**Statement to the Committee of the CRPD**

**By**

**The UN Independent Expert on Enjoyment of Human Rights by Persons with Albinism** 25 August 2017

Madam / Mister Chair,

Distinguished members of the Committee,

My regrets that I could not make this statement in person but I am grateful for this opportunity to have the statement read out to you.

Before addressing the scope of Article 5 of CRPD for persons with albinism, I wish to express gratitude for keeping a constant attention to the situation of persons with albinism in your work. Indeed this is a sign of your willingness to give effect to the key principle of the Sustainable Development Goals, to not only leave no one behind, but also to start with the furthest behind first.

At the outset of my mandate, I clearly stated that discrimination and stigmatisation are among the main barriers to the implementation of the human rights of persons with albinism, which in Sub-Saharan African can range from bullying and harassment at school to more severe forms of discrimination, such as ostracism of entire families, infanticide, physical threats, violent attacks including murder and mutilation, grave exhumation to steal and sell body parts and remains.

On the occasion of the Day of General Discussion, I would like to reaffirm the intersecting discrimination affecting persons with albinism, discuss the transformative scope of Article 5 of the CRPD and highlight the situation of multiple discrimination faced by women and children with albinism. I will then address the State’s duty to guarantee equality and non-discrimination to persons with albinism.

Indeed, I believe it is necessary to reiterate the centrality of the right to equality and non-discrimination for the enjoyment of human rights by persons with albinism. In many contexts, persons with albinism and their families routinely face prejudice and stigmatisation, and are exposed to multiple and intersecting forms of discrimination, including discrimination based on their colour, health, gender, age and visual impairment.

***Intersectionality***

I would like to discuss the notion of intersectionality regarding persons with albinism. The Convention on the Rights of Persons with Disability (CRPD) recognizes multiple and aggravated forms of discrimination, in particular regarding women and children with disabilities. However, the Convention does not address discrimination on the intersecting grounds of disability and colour, except for a preamble reference to discrimination based on colour among other prohibited grounds of discrimination. In that context, the General Comment on article 5 offers an opportunity to explicitly affirm the intersecting discrimination faced by persons with albinism and to affirm the strong potential of specific measures in addressing issues arising from such intersectionality

In that perspective, it appears to be essential to recognize that, in the application of article 5 to persons with albinism, they face different forms of discrimination on the ground of colour, including harmful practices and violence, in the form of physical attacks, mutilation and trafficking in body parts motivated by witchcraft beliefs and practices, often leading to death.

Accordingly, the Committee on the Elimination of Racial Discrimination has recognized that persons with albinism are discriminated against on the basis of their colour, albeit often being of the same race, descent, national and ethnic origin as those who persecute them. The experience of persons with albinism, discriminated on the basis of their colour is, therefore, a manifestation of racial discrimination intersecting with discrimination on the ground of disability.

***Scope of article 5 in the context of persons with albinism***

Article 5 of CRPD lays out four provisions that are all equally important for persons with albinism: equality before the law, legal protection, reasonable accommodation and specific measures. The scope of the equality and non-discrimination provision includes all forms of discrimination including denial of reasonable accommodation, a substantive concept necessary to enable the exercise of rights by persons with albinism on an equal basis with others.

The provision also prohibits discrimination by association, where a person without a disability is discriminated against based on any broad range of connections to a person with disability. Mothers of children with albinism for example often face strong social stigma, discrimination and exclusion would, therefore, fall under the normative protection of this clause.

The scope of article 5 to guarantee equality non-discrimination against persons with albinism is fundamentally transformative. As stated by the OHCHR, the Convention “takes an innovative approach to the principles of equality and non-discrimination in international human rights law. It lays out a powerful vision of substantive equality”. In this sense, the application of the Convention requires transforming societal structures, systems and conception.

This transformative scope means addressing and changing root causes of human rights violations. In my report on the root causes of attacks and discrimination against persons with albinism, I identified underlying societal and structural causes. These include myths, poverty, witchcraft practices and other aggravating factors. Addressing these root causes require a transformative agenda provided by the Convention. Such transformation will be achieved by State compliance with their international human rights obligations to give effect to substantive equality to persons with albinism.

***State duty to ensure equality to persons with albinism***

In view of clarifying the international human rights obligations under the CRPD at article 5, the Committee may consider reaffirming the duties of the State: to address multiple forms of discrimination, the duty to take measures to address discrimination, including special measures of temporary or permanent nature, in consultation with the persons and groups affected, the duty to take policy and legislative measures, the duty to implement plans of action, including human rights’ education and training, the duty to guarantee equality access and non-discrimination in the enjoyment of economic, social and cultural rights, the duty to prioritise access to economic, social and cultural rights for the most vulnerable and marginalised and the duty to equal access to the highest standards of mental and physical health, to the right to education, the right to work, the right to social security and to adequate standards of living.

