclusive of specific provisions for the needs of children with albinism (e.g., the inclusion of sunscreen in the national essential medicines list)? (Yes/No).

- Implementation of health policies: To what extent are albinism-inclusive health policies implemented? (Explain)

- Support to parents of children with albinism: Do parents of children with albinism receive support, including psychological support? (Yes/No. Explain)

## b. Education

While the African Children's Charter provides for the right to education for all children (art. 11), children with albinism experience numerous barriers to accessing and enjoying this right. In countries where ritual attacks, killings, and mutilations of persons with albinism are rampant, going to school can expose them to immense danger, particularly in rural areas, where children must walk long distances to get to school. These safety concerns coupled with myths concerning the intellectual ability of children with albinism have resulted in some parents not sending them to school. In addition, some schools decline to enroll learners with albinism due to the misconception that educating a child with albinism is a futile exercise and the refusal of teachers to engage with children with albinism. Furthermore, the failure of some Member States to ensure their access to reasonable accommodation and assistive devices in an inclusive school environment means that children with albinism do not receive equal access to education and are not able to develop to their fullest potential as required by the African Children's Charter.[5] Most children with albinism on the continent do not receive reasonable accommodation, such as sitting closer to the board, large print documents, or extra time during examinations. Furthermore, they do not receive assistive devices such as prescription glasses, monocular telescopes or magnifying glasses that would amplify their vision, assist them to read better and see the board and charts. Their education is also hampered by a lack of appropriate teacher training to support in mitigating the barriers to their education. Children with albinism report experiencing bullying, segregation, marginalization and name calling in schools.[6] This has led to high drop-out rates, low school attendance and poor academic performance amongst some children with albinism, particularly girls.

In this regard, the following indicators should guide State Parties when reporting on measures undertaken concerning the right to education:

- School attendance, enrolment and completion rates: What is the enrolment, attendance, completion and drop-out rate of children with albinism in Early Childhood Development Centers, primary schools, secondary schools and vocational training centers? (Number of children enroled, attending, completing and dropping out of educational institutions, disaggregated by gender and type of institution)).

- Enrolment in inclusive schools: How many children with albinism are enroled

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[5] Report of the Independent Expert on the enjoyment of Human Rights by Persons with albinism, Muluka-Anne Miti-Drummond, The right to education for persons with albinism, Human Rights Council (02 January 2024) UN Doc A/HRC/55/45 (2024) para 35.

[6] ibid, paras 14 - 22.

in inclusive schools as opposed to special schools or mainstream schools? (Number of children enroled)

- Reasonable accommodation in inclusive schools: How many children with albinism are receiving individualised reasonable accommodations (e.g., large print materials, seating arrangements etc) in schools and on online learning platforms? (Number of children accommodated. Explain).
- Assistive devices: How many children with Albinism have been provided with assistive devices (e.g., magnifying glasses, prescription glasses) in educational settings? (Number of children receiving devices).
- Teacher training on albinism: How many educators have been trained on inclusive education practices specific to children with albinism? (Number of trained educators).
- Educational support programs for families: Does the State Party offer educational support programs for families of children with albinism to encourage school enrolment? E.g., financial aid, material support, bursaries. (Yes/No. Explain).

## c. Child protection and safeguarding

Children with albinism are entitled to the same protection measures as all other children. However, in contrast with other children, they face unique risk of harm in the form of ritual attacks, killings and trafficking. The term 'ritual attacks' refers to attacks that are perpetrated with the aim of obtaining the body parts of persons with albinism for use in witchcraft rituals.[7] Children with albinism are disproportionately represented amongst persons with albinism who are attacked, murdered, and mutilated for ritual purposes in contravention of their right to survival and development (art. 5) and the right to protection against child abuse and torture (art. 16). They constitute two-thirds of documented murders and mutilations. The attacks are driven by superstitious beliefs that using body parts of persons with albinism in witchcraft rituals can bring great wealth and prosperity.[8] Research indicates that children with albinism may in fact be the main targets in these violent attacks due to the erroneous belief that their innocence enhances the potency of witchcraft potions. Children with albinism are attacked in a variety of

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[7] Report of the Office of the United Nations High Commissioner for Human Rights, Persons with albinism, Human Rights Council (12 September 2013) UN Doc A/HRC/24/57 (2013) para 19.

[8] Ines Kajiru and Isaack Nyimbi, 'The impact of myths, superstition and harmful cultural beliefs against albinism in Tanzania: A human rights perspective' (2020) 23 PER / PELJ 1-27; Muthee Thuku, 'Myths, discrimination and the call for special rights for persons with albinism in sub-Saharan Africa' (2011).

environments, including on their way to school, at home or in the community and most often by people who are known to them.[9] In most cases, perpetrators commit these crimes with relative ease and impunity.

