

CHAPTER 2

HUMAN RIGHTS AND ACCESS TO HEALTHCARE FOR PERSONS WITH ALBINISM IN AFRICA

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Summary

Discrimination and stigma relating to persons with albinism remain the norm in many African countries. There are documented reports of how persons with albinism have been subjected to gross human-rights violations owing to their colour. While attention has been given to the killings of persons with albinism worldwide, little attention has been given to other human-rights violations they encounter while seeking social services, particularly healthcare services. Discrimination against persons with albinism can lead to deleterious health consequences and at the same time hinder access to care for them. Women are generally historically disadvantaged and continue to encounter challenges with regard to their sexual and reproductive health. Being a woman with albinism can aggravate the situation as these women may encounter multiple forms of discrimination in healthcare settings. Thus, this paper examines the human-rights challenges relating to the health of persons with albinism with a focus on women with albinism in Africa. It draws on the intersectionality approach to argue that women with albinism suffer from multiple forms of discrimination, which further compound access to healthcare services for them. It discusses the relevance of regional human-rights instruments in addressing the right to healthcare of women with albinism. In particular, the paper discusses the potential of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa and the norms developed by the African Commission on Human and Peoples' Rights as well as its counterparts at the international level

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in advancing the right to health of women with albinism in the region. Furthermore, the paper recommends to the African Commission and African governments measures and steps to adopt in order to safeguard the right to health of women with albinism in the region.

1 Introduction

Albinism is a rare, non-contagious, genetically inherited difference present at birth. It results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light for persons with albinism.¹ The condition is found in both genders, regardless of ethnicity and in all countries of the world.²

There are various types of albinism with diverse implications for persons with this condition. The most common form is known as oculocutaneous albinism (OCA) and this affects the skin, hair and the eyes.³ There are different types and subtypes of OCA with varying degrees of melanin deficiency. The main ones are tyrosinase negative (OCA1) where there is little or no melanin production; and OCA2 type, wherein some melanin is produced, giving rise to white or cream-coloured skin, sandy-coloured hair and light blue, grey or brown irises in those affected. These are the most prevalent in African countries.⁴

Due to ignorance and myths, persons with albinism face severe discrimination and violence. Hundreds of attacks against persons with albinism have been reported in 25 countries.⁵ These acts of violence and abuses against persons with albinism demonstrate how their fundamental human rights are constantly violated or disregarded. Superstitious beliefs about persons with albinism in many African countries are rife and include the belief that they are ghosts, that they never die, that sexual intercourse with a woman or a girl with albinism can cure HIV/AIDs and most grotesque of all, that their body parts can bring about wealth and good luck when consumed in potions and worn as amulets.⁶ In response to human-rights abuses against persons with albinism, the Former UN Secretary-General Ban Ki-moon on 13 June 2016, called on all countries to end all

1 This paper uses the term 'persons with albinism' rather than the term 'albino(s)', which has been labelled as demeaning and offensive by various quarters of the community of persons with albinism for failing to appreciate their humanity first before the condition.

2 Report of the Office of the United Nations High Commissioner for Human Rights on Persons with albinism, HRC (12 September 2013) UN Doc A/HRC/24/57 (2013) paras 10 & 11.

3 ES Hong et al 'Albinism in Africa as a public health issue' (2006) 2 *BMC Public Health* 212.

4 As above.

5 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, HRC (18 January 2016) UN Doc A/HRC/31/63 (2016) para 20. See also Preliminary study on the situation of human rights of persons living with albinism (30 July 2014) UN Doc A/HRC/AC/13/CRP.1 (2014) para 10.

6 See HRC (n 2 above) para 17.

forms of discriminatory practices that threaten the well-being, health and even the lives of people with albinism, and to adopt programmes that would enable them to play a full part in society.⁷

2 Albinism as a form of disability

According to the World Report on Disability, disability is a 'complex, dynamic, multidimensional and contested' concept.⁸ At first, disability was viewed exclusively as a medical condition, but subsequently construed as a social construct, which takes into account social and environmental circumstances. These two views are regarded as the medical and social models respectively.⁹ On the one hand, the medical model 'locates the disability within the person and views persons with disabilities as objects for clinical intervention'.¹⁰ Persons with disabilities are thus primarily seen as 'passive patients' and are not empowered to make decisions concerning their lives.¹¹

On the other hand, the social model of disability makes the distinction between impairment and lost or limited functioning experienced by individuals. The social model further notes that people with disabilities or impairments encounter various barriers simply because of the social structure;¹² thus, such barriers may be as a result of social, cultural, physical, material or attitudinal factors, but they tend to exclude people with impairment from mainstream life. This conceptualisation applies to persons with albinism who daily encounter various forms of barriers to living a life of dignity. The social model is complementary to the rights-based approach to disability, which is applied throughout this paper. Indeed, Thomas has advanced the social-model approach through the 'social relational understanding of disability'.¹³ By this, he identifies the 'significance of impairments effects', that is, the daily impact of living with particular impairments. He further emphasises the implications of understanding the psychosocial effects of disability.¹⁴ With regard to women with albinism, the impairment effects include poor vision, power

7 'On Albinism Awareness Day, Ban urges all countries to break cycle of attacks and discrimination' *UN News* 13 June 2016 <http://www.un.org/apps/news/story.asp?NewsID=54206#.V7DZo7grLIV> (accessed 10 February 2019).

8 World Health Organisation (WHO) 'World report on disability' (2011) xxi.

9 C Ngwena 'Deconstructing the definition of "disability" under the Employment Equity Act: Social deconstruction' (2006) 22 *South African Journal of Human Rights* 619.

10 G Quinn & T Degener *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability* (2002) 11.

11 See C Ngwena 'Interpreting aspects of the intersection between disability, discrimination and equality: Lessons for the Employment Equity Act: Part 1 (Defining disability)' (2005) 2 *Stellenbosch Law Report* 221.

12 Union of the Physically Impaired against Segregation *Fundamental principles of disability* (1976).

13 C Thomas 'How is disability understood? An examination of sociological approaches' (2004) 16 *Disability and Society* 569.