Best practices in this regard include the adoption of national action plans of concrete measures to address extreme forms of discrimination against persons with albinsim as adopted by Malawi and Mozambique in 2015. Moreover, recently, a Regional Action plan on Albinism in Africa 2017-2021 to address attacks and related violations against persons with albinism in Sub Saharan Africa was recently endorsed by the African Commission on Human and People’s Rights.[[1]](#footnote-1) The Regional Action Plan sets out four clusters of measures:

1. Measures of prevention, including public education campaigns, data collection, research on the root causes;
2. Measures of protection, such as law enforcement, legislative framework, health care workers, social welfare, monitoring and reporting of cases);
3. Measures of accountability, such as combating impunity, victim support, reintegration of the displaced;
4. And measures for equality and non-discrimination, such as focal point on albinism, reasonable accommodation, access to health care, intersectionality.

***Special attention to women and children’s rights***

The CRPD’s transformative scope gives special attention to women and children with albinism in articles 6 and 7. Turning to the situation of multiple discrimination affecting women and children with albinism, it means addressing physical attacks, mutilations rape forced expulsion, domestic violence for having a child with albinism, abandonment, and trafficking of body parts. The combined effect of gender-based discrimination and discrimination against persons with albinism multiply the barriers for women with albinism or mothers of children with albinism in accessing justice.

As a case of discrimination by association, mothers of children with albinism, including those who do not have albinism, are often blamed for “causing” the albinism of their children, accused of infidelity, or having contracted a curse. Such social pressure and blame which often comes from their spouses or partners, extended family members and society often puts women in a situation where they have to choose between abandoning their child or being abandoned by their husbands. It often also means expulsion from the community, social isolation (both self and community inflicted) to escape abuse and quarantine the perceived “curse”.

Moreover, due to abandonment, mothers of children with albinism often face poverty upon having the child with albinism. This exposes their child with albinism to further poverty confinement as it negatively affects the child’s access to education and often pushes the child to seek gainful employment. Women whose spouses were involved in attacks against their child with albinism often face threats of reprisal from their extended family and the community at large after testifying against their husbands in investigation and prosecution of attacks.

With regard to children with albinism, they face a very high risk of infanticide and abandonment, either together with their mothers or on their own. In the absence of adequate registration systems of birth and death, and detailed census records targeting persons with albinism, there are no reliable statistics on these crimes, and therefore, cases are likely to go unreported and uninvestigated. It also means early intervention in the areas of health, particularly skin cancer prevention and reasonable accommodation relating to their vision impairment is difficult to cater to as there are no data to guide planning and policy-making processes.

In addition, myths linked to the innocence of children and the alleged power of their body parts makes then a preferred target of attacks. The involvement of family members in a large number of reported attacks as well as the vulnerability of children who are easy to capture as they do not have the necessary physical strength to defend themselves, further increases this risk. Besides, the particular vulnerability of children with albinism in cases of abandonment or where a family member is involved in an attack against them is highly concerning and strongly impacts their access to remedies and protection.

**Conclusion**

In sum, it is important to reiterate the transformative scope of the CRPD to accelerate or achieve de facto equality through special measures and reasonable accommodation with a special focus on multiple discrimination faced by women and children with disability and the intersectionality of disability and colour faced by persons with albinism as a whole. This framework establishes fundamental protections for persons with albinism to achieve substantive equality as well as, in combination with other human rights instruments prohibiting discrimination on the ground of colour, a framework for addressing the root causes of violence against persons with albinism.

The CRPD already has recognized the intersecting discrimination and the violent forms of discrimination that result against persons with albinism. All that is left to do, encompasses an explicit reference to this in the Committee’s General Comment on article 5. Such recognition would reinforce the protective and transformative scope of the Covenant when applied to persons with albinism and other similar groups that have been historically left furthest behind, both within and beyond the umbrella group of persons with disabilities.

Thank you.

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UN IE on the Enjoyment of Human Rights by Persons with Albinism

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**APPENDIX**

**For further information. Does not have to be read out loud**

What is Albinism?

Albinism is relatively rare genetically inherited condition that is non-contagious, and affects people worldwide regardless of ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any of the skin, hair and eyes. The absence of normal quantities of melanin means that most persons with albinism are vulnerable to bright light, skin cancer and have various degrees of vision impairment.

In order for a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance that a child will be born with albinism at each pregnancy. The proportion of persons affected by albinism in the world differs from region to region. For example, in North America and Europe, it is estimated that 1 in 17,000 to 20,000 people have the condition. In sub-Saharan Africa, 1 in 5,000 to 15,000 could be affected with various tribes and sub-groups showing rates as high as 1 in 1,000. While all reports of physical attacks to date have come from the Africa region, reports of gross stigmatisation and exclusion have been reported from nearly all other regions of the world.

1. Resolution 373: Resolution on the Regional Action Plan on Albinism in Africa (2017-2021) - ACHPR/Res. 373 (LX) 2017 (http://www.achpr.org/sessions/60th/resolutions/373/) [↑](#footnote-ref-1)