In addition, children with albinism are often the victims of human trafficking for purposes of removing their body parts.[10] Emerging patterns indicate that there is often more than one person involved in the abduction, sale, and trafficking of children with albinism. Criminal networks that include witch doctors, kidnappers, traffickers and killers, wealthy clients and often times family members are involved but the masterminds are rarely ever caught. Prosecution rates for such crimes remain low partly due to gaps in legal protection including laws related to trafficking in body parts. In many cases, domestic legal systems are ill prepared to address crimes against children with albinism including ritual attacks, trafficking in body parts, possession of body parts and human tissue belonging to persons with albinism. Consequently, children with albinism may be denied the right to access justice and may experience further rights violations due to these attacks including violation of the right to survival and development. Therefore, States need to enact targeted measures that respond specifically to the situation of children with albinism.

In this regard, the following indicators should guide State Parties when reporting on measures undertaken concerning child protection and safeguarding:

- Child protection services for albinism: How many cases of violence, including ritual attacks, human trafficking, infanticide, sexual exploitation and sexual violence, or other forms of violence against children with albinism have been reported and prosecuted? (Number of cases).

- Protection from ritual attacks: Does the State Party have specific laws or policies addressing ritual attacks on children with albinism? (Yes/No).

- Protective care measures: What measures have been taken to protect children with albinism from trafficking, ritual killings, and other violence?

- Family support: What measures is the State implementing to help families of children with albinism in respect of their safety?

- Training of child protection officers: How many child protection officers have been trained on the unique vulnerabilities of children with albinism? (Number of officers trained).

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[9] ibid para 40.

[10] Ikponwosa Ero and others, People With Albinism Worldwide: A Human Rights Perspective (2021) 33.

- Prosecution of perpetrators: How many perpetrators have been brought to justice?(number/explain)?

- Child Sensitive Justice: Is there a safe and friendly mechanisms for reporting cases of violations by children with albinism by themselves? Is there a support system in the reporting process to ensure their safety and security? Is legal aid and counselling for children with albinism tailored to their needs available? (Explain)

- Psychosocial support: Are children with albinism who are survivors or at risk of violence receiving psychotherapy, counselling, and rehabilitation?(Yes or No. Explain)

## d. Family care and alternative care

The rights to protection of the family, parental care and protection enshrined in articles 18 and 19 respectively are often violated for children with albinism. There have been many instances where children with albinism are abandoned at birth by their families due to stigma and discrimination. Some children with albinism are separated from their families and grow up in orphanages, boarding schools, or shelters for various reasons, including parents' inability to meet their health and education needs, stigma and discrimination from society and families relinquishing the burden of care, or fear of attacks against the children from those seeking body parts of persons with albinism. In some cases, parents are forced to send their children far from home due to lack of reasonable accommodation at schools closer to home. In this regard, it is also the duty of State Parties to ensure measures are in place to assist parents of children with albinism to fulfil their parental responsibilities, in accordance with article 20.

Therefore, the following indicators should guide State Parties when reporting on measures undertaken concerning the right to family life:

- Family support programs for children with albinism: Does the State Party offer family support programs specifically targeting stigma reduction and prevention of abandonment of children with albinism? (Yes/No. Explain).

- Parental education programs on albinism: How many parental education programs have been conducted to improve the care and protection of children with albinism? (Number).

- Sibling and family support networks: Are there support groups or networks available for siblings and families of children with albinism? (Yes/No).

- Prevention of separation: What support is in place to ensure that children with albinism are not separated from family and are protected by law from any form of harm?

- Reintegration programs for children with albinism: How many children with albinism have been reintegrated into family settings from institutional care or shelters? (Number).

- Safe Secure shelter/home: Are there temporary care shelters/homes that cater for the needs of children with albinism by the Government? How many are there in number and how are they regulated to ensure the promotion and protection of the rights of children with albinism? What transition program are implemented and what is the trend of the number of children in such institutions?

### e. Name, identity and nationality

The right of children with albinism to a name, identity and nationality is recognised in article 6 of the African Children's Charter. The right acts as an important safeguard against the concealment, abandonment, neglect, segregation and, in some cases, statelessness of children with albinism. Children with albinism, like other children with disabilities, are more likely to not have their birth registered. Cultural prejudices, stigma, and shame associated with the birth of a child with albinism, can lead to parents being reluctant or unwilling to register the birth of their child with albinism. This is a particular concern for children with albinism born at home and in rural areas. Moreover, children with albinism are at heightened risk of infanticide and their birth may not be registered in order to conceal their killing. In some instances, fathers of children with albinism contest the paternity of the child when they are born resulting in late or non-registration of the child. This is prevalent in societies where the cultural practice is to register a child under the father's surname. The lack of birth registration results in the inability to access basic services such as education and health. Moreover, because birth registration is an important source of data, the lack of birth registration makes it difficult for States to plan adequately for social services.