14 As above.

imbalance, social prejudice and potential skin damage due to sun. Buttressing this point, a study carried out among 15 adults with albinism in South Africa has shown the negative effects the disablist external environment can have on self-image and on their sense of belonging at home and within the wider community.¹⁵

In addition to these two approaches to disability, the third model – the human-rights model – has emerged. The human-rights model to disability does not define disability, but recognises it as an ‘evolving concept’.¹⁶ It sees persons with disabilities not as objects of charity, but as subjects of rights.¹⁷ The adoption of the Convention on the Rights of Persons with Disabilities (CRPD)¹⁸ in 2006 and its entry into force in 2008 was a historic shift in protecting the rights of persons with disabilities. The CRPD aims to promote and ensure inclusion of persons with disabilities in all aspects of society. According to Viljoen, the CRPD ensures ‘accountability and legal obligations on states’.¹⁹

As of March 2019, there are currently 161 signatories and 177 ratifications of the CRPD.²⁰ At the core of CRPD are the values and principles of non-discrimination and equality of opportunity. There are eight guiding principles to the CRPD namely: respect for inherent dignity and individual autonomy; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities.²¹ The CRPD targets not only the law, but also prejudicial societal attitudes, which undermine equality. It recognises the personhood of every persons with disabilities and requires states to provide support in exercising that capacity.

15 MBJ Pooe-Moneymore et al ‘The experience of people with oculocutaneous albinism’ (2012) 17 *Health SA Gesondheid* 592.

16 Preamble, para e CRPD.

17 The CRPD adopts this approach and gives a more effective normative legal framework for the protection of the rights.

18 Adopted by the UN General Assembly on 13 December 2006 and came into force on 3 May 2008.

19 F Viljoen *International human rights law in Africa* (2012) 140.

20 See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 4 March 2019).

21 Art 3 CRPD. For an in depth analysis of the CRPD with a special focus on Africa, see TP Van Reenen & H Combrinck ‘The UN Convention on the Rights of Persons with Disabilities in Africa: Progress after 5 years’ (2011) 18 *SUR International Journal of Human Rights* 133; J Biegon ‘The promotion and protection of disability rights in the African human rights system’ in IGD Plessis & TV Reenen *Aspects of disability law in Africa* (2011) 53-83.

In some of its recent decisions, the Committee on the CRPD has affirmed the rights of persons with albinism. For instance, in *Y v Republic of Tanzania*,²² the Committee found that the government of Tanzania was in violation of article 5 when it failed to protect the applicant from violence as a result of albinism. According to the Committee, since these attacks were a form of violence exclusively directed at persons with albinism, failure to investigate constituted a form of discrimination against persons with albinism. The Committee expressed the view that despite discrimination and acts of violence against persons with albinism, the state has failed to take appropriate measures to create awareness and to redress the violations.

An important point to note from this decision is that the Committee found that acts of violence against persons with disabilities were in violation of article 5 on non-discrimination. This is an implicit recognition of albinism as constituting disability. In addition to violation of article 5, the Committee found that the government of Tanzania was equally in violation of articles 7, 8 and 16 of the Convention. This decision by the Committee sends a strong signal that acts of discrimination and violence against persons with disabilities, especially persons with albinism, will not be condoned.

The Human Rights Council appointed an Independent Expert on the enjoyment of human rights of people with albinism for three years in 2015. The mandate includes the promotion and protection of the rights of persons with albinism at the UN and the regional human-rights mechanisms.²³ The mandate of the Independent Expert was extended by Human Rights Council on 22 March 2018.²⁴

At the regional level, there are various human-rights instruments that have a number of provisions that seek to promote and protect the rights of persons with disabilities. The instruments include the African Charter on Human and Peoples' Rights (African Charter),²⁵ the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women (African Women's Protocol),²⁶ the African Charter on the Rights and

22 *Y v Republic United of Tanzania* Communication 023/2014 (Views adopted on 31 August 2018).

23 Resolution 28/6: Independent Expert on the enjoyment of human rights by persons with albinism, HRC (10 April 2015) UN Doc A/HRC/RES/28/6 (2015).

24 Resolution 37/5: Mandate of the Independent Expert on the enjoyment of human rights by persons with albinism, HRC (9 April 2018) UN Doc A/HRC/RES/37/5 (2018). On her various reports, see <https://www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx> (accessed 21 October 2019).

25 The African Charter on Human and Peoples' Rights adopted in 1981 and came into force in 1986, art 2.

26 Protocol to the African Charter on Human and Peoples' Rights and on the Rights of Women in Africa, adopted 11 July 2003, 2nd Ordinary Session of the Assembly of the African Union, AHG/Res. 240 (XXX) (entered into force 25 Nov 2005) art 23.

Welfare of the Child (African Child Charter),²⁷ and the African Youth Charter.²⁸ The African Union (AU) adopted 1999 to 2009 as the African Decade of Disabilities.²⁹

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (African Disability Rights Protocol) was adopted on 30 January 2018.³⁰ The African Disability Rights Protocol is a binding legal document protecting the human rights of persons with disabilities taking into account their lived realities in the continent while maintaining the core values and principles as set out in the CRPD. The Protocol has not come into force as it has yet to be ratified by at least 15 member states.³¹ Article 1 of the Protocol notes that:

[T]he purpose of this Protocol is to promote, protect and ensure the full and equal enjoyment of all human and people's rights by all persons with disabilities, and to ensure respect for their inherent dignity.

The African Disability Rights Protocol complements the CRPD by highlighting the continued exclusion, harmful practices, and discrimination affecting those with disabilities, especially women, children and the elderly. The Protocol in the Preamble recognises the risk of violence and abuse, particularly for those with albinism. It equally refers to maiming and killings of persons with albinism. The Protocol, therefore, makes it abundantly clear that persons with albinism are within the treaty's conceptualisation of persons with disabilities. However, the Protocol fails to address in detail some of the challenges facing persons with albinism in Africa.

The adoption of the African Disability Rights Protocol builds on existing work of the African human-rights system. For instance, on 5 November 2013, the African Commission adopted Resolution 263 on the prevention of attacks and discrimination against persons with albinism.³² Among other things, this resolution requires member states to include in their reports to the African Commission, information on the situation of persons with albinism, including good practices in protecting and

27 African Charter on the Rights and Welfare of the Child, OAU Doc CAB LEG/24.9/49, adopted on 11 July 1990, entered into force on 29 November 1999, art 13.

28 The African Youth Charter, adopted in 2006 and came into force in 2009, art 2.

29 http://sa.au.int/en/sites/default/files/Disability_Decade%20Plan%20of%20Action%20-Final.pdf (accessed 2 March 2019).

30 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities https://au.int/sites/default/files/treaties/35475-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf (accessed 4 March 2019).

31 The Protocol has so far registered only one signature from the Central African Republic. The Protocol can only come into force when it is ratified by 15 of the 54 AU member states that have accepted to be bound by the African Charter.

32 ACHPR 'Resolution 263 on the prevention of attacks and discrimination against persons with albinism' (5 November 2013) <http://www.achpr.org/sessions/54th/resolutions/263/> (accessed 3 August 2016).

promoting their rights.³³ In addition, on the same day, the African Committee on the Rights and Welfare of the Child (ACRWC) adopted a Declaration to End Discrimination and Violence against Girls in Africa in which the situation of children with albinism is addressed.³⁴ While these developments are significant, they will only result in positive outcomes in addressing discrimination and violence against persons with albinism if African countries exhibit the desired political will to implement them at the national level. This will require creating an enabling legal environment where rights of persons with disabilities are respected and protected.

