

REGIONAL DEVELOPMENTS

MOTHERING AND ALBINISM: RECOMMENDATIONS FOR DISABILITY RIGHTS IN AFRICA

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1 About albinism

Albinism is a relatively rare recessive genetic condition that occurs worldwide in different forms. Oculocutaneous Albinism Type 2 (OCA2) is the most prevalent on the African continent.¹ The prevalence of albinism in Tanzania is cited as 1 in 2 673;² in South Africa as 1 in 3 900.³ Both parents must be carriers of OCA2 for their child to have the condition, of which there is a 1 in 4 chance in each pregnancy.⁴ Although both parents must transmit the gene, in various parts of Africa women largely carry the blame for this misunderstood condition.⁵ OCA2 results in a striking

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1 JGR Kromberg et al 'Types of albinism in the black Southern Africa population' (2012) 89 *East African Medical Journal* 20 at 21.

2 The United Republic of Tanzania 'Basic demographic and socio-economic profile' (2014) https://www.tanzania.go.tz/egov_uploads/documents/NATIONAL_SOCIO-ECONOMIC_PROFILE_sw.pdf (accessed 1 June 2021).

3 JRG Kromberg et al 'Children with oculocutaneous albinism in Africa: Characteristics, challenges and medical care' (2020) 14 *South African Journal of Child Health* 50.

4 JGR Kromberg 'Genetic counseling and albinism' in JGR Kromberg & P Manga (eds) *Albinism in Africa: Historical, geographic, medical, genetic, and psychosocial aspects* (2018) 216.

5 S Reimer-Kirkham et al 'Mothering, albinism and human rights: The disproportionate impact of health-related stigma in Tanzania' (2020) *Foundations of Science* 12-13.

physical appearance, particularly in the African context, where a partial or complete lack of melanin manifests as pale white skin, light hair, and sometimes light eye colouring.⁶ Lack of melanin causes a spectrum of visual impairments and heightened risk for developing skin cancer in the absence of meticulous sunscreen use and protective clothing.⁷ Concerns encountered by persons with albinism have increasingly been assessed from a human rights lens over the past decade, because of the levels of misunderstanding, discrimination, stigma and violence they endure, including harmful practices. This commentary focuses on the little-researched experiences of mothers impacted by albinism, whether with albinism themselves or with children with albinism.

2 Human rights research in Tanzania and South Africa

We draw on an ethnographic study in Tanzania and South Africa⁸ on mothers impacted by albinism, conducted by a researcher-advocate-policy network.⁹ Phase I of participatory fieldwork, involving sharing circles, in-depth interviews, and participant observation, was completed in Tanzania's Dar es Salaam and Mwanza regions in 2019. Sixty-two participants engaged in the research, of which 17 were mothers of children with albinism, nine were mothers with albinism themselves, and 36 were key stakeholders. During the global pandemic, similar participatory data collection in South Africa (Phase II) has been replaced with virtual fieldwork in collaboration with the local research team. Through virtual platforms such as Zoom and WhatsApp, 13 mothers and key stakeholders have been interviewed as of August 2021. Along with the fieldwork, the researcher-advocate-policy network is active in community engagement, advocacy, and knowledge mobilisation.

6 JGR Kromberg 'Clinical features, types of albinism, and natural history' in JGR Kromberg & P Manga (eds) *Albinism in Africa: Historical, geographic, medical, genetic, and psychosocial aspects* (2018) 28.

7 As above.

8 Research ethics clearance was obtained from the researchers' universities in Canada; in Tanzania from the National Institute of Medical Research (NIMR) and COSTECH (Tanzania Commission for Science and Technology); and in South Africa from the University of Pretoria.

9 Ikponwosa Ero, the inaugural UN Independent Expert on the enjoyment of human rights by persons with albinism, initiated this network with an invitation to Reimer-Kirkham and Astle to conduct research on albinism, human rights, and cultural/spiritual beliefs and practices. Our acknowledgement to network members: www.motheringandalbinism.com.

