

The Impact of Race and Colour on the Enjoyment of Human Rights and Fundamental Freedoms by Persons with Albinism in South Africa



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Centre for
Human Rights
UNIVERSITY OF PRETORIA

THE IMPACT OF RACE AND COLOUR ON THE ENJOYMENT OF HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS BY PERSONS WITH ALBINISM IN SOUTH AFRICA

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Executive summary

Discrimination based on race and colour is prohibited in various International Human Rights Law instruments at the global and regional levels and in legislation at national level.¹ In spite of this enabling legal framework, persons with albinism in South Africa continue to face discrimination based on race and colour in various aspects of life. In 2019, the then UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Ms Ikponwosa Ero, expressed concern about the prevalence of this

1 At global level, the: UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III) (1948); UN General Assembly, Convention on the Rights of Persons with Disabilities: Adopted by the General Assembly, 24 January 2007, A/RES/61/106 (2007); 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 (1965); UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations, Treaty Series, vol 999, p 171 (1966); UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, United Nations, Treaty Series, vol 1249, p 13 (1979); and the UN General Assembly, Convention on the Rights of the Child, 20 November 1989, United Nations, Treaty Series, vol 1577, p 3 (1989) all prohibit discrimination on various grounds, including race and colour. At regional level, the Organization of African Unity (OAU), African Charter on Human and Peoples' Rights (Banjul Charter), 27 June 1981, CAB/LEG/67/3 rev. 5, 21 ILM 58 (1982); African Union, Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa (11 July 2003); the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (though not yet in force) and the Organization of African Unity (OAU), African Charter on the Rights and Welfare of the Child, 11 July 1990, CAB/LEG/24.9/49 (1990), also contain anti-discrimination clauses prohibiting discrimination on various grounds including race and colour. At national level, the Constitution of the Republic of South Africa, 1996; the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (PEPUDA), and the Employment Equality Act 55 of 1998 all contain provisions prohibiting discrimination on numerous grounds including race and colour.

discrimination following her visit to South Africa. In a preliminary statement made at the end of this visit, Ms Ero lamented the persistent discrimination against persons with albinism in the country; this, in spite of South Africa's triumph over apartheid some 25 years prior and the subsequent enactment of a progressive and inclusive Constitution. In 2016, the Committee on the Elimination of Racial Discrimination issued its concluding observations on South Africa's combined fourth to eighth periodic reports and therein expressed similar concerns about the prevalence of race and colour-based discrimination against persons with albinism in South Africa. Nevertheless, research into the impact of race and colour-based discrimination on the enjoyment of human rights and fundamental freedoms by persons with albinism in South Africa remains scarce, with much of the studies focusing on racism and racial discrimination more broadly. Consequently, data on the impact of this type of discrimination on the rights of persons with albinism are scarce. This research study was conducted to address this knowledge gap by providing a better understanding of the extent and manner in which racism and colourism impact the enjoyment of human rights and fundamental freedoms by persons with albinism in South Africa.

The study found that South Africans with albinism experience social discrimination, marginalisation, and stigmatisation both from their families and society because of their skin colour coupled with widespread misconceptions about albinism. Specifically, the study found that discrimination based on race and colour has an adverse impact on the social dimension of the lives of persons with albinism and on their enjoyment of human rights and fundamental freedoms.

Socially, it affects their sense of identity, creates low self-esteem and impedes social interactions with others. Crucially, it negatively impacts their enjoyment of various human rights and fundamental freedoms, including the right to employment, education, political and public participation, health, access to justice and freedom from exploitation, violence, and abuse.

The report proceeds to make the following recommendations:

- 1 Raise awareness about albinism in the community to combat the lack of knowledge that fuels discrimination.
- 2 Conduct albinism sensitisation amongst key sectors including, education, employment, health, and justice.
- 3 Raise awareness amongst persons with albinism about their right to equality and the legal resources available to them.
- 4 Conduct further research on examples of measures and initiatives that have been initiated in other parts of the world to combat race and colour-based discrimination that would benefit persons with albinism in South Africa.
- 5 Involve media in human rights education and in countering hate speech. The media has an important role to play in countering hate speech and challenging myths and misconceptions.