3 Intersectionality, discrimination and human rights abuses against persons with albinism in Africa

Until recently, international and regional human-rights mechanisms had only fragmentally addressed the needs of persons with albinism.³⁵ For instance, the UN Special Procedures Mandate Holders noted that persons with albinism are seen as ‘ghosts and not human beings who can be wiped off the global map’ and are the ‘target of many false and harmful myths in several countries, especially in the African region’.³⁶

Persons with albinism have continued to live in perpetual fear for their lives and physical integrity. The Human Rights Council adopted a resolution in which it expressed grave concern about the ‘attacks against persons with albinism, including women and children, which are often committed with impunity’.³⁷ There are records of routine infanticide committed on children with albinism among some ethnicities in the region.³⁸ The Special Representative on Violence against Children stated that:

33 ACHPR (n 32 above) para 4.

34 ACERWC ‘The Addis Ababa Declaration on ending discrimination and violence against girls in Africa’ (5 November 2013) <http://sa.au.int/en/sites/default/files/ACERWC%20-%20Addis%20Ababa%20Declaration%20Discrimination%20and%20Violence%20Girls-%20Eng.pdf> (accessed 3 February 2019).

35 Moreover, in response to the call from civil-society organisations advocating to consider persons with albinism as a specific group with particular needs that require special attention, on 26 March 2015 the United Nations Human Rights Council adopted resolution 28/L.10 on creating the mandate of the Independent Expert on the enjoyment of human rights of persons with albinism, HRC (25 March 2015) UN Doc A/HRC/28/L.10 (2015) http://www.un.org/ga/search/view_doc.asp?symbol=A/HRC/28/L.10 (accessed 4 February 2019).

36 ‘African Children’s Charter (art. Not ghosts, but human beings ... persons with albinism)’ *OHCHR* 4 May 2013 <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E> (accessed 5 March 2019).

37 Res 24/33: Technical cooperation for the prevention of attacks against persons with albinism, HRC (8 October 2013) UN Doc A/HRC/RES/24/33 (2013) http://www.ohchr.org/Documents/HRBodies/HRCouncil/AdvisoryCom/A_HRC_RES_24_33_ENG.pdf (accessed 10 February 2019) Preamble.

38 HRC (n 2 above) para 44.

Children with albinism are at high risk of abandonment, discrimination and exclusion as a result of the appearance of their skin, and due to disability factors, such as impaired eyesight and high susceptibility to skin cancer and other health risks associated with albinism.³⁹

According to Franklin et al:

Myths and superstitions, fuelled by a lack of understanding surrounding albinism and the visible difference in the appearance of persons with albinism can lead to stigmatization, rejection, a lack of acceptance, violence, perceptions of difference and limited social integration.⁴⁰

The corollary is discriminatory practices in virtually every area of human endeavour, including the health-care setting. Some of the health challenges facing persons with albinism include the fact that they are viewed as a 'curse' or 'omens of disaster'.⁴¹ This tends to fuel stigma and discrimination against persons with albinism and further creates barriers to social services, including health.

Non-discrimination is a core human-rights principle that is enshrined in different human-rights treaties,⁴² and regional human-rights instruments.⁴³ Article 1 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),⁴⁴ adopts a comprehensive and nuanced definition of discrimination against women. It defines discrimination as:

[A]ny distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

This definition by CEDAW is aimed at achieving substantive equality and not merely formal equality. This is commendable since it is aimed at addressing the historical differences and injustices meted out to women. Other provisions on non-discrimination are found in the Universal

39 Special Representative's submission as highlighted in the OHCHR Report, para 43.

40 A Franklin et al 'Children with albinism in Africa: Heir rights to "being" and "doing"' (2018) 18 *BMC International Human Rights and Health* 5.

41 S Bucaro 'A black market for magical bones: The current plight of East African albinos' (2010) 2 *Public Interest Law Reporter* 15.

42 Art 2 International Covenant on Civil and Political Rights; art 2 International Covenant on Economic, Social and Cultural Rights; art 2 Convention on the Rights of the Child; art 7 International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families; art5 5 Convention on the Rights of Persons with Disabilities. The Convention on the Elimination of All Forms of Racial Discrimination prohibits discrimination on the ground of race and the Convention on the Elimination of All Forms of Discrimination against Women on the ground of gender.

43 Art 2 ACHPR; art 2 African Women's Protocol; art 3 African Children's Charter.

44 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) GA Res 54/180 UN GAOR 34th session Supp 46 UN Doc A/34/46 1980.

Declaration on Human Rights (UDHR),⁴⁵ the International Covenant on Civil and Political Rights (ICCPR)⁴⁶ and the International Covenant on Economic, Social and Cultural Rights (ICESCR).⁴⁷ All these instruments prohibit discrimination on various grounds including 'colour' and the open-ended category 'other status'. This can be purposively interpreted to cover vulnerable groups such as persons with albinism. With specific regard to persons with disabilities, article 2 of the CRPD defines discrimination broadly to include:

[A]ny distinction, exclusion or restriction based on disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights. It includes all forms of disability discrimination, including denial of reasonable accommodation.

It should be noted that article 2 of the CRPD is reinforced by article 5 on equality. It can be argued that the non-discrimination provision of the CRPD is modelled on the CEDAW in that they both aim at achieving substantive equality. In other words, articles 2 and 5 of the CRPD are not only aimed at correcting the past injustices experienced by persons with disabilities, but also aim at ensuring that they live a dignified life. In this regard, the Committee on CRPD has affirmed a new model of inclusive equality to include the following:

(a) [A] fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity.⁴⁸

On the CRPD's disability concept, Ngwena notes that:

It implicitly envisages transcending not just a medicalised notion of disability but also formal equality in order to achieve substantive equality. The CRPD's approach anticipates the imposition of a societal duty to dismantle barriers or

45 Universal Declaration of Human Rights (Universal Declaration) adopted 10 December 1948, UNGA 217 A (III).

46 International Covenant on Civil and Political Rights (ICCPR) adopted 16 December 1966, GA Res 2200A (XXI), UN Doc A/6316 (1966) 993 UNTS 3 (entered into force 23 March 1976).

47 International Covenant on Economic, Social and Cultural Rights (ICESCR) adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 (entered into force 3 January 1976) in accordance with art 27.

