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**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development**

Written statement* submitted by Standing Voice, a non- governmental organization in special consultative status

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[03 February 2020]

* Issued as received, in the language(s) of submission only.



Defending the rights of women and children impacted by Albinism in Africa

Standing Voice is an international NGO defending the rights of people with albinism in Africa. In Africa, people born with the genetic condition of albinism face severe discrimination and violence; many are marginalised from services, and hundreds have been mutilated or murdered, their body parts stolen and harvested for use in ritual witchcraft. Based in Tanzania and Malawi and delivering programmes in Health, Education, Advocacy and Economic Empowerment, Standing Voice seeks to amplify the voices of people with albinism and equip them with the tools to reclaim their place in society.

On the occasion of the forty-third session of the Human Rights Council—and in conjunction with the latest report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (UN document code: A/HRC/43/42)—Standing Voice provides this written statement as a means of identifying current critical challenges in the realisation of human rights for persons with albinism in Africa, and elucidating best practices in the protection and empowerment of this severely marginalised group. In line with the report of the Independent Expert, our statement pays particular attention to the situation of women and children impacted by albinism across Africa.

Albinism is a genetic condition reducing pigmentation in the skin, eyes, and hair, causing complex visual impairment and increased vulnerability to UV-radiation and skin cancer. Visibly paler than their dark-skinned peers and families, people with albinism in Tanzania and Malawi are routinely objects of severe discrimination and myth: many are marginalised from healthcare, education, housing, employment, justice, and mainstream political and developmental processes. Across Africa, beliefs persist in the magical properties of the body parts of people with albinism, which are thought to generate wealth and prosperity when used in witchcraft rituals. This myth has caused 211 murders, and 597 attacks in total, across 28 African countries since 2006. Tanzania presents a uniquely severe case—with 76 murders—though the centre of gravity has recently switched to Malawi, where 161 reports of human rights violations have emerged since 2014. Children—who are comparatively easy to abduct, and whose ‘innocence’ is thought to increase the potency of witchcraft—comprise the majority of victims. In Tanzania, this has precipitated a flawed government policy of relocating children with albinism to protectorate centres, where they are separated from their families and kept behind high walls for their safety.

Women with albinism and mothers of babies with albinism are also disproportionately vulnerable to discrimination and violence. When the violence against people with albinism reached its peak in 2008 in Tanzania, almost twice as many reported attacks were perpetrated against women than men. In Tanzania, the enduring myth that intercourse with a woman with albinism can cure infertility and AIDS places this population at disproportionate risk of sexual violence and contraction of HIV. Sexual violence against women with albinism is chronically underreported: extensive consultation with people with albinism and qualitative data collected by Standing Voice points to a scale and extent of abuse against women not always reflected in official statistics. Mothers of babies with albinism are routinely ‘blamed’ when a baby with albinism is born, abandoned by their husbands and families and left with sole responsibility for the health, education and security (both physical and socioeconomic) of their children in the face of severe social exclusion and abandonment. As the report of the Independent Expert shows, the abandonment of many women by their partners upon the birth of a baby with albinism places restrictions on the ability of these women to participate in income-generating activities. This further jeopardises the health and security of both mother and child.

The report of the Independent Expert identifies a number of best practices to promote the enjoyment of human rights by women and children impacted by albinism. These span a diversity of sectors and include initiatives developed and supported by Standing Voice.

We are particularly encouraged by the Independent Expert’s recognition of our work in promoting the health and socioeconomic security of women and children impacted by albinism. Our Skin Cancer Prevention Programme currently provides an outreach service of health information and treatment to more than 6,000 people with albinism at 69 locations

across Tanzania and Malawi. Approximately half of these patients are women, and many are children. Each clinic provides skin cancer screening, liquid nitrogen cryotherapy, preventative education, sun-protective clothing, surgery referral where necessary, and a regular supply of sunscreen. Our Vision Programme provides a parallel package of eye care and education to over 3,000 people with albinism across Tanzania, of whom the majority are children and half are women. By supporting the health of women and children impacted by albinism, we are building their capacity to claim their other rights and lead prosperous, healthy lives.

A growing area of innovation within our programming pertains to the socioeconomic security of women and children impacted by albinism. Since 2013, we have supported women to monitor and subvert albinism-related stigma in communities across the Tanzanian Lake Zone. We have also created platforms for women to interact with entrepreneurs, local government representatives, and other key decision-makers to determine accountability for the reduction of inequalities they and their children face. We have also partnered with women impacted by albinism to co-produce training programmes that can strengthen their economic security. Delivered from our Umoja Training Centre on Ukerewe Island in Lake Victoria, these have included bespoke skills development programmes in tailoring, textiles and soapmaking. We are also proud to provide free production space to Upendo wa Mama, a community-based organisation empowering vulnerable women affected by albinism to develop skills in jewellery-making, making beeswax products, sewing and baking.

Moving forward, it is incumbent upon us not only to nurture and grow these programmes, but also to ensure that the voices and perspectives of women and children impacted by albinism are prioritised and embedded in the future replication of all best practices relating to their welfare. For too long, interventions to promote the wellbeing of people with albinism have bypassed women and children and disregarded their experiences and expertise. Rectifying that imbalance should be a cornerstone of programming by all stakeholders in future.

Standing Voice is delighted to participate in the forty-third session of the Human Rights Council and support the findings illuminated by the latest report of the Independent Expert on the Enjoyment of human rights by persons with albinism (A/HRC/43/42). With the mounting support of the United Nations—and the strengthening of collaboration between all stakeholders across affected states—we will break the cycle of marginalisation and violence that continues to harm persons with albinism in Africa today.