3 Human rights situation of mothers impacted by albinism: Making the case for a human rights approach

Our research underscores the need for a human rights approach to address mothers' experiences of discrimination, harmful practices, gender inequality, and lack of access to necessary services.

3.1 Discrimination

The study has revealed a near-universal experience of multiple and intersecting discrimination for persons with albinism and their families, with mothers bearing a disproportionate burden.¹⁰ Fueled by superstitious beliefs about albinism, mothers in our study faced discrimination along a continuum of severity from verbal insults, to reduced or hindered access to education and health services for their child, social exclusion, intimate partner violence, and abandonment. Discrimination started at the birth of an infant with albinism, from the reactions of healthcare providers, family, and community members, and continued across the life span of the child or mother with albinism. The discrimination was often based on the colouring of their child with albinism. Due to the hypervisibility of persons with albinism in contrast to the dominant Black citizenry in most parts of Africa, judgements and stigmatisation occur quickly. For example, a South African participant recalled her son being called 'golden boy' and 'swine' while a Tanzanian mother with albinism recalled growing up with dehumanising language such as 'white monkey' and 'ghost' (*zeruzeru*). Based on data from Tanzania and South Africa, mothers of children with albinism face multiple and intersecting discrimination on the basis of gender, disability, and race, resulting in reduced quality of life, heightened morbidity (for example, mental health challenges), and deprivation such as unstable incomes, food insecurity, and unstable housing and shelter.¹¹

3.2 Harmful practices

Mothers impacted by albinism report the extraordinary burden of care and surveillance that is required, especially to protect their children from

10 UNGA 'Women and children impacted by albinism' *Report of the Independent Expert on the enjoyment of human rights by persons with albinism*, Ikponwosa Ero A/HRC/43/42 (24 December 2019). This was based on a survey of persons with albinism and their representative organisations as well as government and other CSOs and national human rights institutions.

11 Reimer-Kirkham et al (n 5) 16.

harmful practices.¹² Harmful practices range from utterance of threats, to forceful removal of hair, trafficking in persons and in body parts, mutilation, and murder.¹³ In Tanzania, where there has been a relatively high incidence of reported attacks,¹⁴ particularly against children with albinism, many mothers in our study intervened in direct ways, for example, by accompanying their children to school, quitting jobs to be present with their children, and interrupting kidnapping attempts.¹⁵ In South Africa, where there have been fewer reported incidents, mothers of children with albinism in our ongoing study nonetheless describe a constant state of worry and unease.¹⁶

Harmful practices, particularly those forms that are accusations of witchcraft and ritual attacks, have been identified as a root cause of human rights violations perpetuated against persons with albinism and their families.¹⁷ In relation to harmful practices in general, the Protocol to the African Charter on the Rights of Women in Africa (the Maputo Protocol)¹⁸ and the African Charter on the Rights and Welfare of the Child (ACRWC)¹⁹ allude to and prohibit harmful practices. The Maputo Protocol lists some measures on how to respond, while the African Disability Protocol has greatly elaborated on the issue. The African Disability Protocol defines harmful practices taking a broad approach including 'behaviour, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the human rights and fundamental freedoms of persons with disabilities or perpetuate discrimination'.²⁰ This open-ended list means that the Protocol may accommodate any other forms of emerging harmful practices. This is an important factor, given the dynamic and constantly evolving forms that these practices tend to take in the region with regards to persons with

12 Ero et al 'Women human rights defenders: A case of activism of mothers of children with albinism in Tanzania' in *Handbook of Critical Disability Studies in a Globalizing World* (in review) 12-13.

13 UNGA 'Report of the Independent Expert on the enjoyment of human rights by persons with albinism: A preliminary survey on the root causes of attacks and discrimination against persons with albinism' (2016) A/71/255 (29 July 2016) paras 16 and 39-48.

14 UNGA 'Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to the United Republic of Tanzania' (2017) A/HRC/37/57/Add.1 (20 December 2017) para 52.

15 Ero et al (n 12) 12-13.

16 Interviews with South African participants, January 2021.

17 United Nations General Assembly (UNGA) 'Achievements, accomplishments, challenges and the way forward: An overview of work on the mandate' (2020) *Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero* A/HRC/46/32 21 (December 2020) para 65.