Acronyms & Abbreviations

ACRWC African Charter on the Rights and Welfare of the Child

CEDAW Convention on the Elimination of All Forms of Discrimination Against Women

CERD Convention on the Elimination of All Forms of Racial Discrimination

CRC Convention on the Rights of the Child

CRPD Convention on the Rights of Persons with Disabilities

EEA Employment Equity Act

ICCPR International Covenant on Civil and Political Rights

PEPUDA Promotion of Equality and Prevention of Unfair Discrimination Act

SAHRC South African Human Rights Commission

UDHR Universal Declaration of Human Rights

1

Introduction

The pigmentation deficiency associated with albinism causes persons with albinism to have a lighter skin colour than other members of their racial groups. For black persons with albinism in particular, their light skin colour sets them apart from other black South Africans. In a superstitious setting, where little is known about albinism, it is often perceived and portrayed merely as a pointer of distinction and deviance resulting in the stigmatisation and discrimination of persons with albinism based on the colour of their skin.² While racism is often studied broadly as a determinant of discrimination in South Africa, both racism and skin tone bias specifically against persons with albinism have received less attention from scholars and researchers.³ It is only recently that studies into the prevalence of discrimination based on race and colour are beginning to be acknowledged in South Africa. However, few of these studies focus on the impact of this discrimination on the enjoyment of human rights. Against this background, this research study seeks to increase knowledge and deepen understanding of

2 LP Twohig & V Kalitzkus *Social studies of health, illness and diseases: Perspectives from the social sciences and humanities* (2008) 115.

3 MM Mswela & MN Slabbert 'Colour discrimination against persons with albinism in South Africa' (2013) 6 *SABJL* 25.

the experiences of persons with albinism with respect to the extent and impact of racism and colourism.

The report is divided into five parts. The first part introduces the research study, setting out the methodology adopted for the study, the clinical aspects of albinism as well as the construction of albinism as a disability. The distinction between the concepts of racism and colourism is not always apparent, therefore, the second part of the report focuses on defining the terms racism and colourism within the context of albinism. The third part of the report analyses the findings of the focus group discussions in order to determine the extent and impact of racism and colourism against persons with albinism of African descent in South Africa. The fourth part addresses the national, regional, and global instruments applicable to discrimination against persons with albinism. The fifth part concludes the report and provides some recommendations for addressing and eliminating discrimination based on race and colour against persons with albinism in South Africa.

2

About the Research Study: Methodology & Foundational Concepts

2.1 Methodology

The study employed two research methods, namely, desk-top research and empirical research. The document-based literature study, consisted of a review of legal and other relevant sources concerning the topic, including books, legislation, case law, journal articles, newspaper reports and internet sources.

The empirical research component was conducted with two focus groups on 24 April 2023 in urban Pretoria, at a university site. Participants were recruited from organisations working on albinism and disability from across South Africa's nine provinces. The composition of the sample was intended to represent different organisations working on albinism and their collaborations with persons with albinism. Convenience sampling was applied during the recruitment of participants, recruiting reachable as well as available organisations. The participants' entry to the focus group was based on an emailed invitation to participate. The total number of participants was 18, the majority of whom were persons with albinism. The Research Ethics Committee at the Faculty of Law, University of Pretoria, approved aspects relating to the research protocol, and participants indicated their consent to participate in the study after reviewing the disclosure form. Female

moderators led the focus group, following an interview technique. Conversations from this focus group were then digitally recorded during the focus group discussion and transcribed and analysed for inclusion in the research report at a later stage.