48 CRPD Committee, General Comment 6: Equality and non-discrimination (2018) UN Doc CRPD/C/GC/5 dated 9 March 2018 para 18.

to restructure the socio-economic environment in order to enable disabled people to participate equally.⁴⁹

This concept of disability recognises multiple forms of discrimination. In this line, the Committee on CRPD has further noted that:

The concept of intersectional discrimination recognizes that individuals do not experience discrimination as members of a homogenous group but, rather, as individuals with multidimensional layers of identities, statuses and life circumstances. It acknowledges the lived realities and experiences of heightened disadvantage of individuals caused by multiple and intersecting forms of discrimination, which requires targeted measures to be taken with respect to disaggregated data collection, consultation, policymaking, the enforceability of non-discrimination policies and the provision of effective remedies.⁵⁰

The Committee's recognition of intersectionality as crucial to addressing discrimination against persons with disabilities is useful in the context of persons with albinism. For persons with albinism, life can be unbearable due to the level of stigma and violence they experience on a daily basis. The situation is even compounded for women with albinism as they are exposed to discrimination on account of colour or skin, gender and disability. These different levels or forms of discrimination are often referred to as intersectionality. In her seminal work on intersectionality, Crenshaw in capturing the plight of black American women has noted that 'boundaries of sex and race discrimination doctrine are defined respectively by white women's and Black men's experiences'.⁵¹ In order to highlight the diverse nature of discriminatory practices black women encounter, she metaphorically explains as follows:

Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars travelling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in an intersection, her injury could result from sex discrimination or race discrimination ... But it is not always easy to reconstruct an accident: Sometimes the skid marks and the injuries simply indicate that they occurred simultaneously, frustrating efforts to determine which driver caused the harm.⁵²

49 C Ngwenya 'Developing juridical method for overcoming status subordination in disability: The place of transformative epistemologies' (2014) 30 *South African Journal on Human Rights* 287.

50 CRPD General Comment 3: Art 6: Women and girls with disabilities (2016) UN Doc CRPD/C/GC/3 dated 2 September 2016 <https://www.refworld.org/docid/57c977344.html> (accessed 10 January 2019).

51 K Crenshaw 'Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics' (1989) 1 *University of Chicago Legal Forum* 143.

52 Crenshaw (n 51 above) 149.

In essence, Crenshaw calls for a rethinking of the definitions of discrimination, which perceive sex and race as mutually exclusive, thereby rendering the simultaneous experience of gendered racism almost non-existent. Rather she argues for a more nuanced and realistic definition taking cognisance of historical and structural oppression of black women. Echoing Crenshaw, Carastathis notes that:

[I]ntersectionality has become the predominant way of conceptualising the relation between systems of oppression which construct our multiple identities and our social locations in hierarchies of power and privilege.⁵³

Some of the benefits of applying intersectionality include simultaneity, complexity, irreducibility and inclusivity.⁵⁴ Intersectionality responds to lived experiences and helps to capture how oppressions are experienced simultaneously. In a true-life scenario a person is not a woman on Monday, a woman with albinism on Tuesday and a woman from a disadvantaged background on Wednesday. These diverse experiences are captured simultaneously and not treated exclusive of each other. This is consistent with Crenshaw's notion of structural intersectionality, which seeks to 'render visible phenomenological experiences of people who face multiple forms of oppression without fragmenting those experiences through categorical exclusion'.⁵⁵ Crenshaw's theory resonates perfectly with the lived experiences of persons with albinism in general and women with albinism in particular.

4 The right to health of persons with albinism under international law

The right to health is well recognised in numerous international and regional human-rights instruments. The starting point for the recognition of the right to health is the UN Charter of 1945.⁵⁶ The Charter urges states parties to it to respect rights to a higher standard of living and solutions to international health problems. This is buttressed by the Preamble to the World Health Organization (WHO) where it is provided that:

Health is a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of all human beings without distinction as to race, colour, and religion.⁵⁷

53 A Carastathis 'The concept of intersectionality in feminist theory' (2014) 9 *Philosophy Compass* 304.

54 As above.

55 Carastathis (n 53 above) 307.

56 Art 55 of the Charter of the United Nations, 26 June 1945 (entered into force 24 October 1945) TS 67 (1946).

57 The Constitution of the WHO was adopted by the International Health Conference, New York, 1922 June 1945; opened for signature on 22 July 1946 by the representatives of 61 states; 14 UNTS 185.

Article 25(1) of the UDHR provides that ‘everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services’.⁵⁸ Although the Universal Declaration is not a treaty, it has been widely accepted as an authoritative document on human rights by states worldwide. In short it is established that some of the norms set out in the UDHR constitute part of customary international law.⁵⁹ By far, however, the most authoritative provision on the right to health can be found in article 12 of the ICESCR.⁶⁰ Article 12 of the ICESCR provides that ‘states parties to the present Covenant recognize the right to every one of the highest attainable standard of physical and mental health’. In article 12(2) states are urged to take necessary measures, including taking into consideration underlying determinants of health to realise the right to health.

The Committee on the Covenant on Economic, Social and Cultural Rights (CESCR) in General Comment 14 has elaborated on the meaning of the right to health.⁶¹ According to the Committee, the right to health entails both ‘freedoms’ and ‘entitlements’—the former relates to the right to non-consensual medical treatment while the latter relates to access to healthcare services.⁶² The Committee emphasises that the right to health does not mean that states must guarantee good health as this is impossible given individuals’ idiosyncrasies. The Committee notes that the right to health contains four essential elements namely: availability; accessibility; acceptability; and quality (AAAQ).⁶³ The Committee explains that availability means that healthcare services must be of sufficient quantity, accessibility implies that healthcare services must be physically and economically accessible, particularly to vulnerable and marginalised groups.⁶⁴ It further explains that acceptability requires states to ensure healthcare services that are culturally and ethically acceptable. The Committee remarks that quality healthcare services require states to invest in the healthcare sector through training of health providers, payment of competitive wages and provision of facilities.⁶⁵

While the Committee recognises that the right to health may be realised progressively, it however, notes that the minimum core contents

58 Universal Declaration of Human Rights, GA Res 217 A (III), UN Doc A/810 (10 December 1948).

59 JP Humphrey ‘The Universal Declaration of Human Rights: Its history, impact and juridical character’ in BG Ramcharam (ed) *Human rights: Thirty years after the Universal Declaration* (1979) 21, 28

60 International Covenant on Economic, Social and Cultural Rights adopted 16 December 1966; GA Res 2200 (XXI) UN Doc A/6316 (1966) 993 UNTS 3 (entered into force 3 January 1976).

61 CESCR General Comment 14: The right to the highest attainable standard of health (2000) UN Doc E/C/12/2000/4 dated 11 August 2000.