18 African Union, Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa, adopted on 1 July 2003, entered into force 25 November 2005.

19 African Union, African Charter on the Rights and Welfare of the Child, adopted July 1990, at 12 and 13.

20 African Union, Protocol to the African Charter on Human and Peoples' Rights on the Rights of People with Disabilities in Africa (2018) 4 https://au.int/sites/default/files/treaties/36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf (accessed 1 June 2021).

albinism. Article 11 of the same Protocol includes as harmful practices 'omens', 'witchcraft', 'ritual killings', 'concealment' and 'derogatory language'.²¹ It also protects persons with disabilities from 'exploitation, violence and abuse within and outside the home'.²² The Protocol proscribes negative representations and stereotyping of persons with disabilities, in both traditional and modern cultural activities, and through the media,²³ and affirms the right to live in the community.^{24,25} The Convention on the Rights of Persons with Disability (CRPD) in article 8(1)(b) calls on states to combat stereotypes, prejudices and harmful practices relating to persons with disabilities.²⁶

3.3 Gender equality

For the mothers in our study, gender inequality operated in complex ways in their everyday lives and was sustained by entrenched constructions about masculinity and femininity in the family context. Gender-based violence and abandonment were experienced by many of the mothers in our study. Women were typically blamed for the birth of a child with albinism, with gendered speculations such as infidelity with a white man, or spiritualised interpretations such as albinism occurring as punishment from god(s), spirits or ancestors for an alleged wrongdoing by the mother.²⁷ The perceived worth of mothers plummeted as they were deemed 'not woman enough',²⁸ either because they had albinism or because they gave birth to a child with albinism. Gender inequality meant that for many they were left without resources, power, and control, while being burdened with full responsibility for the welfare of their children.²⁹

3.4 Stigma and access to services

Mothers from Tanzania and South Africa provided multiple accounts of how stigma interfered with their access to health upon having the child with albinism.³⁰ Mothers were often not informed that their child was a child with a disability; rather the information tended to focus on the mystique of the child, leaving the mother without access to health information and support. There was often limited access to sunscreen to protect their children from skin cancer. Nearly all the support they received was self-generated through informal cooperation through which they

21 The African Disability Protocol (n 20) 9.

22 The African Disability Protocol (n 20) arts 8 and 9(2)(c).

23 The African Disability Protocol (n 20) arts 18 and 25(g).

24 The African Disability Protocol (n 20) arts 10 and 14.

25 The African Disability Protocol (n 20) arts 21, 22 and 31.

26 UN General Assembly, Convention on the Rights of Persons with Disabilities (2007) UN Doc A/RES/61/106 (24 January 2007).

27 Reimer-Kirkham et al (n 5); UNGA (n 10).

28 Reimer-Kirkham et al (n 5) 9.

29 Reimer-Kirkham et al (n 5 above) 13.

30 Reimer-Kirkham et al (n 5).

nurtured resilience and built viable micro-enterprises, often with support from non-governmental organisations.³¹

4 Using the Convention on the Rights of Persons with Disabilities (CRPD) and African Disability Protocol to address experiences of mothers impacted by albinism

The CRPD³² which has been ratified by both Tanzania and South Africa - and its African counterpart, yet to come into force, the African Charter on Human and Peoples' Rights on the Rights of People with Disabilities in Africa (African Disability Protocol) - if applied simultaneously can adequately³³ respond to human rights violations experienced by mothers impacted by albinism.³⁴ According to the CRPD, state parties have a duty to prohibit 'all discrimination'³⁵ and this includes 'discrimination by association'³⁶ affecting mothers of children with disabilities. This warrants formal measures such as 'effective legal remedies and sanctions in civil, administrative and criminal proceedings, including protection from any acts of discrimination carried out by private entities',³⁷ as well as 'specific measures'.³⁸ The African Disability Protocol similarly recognises the need for states to protect family members of persons with disabilities from indirect discrimination. Article 5(2)(b)³⁹ of the Protocol also calls for specific measures in a manner analogous to the CRPD.⁴⁰ These treaties recognise the essential role that families, guardians and caregivers play in the lives of persons with disability. Similarly, the CRPD and the African Disability Protocol recognise multiple and intersecting discrimination. The CRPD's preamble recalls the 'difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination'⁴¹ whilst the Protocol expresses concern at the multiple forms of discrimination people with disabilities face.⁴²