According to Africa's Agenda for Children 2040, the lack of birth registration of children born to parents who are asylum seekers or refugees, or on the move in general, and/or stateless, including children with albinism, can result in them being stateless. Statelessness compounds the challenges associated with the lack of registration, particularly access to healthcare services and education which are crucial for children with albinism given their unique health care needs and general exclusion in education. Statelessness further exposes children with albinism to greater security risks such as ritual attacks and trafficking for body parts because it easier for perpetrators to kill and attack unregistered and undocumented children with near impunity.

In this regard, the following indicators should guide State Parties when reporting on measures undertaken concerning the right to name, identity and nationality:

- Birth registration access: How many children with albinism have been registered at birth, including children with albinism on the move and/or stateless or born to stateless parents? (Number of registrations).[11]

- Issuance of identity documents: How many children with albinism have been issued identity documents (e.g., national IDs) during the reporting period? (Number).

- Access to nationality for stateless children: How many stateless children with albinism have been granted nationality during the reporting period? (Number).

- Discrimination in access to identity and nationality: How many cases of discrimination against children with albinism in acquiring identity documents have been reported and addressed? (Number of cases).

- Awareness campaigns on the right to identity: How many nationwide awareness campaigns have been conducted to promote the right to identity and nationality for children with albinism, including children on the move, stateless children, children of refugees, asylum seekers and stateless persons ? (Number of campaigns).

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[11] State Parties who do not collect data on the registration of the birth of children with albinism should begin to do so.

### f. children on the move and stateless children with albinism

The protection of children with albinism on the move, including refugees, asylum seekers, internally displaced children and stateless children in Africa remains inadequate.[12] There is a general lack of data on child refugees, asylum seekers, internally displaced children, and stateless children with albinism mainly because data on children on the move is not disaggregated.[13] The primary drivers of displacement for children with albinism and their families include aggravated forms of discrimination, extreme forms of persecution including violent attacks, inadequate access to critical health goods and services and increasingly, the adverse effects of climate change. Research indicates that there are several human rights challenges experienced by children with albinism on the move.[14] While on the move, children with albinism experience barriers to accessing the right to education including the lack of reasonable accommodation and support in schools, bullying and discrimination. In addition, they also struggle to have regular access to the essential health services that they require because of their condition. There have also been reports of children with albinism being subjected to stigma and discrimination while in camps, settlements, and host communities.[15]

In this regard, the following indicators should guide State Parties when reporting on measures undertaken concerning the protection of child refugees, children on the move, and stateless children with albinism:

- Protection of children on the move, and stateless children with albinism: What protection services does the State Party provide to child refugees, asylum seekers and internally displaced children with albinism and how many have received these services during the reporting period? (Explain).

- Access to healthcare services for children on the move and stateless children with albinism: How many child refugees, asylum seekers, internally displaced, and stateless children with albinism have received specialized healthcare services (e.g., dermatological, ophthalmological care)? (Number of children receiving care).

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[12] Report of the Independent Expert on the enjoyment of Human Rights by Persons with albinism, Muluka-Anne Miti-Drummond, People with albinism on the move, Human Rights Council (20 July 2022) UN Doc A/77/199 (2022) paras 50-52.

[13] In countries such as Republic of Uganda, Republic of Malawi, and United Republic of Tanzania where some data is available, children with albinism constitute close to half of all refugees with albinism. For instance, data collected from a refugee camp in the Republic of Uganda in 2022 showed that 30 of the 56 refugees with albinism were children. Refugees with albinism are mainly from the Democratic Republic of Congo, United Republic of Tanzania, Republic of Burundi, Republic of Mali, Federal Republic of Somalia, Federal Democratic Republic of Ethiopia, Republic of Rwanda, Republic of Malawi, and the Republic of Cameroon according to available data.

[14] Human Rights Council (n 12) paras 31-59.

[15] ibid, paras 50-52.

- Education access for children on the move and stateless children with albinism: How many child refugees, asylum seekers, internally displaced, and stateless children with albinism enrol in schools within host countries? (Number of child refugees with albinism enroled)

- Support in refugee camps: How many refugee camps or shelters have implemented programs to address the specific needs of children with albinism? (Number of camps/shelters. (Types of programs). How many refugee children with albinism are without parental care (number)?

- Training of protection officers: How many refugee and other protection officers have been trained to address the specific vulnerabilities of children on the move and stateless children with albinism? (Number of officers trained).

## 3. Accessibility

Accessibility is a fundamental pre-requisite for ensuring that children with albinism are effectively included in society and enjoy their human rights and fundamental freedoms as eshrined in the African Children's Charter. Because of their visual impairment, the physical environment, transportation systems, including signage at bus and train stations, information and communication systems in places where public services are offered, all need to be accessible to children with albinism

In this regard, State Parties should be guided by the following indicators when reporting on accessibility.