62 General Comment 14 (n 61 above) para 33.

63 General Comment 14 (n 61 above) para 34.

64 As above.

65 As above.

of the right are not subject to progressive realisation.⁶⁶ The Committee identifies the principle of non-discrimination as one of the core contents of the right to health, which must be realised immediately. In the Committee's view, states are obligated to ensure the provision of healthcare services to all on a non-discriminatory basis paying attention to the needs of vulnerable and marginalised groups in society.⁶⁷ The Committee identifies children, persons with disabilities, people living with HIV and immigrants as vulnerable and marginalised groups that deserve special attention in health-care services. This clarification of the Committee is important in assessing steps and measures taken by states to realise the right to health of everyone, including persons with albinism.

In addition to the provision of the ICESCR, all other human-rights instruments relevant to the discussion in this paper include article 12 of the CEDAW⁶⁸ and article 25 of the CRPD. Article 25 of the CRPD provides that 'persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'. It further enjoins states parties to ensure access to healthcare services that are gender-sensitive. The provision also covers access to sexual and reproductive health services and requires states to eliminate discriminatory practices in the healthcare setting against persons with disabilities.

The Committee on the CRPD has noted in General Comment 3 on women and girls with disabilities that states should adopt measures that give priority to healthcare services for persons with disabilities.⁶⁹ The Committee further notes that women and girls with disabilities particularly encounter challenges with regard to access to sexual and reproductive health services, and to family-planning information, services and methods as well as access to HIV/AIDS services.⁷⁰ It laments the various challenges facing women and girls with disabilities in the context of healthcare services, which may include discrimination, lack of respect for confidentiality and autonomy, lack of access to information and health facilities, forced or coercive treatment and negative attitudes of healthcare providers.

Furthermore, the Committee affirms that 'article 6 is a binding non-discrimination and equality provision that unequivocally outlaws discrimination against women with disabilities and promotes equality of opportunity and equality of outcomes'.⁷¹ In the Committee's view, girls with disabilities face multiple and intersectional discrimination on account of their age, gender, sex and disability. This may further predispose them

66 General Comment 14 (n 61 above) para 46.

67 As above.

68 n 44 above.

69 General Comment 3 (n 50 above) CRPD.

70 General Comment 3 (n 50 above) para 7.

71 General Comment 3 (n 50 above) para 9.

to human-rights abuses including acts of violence, violation of the right to dignity and denial of access to healthcare services.

Thus, the Committee notes that ‘States parties must guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds’.⁷² In *Munir al Adam v Saudi Arabia*,⁷³ the Committee found that failure by the government of Saudi Arabia to provide urgent surgery to save the applicant’s ear impairment from becoming permanently worse was a violation of the right to health guaranteed in article 25 of the Convention. It further notes that ‘States Parties to the Convention are under an immediate legal obligation to respect, to protect and to fulfil the rights of women and girls with disabilities under article 6’ in order to guarantee them the enjoyment and exercise of all human rights and fundamental freedoms.⁷⁴ While the Committee does not specifically refer to persons with albinism, it is argued that the clarification provided in General Comment 3 on women and girls with disabilities will apply to them. This is further supported by the Committee’s decision in *Y v Republic of Tanzania* discussed earlier in this paper.⁷⁵ The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health noted that ‘people living with albinism often do not receive the necessary special attention, health care or treatment that corresponds to their health needs’.⁷⁶

At the regional level, articles 16 of the African Charter, 24 of the African Children’s Charter and 14 of the African Women’s Protocol all guarantee the right to health. In interpreting the right to health in the African Charter, the African Commission on Human and Peoples’ Rights (African Commission) has adopted a purposive approach linking the enjoyment of this right with other rights, including life, dignity and non-discrimination.⁷⁷ For instance in *International Pen (on behalf of Ken Saro Wiwa) v Nigeria*,⁷⁸ the African Commission affirmed that a denial of access to treatment to a prisoner would result in violation of the rights to life and dignity.

72 General Comment 3 (n 50 above) para 15.

73 Communication 038/2016 (Views adopted 20 September 2018).

74 Communication 038/2016 (n 73 above).

75 (n 23 above).

76 See UN News ‘Persons with albinism must not be treated as ‘ghosts’, UN experts stress’ available at www.new.un.org (accessed on 25 November 2019)

77 For more on the approaches of the African Commission to the enjoyment of the right to health in Africa, see E Durojaye ‘The approaches of the African Commission to the right to health under the African Charter’ (2013) 17 *Law Development and Democracy* 393.

78 AHRLR 212 (ACHPR 1998).

The African Commission in *Purohit v The Gambia*,⁷⁹ a case involving the maltreatment of persons with mental disabilities, noted that articles 2 and 3 of the Charter relating to non-discrimination and equal protection of the law are crucial to the enjoyment of all other rights guaranteed in the Charter. Article 2 of the African Charter provides that states must prohibit discrimination on various grounds including 'other status', a phrase that can be interpreted to cover persons with disabilities, including persons with albinism.

The Commission further noted that non-discrimination is a fundamental principle of the Charter that is not subject to derogation. The Commission had reasoned in that case, among other things, that failure to provide proper medical attention to patients with mental disabilities is a violation of the right to health guaranteed in article 16 of the African Charter. This case provides an illustration of how a state may be held accountable for failure to meet the health needs of persons with disabilities, including persons with albinism.

The African Commission in recent times has begun to develop important norms to clarify state obligations with regard to provisions of the African Women's Protocol. For instance, the Commission has issued two important general comments to clarify the content of article 14 of the Protocol.⁸⁰ Although these clarifications relate to women in general, they remain very useful in advancing the sexual and reproductive health and rights of women with albinism in Africa. Both General Comments 1 and 2 emphasise the need for African governments to ensure access to sexual and reproductive healthcare services to all women on a non-discriminatory basis. Furthermore, they reinforce the importance of paying more attention to the health needs of vulnerable and marginalised groups in society such as refugee women, women with disabilities and women living with HIV. Undoubtedly, this reasoning of the Commission would seem to apply to persons with albinism in general and women with albinism in particular. In other words, African governments are obligated to eliminate discriminatory practices in access to healthcare services for persons with albinism, especially women with albinism.

As noted earlier, Africa remains the region with the highest number of persons with albinism and experience has shown that they are subjected to discriminatory practices daily. This can undermine their right to dignity and other related rights. In *Hoffman v SAA*,⁸¹ the South African

79 Communication 241/2001 decided at the 33rd Ordinary Session of the African Commission held from 15th–29th in Niamey, Niger May 2003.

80 See ACHPR General Comments: Article 14(1)(d) and (e) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (2012); ACHPR General Comment 2: Article 14(1)(a),(b),(c) and (f) and Article 14(2)(a) and (c) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (2014).