31 Ero et al (n 12) 7-8.

32 CRPD (n 26).

33 The African Disability Protocol (n 20).

34 African Union 'List of countries which have signed, ratified/acceded to the Protocol to the [African Disability Protocol]' (2020) 1.

35 CRPD (n 26) art 5(2).

36 CRPD Committee, General Comment 6 (2018) on equality and non-discrimination (2018) UN Doc CRPD/C/GC/6 dated 26 April 2018, paras 17 and 18(b).

37 Para 22 of General Comment 6.

38 Para 28 of General Comment 6.

39 African Disability Protocol (n 20) 6.

40 See art 5(4), paras 28 and 29.

41 CRPD (n 26) 2.

42 African Disability Protocol (n 20).

5 Unsettled issues

Associated racial discrimination experienced by mothers of children with albinism is often not addressed. The International Convention on the Elimination of Racial Discrimination (CERD) defines racial discrimination as ‘based on any distinction, exclusion, restriction or preference based on’ *inter alia*, colour

which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.⁴³

The grounds for discrimination listed in article 1 do not need to be combined, and discrimination based on any one of these triggers are not only subject to the Convention, but also all the instruments applicable in the efforts to combat racial discrimination are equally applicable to persons with albinism.⁴⁴ Recently there have been calls for the crimes against people with albinism to be considered hate crimes on the basis of colour.⁴⁵ The Independent Expert has called for guidance from the CERD on this matter.^{46,47}

6 Recommendations

6.1 The obligation to take specific measures

Multiple and intersecting discrimination for a small, marginalised group that is historically misunderstood, and which faces harmful practices of a particular and ‘stunningly vicious’⁴⁸ nature, calls for adoption of specific measures. Specific measures are used in human rights to accelerate equality and provide advantages to a certain (often historically) underrepresented or marginalised group. While the measures are usually temporary, they can be permanent, depending on ‘context and

43 UN General Assembly, International Convention on the Elimination of All Forms of Racial Discrimination, 21 December 1965, United Nations, Treaty Series, vol 660, p 195, art 1(1), entered into force 4 January 1969, 2.

44 Such as action plans and other measures taken to implement the Durban Declaration and Programme of Action. See Concluding Observations on the combined fourth to eighth periodic reports of South Africa, Committee on the Elimination of Racial Discrimination (5 October 2016) UN Doc CERD/C/ZAF/4-8 (2016) paras 20-21

45 UNGA (n 17 above) 17-19.

46 As above.

47 UNGA ‘Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the expert workshop on witchcraft and human rights’ A/HRC/37/57/Add.2 (2018) para. 28.

48 OHCHR ‘Zeid calls for action after surge in “stunningly vicious attacks” on people with albinism in East Africa’ (2015) <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15673&LangID=E> (accessed 1 June 2021) para 2.

circumstances, including by virtue of a particular impairment or the structural barriers of society'.⁴⁹

As state parties to the CRPD, South Africa and Tanzania have a duty to adopt long-term, in-depth, and widespread measures to deal with the multiple and intersecting discrimination experienced by mothers of children with albinism. Such measures include education about the genetics of albinism and the human rights framework, specifically targeting health workers and community leaders, or other custodians of culture at the community level, targeting parents of children with albinism such as support groups for mothers impacted by albinism with the objective of facilitating the implementation of preventive and accountability measures where rights have been violated. Long term, specific measures are more effective at transforming cultural norms and structures that uphold human rights standards.