- Accessibility standards: What accessibility standards has the State Party developed that take the accessibility needs of children with albinism into account? (Explain)

- Physical accessibility in schools and public facilities: How many schools and public facilities are accessible for children with albinism, considering their visual impairments and sensitivity to light? (Explain).

- Availability of sun protection products: Are sunscreen lotions and other essential products provided tax-free or at subsidized costs on a regular and consistent basis at nationwide level? (Explain).

- Assistive technologies for children with albinism: How many children with albinism have access to assistive technologies and devices that are suited to their individual needs (e.g., prescription glasses, magnifying tools)? (Number).

- Accessible information in public services: How many public service centers provide information in accessible formats for children with albinism? (Number).

## 4. Participation of children with albinism

The participation of children with albinism in the development and monitoring of the programmes that relate to them is integral to the protection and promotion of their human rights and fundamental freedoms. Their lived experience provides them with a unique perspective and insight into their own situation. Therefore, children with albinism should be permitted to participate in the development and implementation of laws, policies and programmes that relate to them.[16] This not only entails having the opportunity to provide information and advice on the challenges and possible solutions, but also includes receiving support from the State Party to strengthen their capacity as self-advocates.

The following indicators should guide State Parties when reporting on measures undertaken concerning the participation of children with albinism:

- Involvement in law, policy and programme development: How effectively does the State Party involve children with albinism in the development of laws, policies and programmes affecting them? (Explain).

- Representation in public decision-making bodies: How many children or representatives of children with albinism are included in national child protection or disability committees? (Number).

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[16] See for example Report of the Independent Expert on the enjoyment of Human Rights by Persons with Albinism, Muluka-Anne Miti-Drummond, Women and Children Impacted by Albinism, Human Rights Council (24 December 2019) UN Doc A/HRC/43/42 (2019) para 83.

- Monitoring and evaluation participation: How does the State Party include children with albinism in the monitoring and evaluation of programs targeting them? (Explain).

## 5. Inclusive budgeting

Inclusive budgeting is essential for ensuring the successful implementation of laws, policies and programs aimed at promoting the rights of children with albinism. The majority of children with albinism come from low-income backgrounds and cannot afford the additional costs that they have to incur including the cost of assistive devices, skin care and eye care products.[17] State Parties must therefore, have targeted budget allocations for children with albinism to enable them to meet their inclusion objectives. Budget allocations can cater for social services including family and/or child allowances for children with albinism, scholarships or bursaries, health services and products, education, and child protection measures, including programs aimed at preventing violence against children with albinism.

In this regard, State Parties should be guided by the following indicators in terms of inclusive budgeting.

- Budget allocation for albinism programs: Does the State Party have specific budget allocations for services and programs supporting children with albinism? (Explain).

- Monitoring and reporting on budget allocations: Does the State Party have mechanisms to monitor and report on the expenditure for programs supporting children with albinism? (Yes/No).

- Tax exemptions for essential products: Are sunscreen and assistive devices for children with albinism exempt from taxes or provided at subsidized costs? (Yes/No).

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[17] Human Rights Council (n 5) para 69.

## 6. Accountability and governance

While some State Parties have made progress in recognizing and addressing the rights of children with albinism, significant gaps remain in terms of accountability and governance. For example, many countries do not systematically gather or disaggregate data on children with albinism in national censuses and surveys, making it difficult to assess the extent of challenges they face and to develop targeted interventions. Without full comprehensive data, efforts to address discrimination, improve access to essential services, and ensure the full inclusion of children with albinism remain fragmented and inconsistent. Even where policies exist, a lack of clear monitoring and evaluation frameworks means that implementation is inconsistent, and the impact remains difficult to measure.

In this regard, the following indicators should guide State Parties when reporting on their efforts to improve accountability and good governance.

- Data collection process on children with albinism: How does the State Party collect data on children with albinism (for example, during national surveys and censuses?) Is this data disaggregated? Provide details)

- Frequency of data collection on children with albinism – How often does the State Party collect data on children with albinism. (Explain)

- Frameworks for monitoring and evaluation: Does the State Party have specific frameworks to monitor and evaluate the implementation of policies for children with albinism? (Provide explanation).

- Use of data: How does State Parties use the collected data to inform their legislative, administrative, and budgetary measures? (Provide explanation)

- Legislative frameworks: What kind of legislative framework is available in the State to provide protection for children with albinism?

- Institutional mechanisms: Does the State have institutional mechanisms that deal with the rights of children with albinism? (Provide explanation).

The Committee encourages State Parties to adhere to the above recommendations in their state reporting bearing in mind that this Guiding Note is to be read alongside the Committee’s Guidelines on the Form, Content and Consideration of Initial and Periodic Reports.