81 2001 1 SA 1 (CC).

Constitutional Court explains that the denial of employment opportunity to an individual solely based on his HIV status not only violates the right to equality in section 9 of the Constitution, but also impairs the dignity of the individual.⁸² In explaining the connection between the right to equality and dignity the court reasons as follows:

At the heart of the prohibition of unfair discrimination is the recognition that under our Constitution all human beings, regardless of their position in society, must be accorded equal dignity. That dignity is impaired when a person is unfairly discriminated against. The determining factor regarding the unfairness of the discrimination is its impact on the person discriminated against.⁸³

While the *Hoffman* case deals specifically with discrimination in the context of HIV, the principle of law established by the court is relevant in addressing discriminatory practices against persons with albinism, including women with albinism. Thus, failure by African governments to ensure access to healthcare services to women with albinism will amount to a violation of the right to dignity. Dignity requires that all human beings be treated with decency and respect. The notion of dignity is an intrinsic part of every human being, which is not subject to variation or modification. It is how people feel, think and behave in relation to the worth or value of themselves or others. Hence, the right to dignity is universal and unfringeable by the state or private parties. It should be noted that a violation of the right to dignity not only affects the victim, but the society as a whole, in that it questions how we choose to live or relate to others.⁸⁴

5 Barriers to access to healthcare for persons with albinism

The various forms of discrimination highlighted above are interrelated. The CESCR in General Comment 14 has emphasised that the right to health is closely related to and dependent upon the realisation of other human rights, including the rights to food, work, education, human dignity, life, non-discrimination and the prohibition against torture.⁸⁵

This is particularly important as women and children with albinism are vulnerable and exposed to multiple forms of discrimination and violations of their rights such as infanticide, physical attacks, lack of access to education, unemployment, sexual violence and lack of access to

82 As above.

83 *Hoffman* (n 81 above) para 27

84 C Dupre 'What does dignity mean in a legal context?' <http://www.guardian.co.uk/comments/free/libertycentral/2011/mar/24/dignity-uk-europe-human-rights> (accessed 23 February 2019).

85 General Comment 14 (n 61 above) para 3.

healthcare. As earlier indicated, violence against persons with albinism is fuelled by cultural practices and misconceptions. This is often extended to the healthcare setting where discriminatory practices manifest against persons with albinism, since healthcare providers are products of the society.

Unlike a monistic approach to oppression, which tends to reduce complex experiences of simultaneous oppressions to simplistic categories, intersectionality uses the intra-categorical lens, to reveal various forms of oppressions and lived experiences of certain groups.⁸⁶ According to King, 'a hallmark of intersectionality is the necessity of addressing all oppressions'.⁸⁷ Proponents of intersectionality argue that it offers the promise of addressing

white solipsism, heteronormativity, elitism, and ableism of dominant power and hegemonic feminist theory by making social locations and experiences visible that are occluded in essentialist and exclusionary constructions of the category 'women'.⁸⁸

This approach is no doubt applicable to women with albinism, who daily encounter discrimination based on their skin and gender. This in turn has led to other forms of discrimination, especially with regard to healthcare services. These multiple forms of discrimination cannot be treated in isolation but must be seen as intersecting. Echoing the social-model approach, the multiple forms of discrimination persons with albinism encountered are often rooted in cultural superstition that tends to disable them from living a dignified life. Consequently, based on prejudices and unfounded societal myths, persons with albinism are deprived of social services, including healthcare services.

The CEDAW Committee has referred to women with albinism as a group of women in a vulnerable situation.⁸⁹ Also, the Special Rapporteur on violence against women, its causes and consequences has noted:⁹⁰

[V]iolence against women is deeply rooted in multiple layers of discrimination and inequality. As these layers of discrimination intersect,

86 As above.

87 D King 'Multiple jeopardy, multiple consciousness: The context of a black feminist ideology' (1988) 14 *Signs: Journal of Women in Culture and Society* 42.

88 Carastathis (n 53 above); see also E Spelman *Inessential woman: Problems of exclusion in feminist thought* (1988).

89 In its Concluding Observations on the United Republic of Tanzania, the Committee expressed concern at reports that women and girls with albinism had been targeted in ritual killings, recommending that the state party protect them. See Report of the CEDAWFortieth session (14 January-1 February 2008) Forty-first session (30 June-18 July 2008) UN Doc A/63/38 (2008) [https://undocs.org/pdf?symbol=en/A/63/38\(SUPP\)](https://undocs.org/pdf?symbol=en/A/63/38(SUPP)) (accessed 19 November 2019) paras 142 & 143

90 See HRC Report of the Special Rapporteur on violence against women, its causes and consequences UN Doc A/HRC/17/26 dated 2 May 2011 <http://www2.ohchr.org/english/bodies/hrcouncil/docs/17session/A-HRC-17-26.pdf> (accessed 5 March 2019).

violence against women intensifies. Addressing systematic discrimination and marginalization is crucial to ending violence against women.

Additionally, the General Assembly's Resolution on 'Realizing the millennium development goals for persons with disabilities' called for states to pay special attention to the gender specific needs of persons with disabilities, including by taking measures to ensure their full and effective enjoyment of all human rights and fundamental freedoms.⁹¹

Several other studies and reports have documented discriminatory practices and human-rights violations persons with albinism experience in Africa.⁹² Hong et al have captured the different health challenges of persons with albinism in some African countries.⁹³ In their very comprehensive article they identified some of the public-health issues relating to persons with albinism in the continent. It was noted that persons with albinism would seem to have shorter life expectancy compared to others in society. For instance, they noted that in the East Central state of Nigeria, 89 per cent of identified people with albinism were in the age range of 0–30 years⁹⁴ while another study reported that 77 per cent were under the age of 20 in the same Nigerian state.⁹⁵ A mean age of 17.8 years was reported in Soweto, South Africa.⁹⁶ The study further notes that a lack of proper medical attention for persons with albinism often compromises their health needs. It explains that in many African countries due to stigma and discrimination against persons with albinism and lack of trained personnel, persons with albinism encounter difficulty in accessing healthcare services.

The Cancer Association of South Africa (CANSA) has acknowledged that persons with albinism face the highest risk of developing skin cancer. CANSA found that albinism increases skin cancer risk in South Africa. The risk is especially higher for people who rely on state hospitals for the provision of their sunscreen.⁹⁷ A researcher at the University of South Africa (UNISA) has noted that:

91 GA Resolution 63/150: Realizing the millennium development goals for persons with disabilities dated 18 December 2008 para 8.