The need for specific measures was one of the lessons learned from the Millennium Development Goals (MDGs), an international agenda pursued by all member states of the UN, including Tanzania and South Africa. Many of these goals targeted only a percentage of the mainstream population and progress was measured with averages, instead of disaggregated indicators. Consequently, inequalities affecting specific groups and sub-groups were neither measured nor addressed, even though the situation of many of the groups was 'deteriorating'.⁵⁰ The Sustainable Development Goals (SDGs) which set out to continue the MDGs, contain a central pledge 'to leave no one behind'.⁵¹

The objective of leaving no one behind includes a core aim of ending absolute poverty and discrimination by prioritising and fast-tracking action for those furthest behind. Affirmative action should be taken to ensure that 'populations at risk of being left behind are included from the start' and requires 'enabling people and groups who are left behind to progress at a higher rate than those who are better off'.⁵²

Fundamentally, leaving no one behind promotes the right to equality and non-discrimination, which is intrinsic to sustainable development. The adoption of specific measures for mothers impacted by albinism is in accordance with international human rights standards and obligations, and is instrumental in the universal pledge of leaving no one behind. The

49 Para 29 of General Comment 6.

50 UNGA 'Enjoyment of human rights by persons with albinism' *Report by the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero A/73/181* (2018) 14.

51 United Nations Sustainable Development Group 'Leave no one behind' <https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind> (accessed 1 June 2021).

52 E Stuart & E Samman 'Defining "leave no one behind"' (2017) *Overseas Development Institute* 2 and 3.

Regional Action Plan on Albinism⁵³ is a compendium of specific measures that both Tanzania and South Africa as member states of the African Union have been called upon to adopt at the national level.⁵⁴

6.2 Recognition of discrimination by association

This commentary has implications for disability rights more broadly. First, the multiple and intersecting discrimination experienced by mothers of children with albinism reflect what can be the case for other mothers of children with disabilities. There is often a lack of recognition of multiple and intersecting discrimination or discrimination by association in the region, as well as a lack of effective mechanisms of legal redress and reparation. Those related to people with disabilities need to receive education on their own rights, and how disability rights laws, among others, protect them. As this research continues, there will be a need to conduct a deeper assessment of how member states have dealt with discrimination by association including emerging patterns from international and regional jurisprudence.

Second, because of these intersecting violations, the case of mothers impacted by albinism illustrates the need for multi-level, multi-vector analyses, instruments, and interventions for sustained change; bringing together national, regional, and international attention and intervention. While the multisectoral approach and the mainstreaming of disability rights has been in progress for many years, this process appears to be slower in the countries we have studied. There is a need to invest in mainstreaming disability rights in Tanzania and South Africa, and to assist in the transition of the concept of disability from the socio-cultural approach to the human rights approach.

7 Conclusion

This study on mothering and albinism underscores the importance of immediate ratification and implementation of the Africa Disability Protocol. This is crucial for the protection of people with disabilities, but particularly for people with albinism and their families in Africa, who are often vulnerable to harmful practices. Harmful practices are recognised in the Africa Disability Protocol as forms of human rights violations indefensible by culture or tradition.⁵⁵ We have evidence from this study that harmful practices are often culturally entrenched actions that threaten

53 [Actiononalbinism.org](http://actiononalbinism.org) (accessed 1 June 2021).

54 ACHPR 'Resolution on the regional action plan on albinism in Africa (2017-2021)' ACHPR/Res.373(LX) (2017) 1 <https://www.achpr.org/index.php?url=sessions/resolutions&id=415#:~:text=Endorses%20the%20Regional%20Action%20Plan> (accessed 1 June 2021).

55 N 20, 4, 6 & 9.

the right to life and security of people with albinism and their family members, and constitute significant attitudinal and structural barriers to the transition from the socio-cultural approach to disability to the human rights approach. Overall, the emerging data from our research underscores the role of the Protocol as a strong complement to the CRPD, for the promotion of disability rights in these countries, and arguably in neighbouring countries with analogous concerns. Therefore, we argue for immediate ratification of the Protocol as an essential platform to promote and protect human rights of people with albinism, mothers and other family members, as well as all other people with disabilities.