2.2 Understanding albinism

2.2.1 Clinical aspects of albinism

Albinism is a rare genetic condition, which is non-contagious and is characterised by a lack of or significant reduction in pigmentation in the skin, hair, and eyes.⁴ The condition can be found in both genders, irrespective of race and ethnicity.⁵ There are several types of albinism, each with varied individual implications. In sub-Saharan Africa, Oculocutaneous albinism (OCA) is prevalent.⁶ However, this report refers collectively to all persons with albinism, irrespective of type, using the terms ‘people/persons with albinism’ and ‘albinism’.

Albinism is often noticeable at birth from the lack of pigmentation, which results in persons with albinism having fairer skin and hair.⁷ The occurrence of albinism differs across the world.⁸ It is estimated that globally 1 in 20000 people is

4 SA Scott ‘New category of color: Analyzing albinism under the Title VII and the Americans with Disabilities Act’ (1999) 2 *The Journal of Gender, Race and Justice* 493 at 494; and J Jack et al *Clinical ophthalmology: A systematic approach* (2011) 648.

5 The National Organization for Albinism and Hypopigmentation ‘What is albinism?’ <http://www.albinism.org> NOAH-What-is-Albinism_2020_low-res.pdf (accessed 16 July 2023).

6 AWN Roy & RM Spinks *Real lives: Personal and photographic perspectives on albinism* (2005) 12.

7 Horobin W (ed) *Diseases and disorders* (2008) 29.

8 MM Mswela ‘A selection of legal issues relating to persons with albinism’

born with albinism.⁹ The occurrence of albinism in parts of Africa is far higher than the global average,¹⁰ with sub-Saharan Africa recording a significantly higher prevalence rate, with estimates of 1 in 1 400 people being affected in South Africa.¹¹ Studies indicate that albinism has a higher frequency among the Sotho people of Northern South Africa.¹²

2.2.2 Framing albinism as a disability

In recent years, albinism has been classified as a type of disability. Albinism fits into the understanding of disability found in the Convention on the Rights of Persons with Disabilities (CRPD). According to Preamble paragraph (e) of the CRPD, disability results from the interaction between persons with impairment and environmental and attitudinal barriers that hinder their full and effective participation in society on an equal basis with others. Persons with albinism have impairments in the form of low vision, nystagmus, photophobia and a lack of pigmentation which makes them susceptible to skin cancer caused by the sun. In addition, they often face attitudinal and environmental barriers that impede their full and effective participation in society on an equal basis

LLD thesis, University of South Africa, 2016 at 23.

- 9 B Kamaraj & R Purohit 'Mutilation analysis of oculocutaneous albinism: A compact review' (2014) Article 905472 *Bio Med Research International* 1 at 2.
- 10 SM Uromi 'Violence against persons with albinism and older women: Tackling witchcraft accusations in Tanzania' (2014) 2 *International Journal of Education and Research* 324.
- 11 HS Sacharowitz 'An overview of oculocutaneous albinism in South Africa' in CS Stein *Vision rehabilitation: Assessments, interventions and outcomes* (2000) 45. See also SM Uromi SM 'Violence against persons with albinism and older women: Tackling witchcraft accusations in Tanzania' (2014) 2 *International Journal of Education and Research* 324.
- 12 ES Hong et al 'Albinism in Africa as a public health issue' (2006) 6 *BMC Public Health* 1. See also PM Lund & RA Gaigher 'Health intervention programme for children with albinism at a special school in South Africa' (2002) 17 *Health Education Research* 365.

with others.¹³ Therefore, they fall within the ambit of the CRPD's understanding of disability. That albinism is a type of disability, was recognised by the Committee on the Rights of Persons with Disabilities (CRPD Committee) in *X v United Republic of Tanzania* (X case). X, a person with albinism, brought a communication before the CRPD Committee alleging that he was discriminated against on the basis that he is a person with albinism and that this constitutes disability discrimination in contravention of article 5 of the CRPD.¹⁴ The CRPD Committee agreed with Mr X and therefore, acknowledged that albinism is a form of disability. Furthermore, in its concluding observations on the report submitted by South Africa, the CRPD Committee referred to albinism as a disability.¹⁵