92 See for instance, Human Right Council Advisory Committee 'Study on the situations of the human rights of persons living with albinism' submitted to the twenty-eighth session of the Human Rights Council (2015) UN Doc A/HRC/28/75 dated March 2015; International Federation of the Red Cross and Red Crescent Societies *Through albino eyes: The plight of albino people in Africa's Great Lakes region and a Red Cross response* (2009); S Fellows *Trafficking body parts in Mozambique and South Africa* (2010).

93 Hong (n 3 above) 212.

94 AN Okoro 'Albinism in Nigeria' (1975) 92 *British Journal of Dermatology* 485.

95 RA King et al 'Albinism in Nigeria with delineation of new recessive oculocutaneous type' (1980) 17 *Clinical Genetics* 259.

96 JGR Kromberg et al 'Albinism and skin cancer in Southern Africa' (1989) *Clinical Genetics* 43.

97 CANSA 'Research findings: Albinism increases skin cancer risk in South Africa' (12 March 2015) <http://www.cansa.org.za/albinism-increases-skin-cancer-risk-in-south-africa/> (accessed 30 January 2019).

[D]iscrimination against persons living with albinism impedes their right of access to healthcare services, and the government should adopt a comprehensive approach to ensuring that healthcare services specifically cater for the unique needs of this group of people.⁹⁸

A study to ascertain the barriers to accessing safe motherhood and reproductive health services in Lusaka for women with disabilities identified the deep traditional beliefs about the cause and transmission of disability which prevents women with albinism from integrating at antenatal clinics.⁹⁹ An interviewee stated:

[W]hat you must realise is that for the fellow pregnant women, the able bodied, pregnancy is a very difficult time for most of the mothers and it's got a lot of superstitions about it. So, one, there's a common belief that the child you are carrying, for example, you want to avoid people like albinos ...¹⁰⁰

In some situations, healthcare providers exhibit prejudices and hostile attitudes towards persons with albinism. While this situation limits access to healthcare to persons with albinism in general it can lead to more devastating effects for women with albinism seeking sexual and reproductive health services. In communities where persons with albinism are isolated, women and girls with albinism may find it difficult to seek information and services relating to contraception, unwanted pregnancies or maternal care. In essence, multiple forms of discriminatory practices against persons with albinism may aggravate their health condition and well-being and at the same time may predispose them to sexual and reproductive ill health. Moreover, the study documents failure by states to adopt appropriate laws, policies and programmes relating to the health needs of persons with albinism.

This would seem inconsistent with the AAAQ approach of the CESCR in its General Comment 14 discussed above. According to the Committee, accessibility has four dimensions, including physical accessibility, information accessibility, economic accessibility and non-discrimination. In essence, states would need to ensure that persons with albinism enjoy unhindered access to healthcare services. More importantly, states must ensure that services to persons with albinism are ethically and medically acceptable and do not undermine their dignity.

Failure to meet the health needs of persons with albinism clearly shows lack of political will on the part of African governments in meeting the health needs, including sexual and reproductive health of persons with

98 'People with albinism need urgent protection' *UNISA* 10 August 2016 <http://www.unisa.ac.za/sites/corporate/default/News-&Media/Articles/People-with-albinism-need-urgent-protection> (accessed 27 February 2019).

99 E Smith et al 'Barriers to accessing safe motherhood and reproductive health services: The situation of women with disabilities in Lusaka, Zambia' (2004) 26 *Disability and Rehabilitation* 125.

100 As above.

albinism. In its Concluding Observations to the government of Ethiopia, the Committee on CRPD has recommended that the government:

[E]nsure that hospital and health-care centre staff are given regular and compulsory training on the rights of persons with disabilities, including on the individual right to free and informed consent, sexual and reproductive health, HIV and sexually transmitted infections.¹⁰¹

At the International Conference on Population and Development (ICPD) in Cairo, the international community affirmed the rights of women and girls to reproductive healthcare including the right to determine the timing and number of their children.¹⁰² It was further affirmed that all individuals shall have the right:

[T]o be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice of regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.¹⁰³

This was reaffirmed in Beijing during the Fourth World Conference on Women. This landmark declaration has now been codified in article 14 of the African Women's Protocol. This provision can be interpreted broadly to protect the sexual and reproductive health of persons with albinism, especially women with albinism.

In clarifying the provision of article 14 of the Maputo Protocol the African Commission has urged states to take appropriate measures towards eliminating stigmatisation and discrimination in relation to sexual and reproductive health.¹⁰⁴ This broadly covers HIV-related stigma and discrimination which often hinder women and girls from seeking information and services in healthcare institutions. More importantly, the Commission enjoins states to adopt legislative measures, administrative policies and procedures to ensure that 'no woman is forced because of her HIV status, disability, ethnicity or any other situation, to use specific contraceptive methods or undergo sterilization or abortion'.¹⁰⁵ This position of the Commission provides a bulwark for persons with albinism who often encounter discrimination in healthcare services. It requires states to take a substantive-equality approach to addressing the multiple forms of discriminatory practices against persons with albinism in society.

101 See Concluding Observations on the initial report of Ethiopia, CRPD Committee (3 November 2016) UN Doc CRPD/C/ETH/CO/1 (2016) para 56.

102 UN 'Report of the International Conference on Population and Development (ICPD): 5-13 September 1994' UN Doc A/CONF.171/13 (18 October 1994) <https://www.un.org/popin/icpd/conference/offeng/poa.html> (accessed 4 March 2019).

103 UN (n 102 above) para 7.2.

104 UN (n 102 above) para 44

105 UN (n 102 above) para 47

More importantly, it requires states to adopt positive measures including the provision of sunglasses, training of healthcare providers and allocation of resources to meet the needs of persons with albinism. In addition, persons with albinism must be involved in any measures aimed at addressing stigma and discrimination against them. This would be consistent with the common principle ‘nothing for us without us’.

6 Way forward

From the foregoing, it has become more urgent than ever, that African governments exhibit political will to address the different challenges facing persons with albinism in the region. In the face of persistent acts of prejudice and violence against persons with albinism which may lead to dire health consequences for them, it has become crucially urgent that African governments embark on massive awareness and education programmes to address prejudices and myths relating to persons with albinism. This will go a long way in correcting misconceptions and superstitious beliefs about persons with albinism. It should be noted that articles 2 and 5 of the African Women’s Protocol urge African governments to embark on education and awareness programmes with a view to addressing cultural practices that may impair women from enjoying their rights. These provisions can broadly be interpreted to include prejudices and misconception, which impair women with albinism from enjoying their rights.

As noted above, it will also be important that governments and policy makers include persons with albinism in the development of policies and programmes affecting their health and well-being. A report has noted that any effort to address inequities in health of people must address power imbalance and empower disadvantaged people to participate in decision-making that affects their well-being.¹⁰⁶ The right to participation is recognised in articles 29 of the CRPD and 21 of the Protocol to the African Charter on the Rights of Persons with Disabilities. Participation is generally believed to constitute an element of a rights-based approach. Indeed, Mary Robinson, former UN High Commissioner for Human Rights, opines that ‘[p]articipation and active involvement in the determination of one’s own destiny is the essence of human dignity’.¹⁰⁷ With regard to the right to health, participation requires that every individual, including vulnerable and marginalised groups should be involved in the decision-making process relating to the adoption of policies and programmes about their health.

106 WHO Commission on Social determinant of health ‘Closing the gap in a generation: Health equity through action on the social determinant of health’ (2008) <http://repository.essex.ac.uk/9714/1/participation-right-highest-attainable-standard-health.pdf> (accessed 5 March 2019).

107 Cited in H Potts *Participation and the right to the highest attainable standard of health* (2008) 8.

The CESCR has noted that ensuring participation of all individuals in the development of laws and policies on health constitutes part of the right to health.¹⁰⁸ Participation is a powerful means of ensuring the autonomy of people to make decisions concerning their lives. It allows vulnerable and marginalised groups to air their views on issues that affect their lives. Yamin has argued that effective participation enables disadvantaged groups to challenge political and other forms of exclusion that prevent them from exercising agency over decisions and processes that may affect their lives and health.¹⁰⁹ In Potts's view, people who are likely to be affected by a health policy or programme should have equal opportunity to be part of the decision-making process.¹¹⁰

The former Special Rapporteur on extreme poverty and human rights has noted that participation empowers marginalised and disadvantaged groups to have a say in matters affecting their lives.¹¹¹ It ensures that the views of disadvantaged and marginalised groups are adequately taken into consideration before decisions are made. This is very important in the context of meeting the health needs of persons with albinism in general and in particular. Exclusion of persons with albinism from participating in decision-making about their health is not only a violation of their right to health, but may also impair the rights to dignity and non-discrimination. Yamin has noted that:

If health is a matter of rights, it cannot be considered a handout, and the people who receive services are not objects of charity from their own governments...; they are agents who have a role to play in the definition of programs and policies that structure the possibilities for their own well-being.¹¹²

In addition, African governments need to commit adequate resources to the health sector to meet the specific needs of persons with albinism. In this regard, Cruz-Inigo et al have suggested that:

In the clinical setting, individuals with albinism should be provided with dermatologic examinations, guidelines on how to shield themselves from the sun, and sun protection products such as sunscreen, sunglasses, opaque clothing that covers most of the skin, scarves, high socks, and wide-brimmed hats. Given that most albinos are unemployed, they cannot afford sun-protective gear, which is expensive in Africa, thus it should be encouraged that society establish measures to support albinos and their families. Governmental endeavors may include assistance with indoor job placement,

108 General Comment 14 (n 61 above).

109 A Yamin 'Suffering and powerlessness: The significance of promoting participation in rights-based approaches to health' (2009) 11 *Health and Human Rights* 6.

110 Potts (n 107 above) 15-25.

111 See Report of the Special Rapporteur on extreme poverty and human rights: Participation of people living in poverty in decisions affecting their lives (11 March 2013).

112 Yamin (n 109 above) 4.

supplying adequate amounts of sun-protective products and funding for organizations involved in albinism awareness and support.¹¹³

Given the constant acts of prejudice and discriminatory practices against persons with albinism, it will be necessary that African governments enact appropriate laws and policies to eliminate discriminatory practices against them. Where similar legislation already exists, it should be broadly interpreted to cover specific discriminatory practices against persons with albinism. On the other hand, any legislation or policy that may potentially fuel discriminatory practices against persons with albinism generally and in relation to healthcare should be repealed immediately.

Recently, the UN Independent Expert on the rights of person with albinism, Ikpowonsa Ero, has proposed a continental framework to address human-rights violations experienced by persons with albinism.¹¹⁴ The Plan of Action is broadly divided into four sections namely: preventive measures; protective measures; accountability measures; and equality and non-discrimination. In essence, the Plan of Action urges African governments to take proactive measures in order to nip in bud any form of human-rights violations against persons with albinism. The protection measures require African governments to adopt appropriate laws and policies to protect persons with albinism and further ensure their effective implementation. They also require training of healthcare providers on issues relating to the rights of persons with albinism in healthcare settings. The accountability measures require African governments to ensure that perpetrators of human-rights violations against persons with albinism are brought to book.

More importantly, African governments are enjoined to provide support services such as psychosocial, medical, legal and socioeconomic support to persons with albinism that have experienced violations of their rights. Equality and non-discrimination measures require more involvement of persons with albinism in decision-making in society. They also require the creation of a post for persons with albinism with appropriate ministries such as disability, gender or social development. Furthermore, states are required to implement and adhere to the principle of reasonable accommodation in all facets of life for persons with albinism. The Regional Action Plan has now been adopted as a resolution by the African Commission.¹¹⁵ Undoubtedly, these are very practical and

113 AE Cruz-Inigo 'Albinism in Africa: Stigma, slaughter and awareness Campaigns' (2011) 29 *Dermatologic Clinics* 82.

114 Regional Action Plan on Albinism in Africa 2017-2021: Five-year plan to address attacks and related violations against persons with albinism in Sub-Saharan Africa presented at the 60th Ordinary Session of the ACHPR held in Niamey, Niger from 8-22 May 2017. See Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Regional Action Plan on Albinism in Africa (2017–2021), HRC (19 December 2017) UN Doc A/HRC/37/57/Add.3 (2017).

115 See Resolution 373 on the Regional Action Plan on Albinism in Africa (2017-2021), ACHPR (22 May 2017) ACHPR/Res. 373 (LX) (2017).

important measures that are capable of addressing human-rights violations experienced by persons with albinism in the region. It will also go a long way in addressing barriers to the enjoyment of the right to health of persons with albinism. The ball is now in African governments' court to ensure the full and effective implementation of this Action Plan.

7 Conclusion

This paper has shown that persons with albinism encounter stigma and discrimination in virtually every aspect of their lives. More importantly, persons with albinism face challenges in accessing healthcare services. While no human-rights instrument specifically addresses the human rights of persons with albinism, the existing provisions in international and regional human-rights instruments are applicable to them. In particular, the provisions on non-discrimination, dignity and health recognised by the CRPD, African Charter and African Women's Protocol are relevant in advancing the sexual and reproductive health and rights of women living with albinism. In line with their obligations under international law, African governments are required to take appropriate measures to address discriminatory practices against persons with albinism in general and women with albinism in particular. This requires committing more resources to address the health needs of persons with albinism. In addition, African governments must commit to training healthcare providers in order to meet the specific needs of persons with albinism.