Similarly, at regional level, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (Africa Disability Protocol) recognises albinism as a disability. In its Preamble, the African Disability Protocol

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- 13 D Msipa 'Albinism as disability: The key to ensuring equal access to justice for the vindication of economic, social and cultural rights by persons with albinism in South Africa?' (2022) *Southern Africa Albinism Socio-Economic Rights Journal* (forthcoming) at 2-3. Also see, M Mswela 'Does albinism fit within the legal definition of disability in the employment context? A comparative analysis of the judicial interpretation of disability under the SA and US non-discrimination laws' (2018) 21 *PELJ* 3 <http://dx.doi.org/10.17159/1727-3781/2018/v21i0a3222> (accessed 16 July 2023).
 - 14 Committee on the Rights of Persons with Disabilities, *X v United Republic of Tanzania*, Communication 22/2014, CRPD/C/18/D/22/2014 <https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/CRPD-C-18-DR-22-2014.pdf> (accessed 12 July 2022).
 - 15 Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of South Africa, 23 October 2018, UN Doc CRPD/C/ZAF/CO/1 (2018) <https://www.ohchr.org/en/documents/concluding-observations/crpdcazafco1-concluding-observations-initial-report-south-africa> (accessed 13 May 2022).

acknowledges the risk of violence and abuse for persons with albinism condemning the maiming and killing of persons with albinism, which is common in parts of Africa, including in South Africa.¹⁶ By including provisions on persons with albinism, the African Disability Protocol makes it clear that albinism is a type of disability.¹⁷

Viewing albinism as a disability is significant because it enables persons with albinism to benefit from the comprehensive understanding of disability as a social construct. Disability is now perceived as the result of the interaction between impairment and external societal factors, not simply impairment alone. This understanding acknowledges the contribution of external social barriers both to the disadvantaging of persons with impairment and to addressing barriers and empowering persons with impairment. Understanding albinism as a disability acknowledges that the disadvantage associated with albinism is not caused by the impairment alone, but by the interaction between the person with impairment and the environment. It takes into account the social issues associated with the condition and challenges the experiences of violence, marginalisation, and discrimination towards persons with albinism. It also highlights the vast societal issues persons with albinism are facing due to the way others respond to them and the numerous barriers they encounter in their social and physical environment. More importantly, it acknowledges that interventions to ameliorate the discrimination against persons with albinism should seek to address these societal ills.

16 See, art 38 of the African Disability Protocol.

17 Msipa (n 12); E Durojaye & S Nabaneh 'Human rights and access to health care for persons with albinism in Africa' (2019) 7 *African Disability Rights Yearbook* 35.

2.3 Understanding discrimination based on race and colour

The concepts of racism and racial discrimination are closely related. Racism refers to prejudice, or antagonism directed against someone of a different race based on the belief that one's own race is superior.¹⁸ It occurs as a result of attaching values to different racial categories with the white race being generally regarded as superior and the black race being regarded as inferior.¹⁹ Through the operation of racism, actions, attitudes, policies, and systems can generate unfair opportunities and outcomes for people on the basis of their race.²⁰ Racial discrimination is the manifestation of racism through differential treatment that is accorded in accordance with one's race.

Colour-based discrimination is differential treatment based on skin-tone variance,²¹ whereby light-skinned people are treated more favourably or are highly valued compared to dark-skinned people.²² Colourism creates a system of inequality based on a variance in skin colour. It functions both intra-racially and inter-racially. Intra-racial skin colour discrimination occurs where differential treatment is accorded to people belonging to the same racial group, based on skin tone or colour whilst inter-racial colourism occurs where differential treatment is accorded on the basis of skin tone to people belonging to different racial groups.

18 Oxford Learners' Dictionaries 'Racism' <https://www.oxfordlearnersdictionaries.com/definition/english/racism> (accessed 07 November 2023).

19 N Blankenberg 'That rare and random tribe: Albino identity in South Africa' (2000) 14 *Critical Arts* 6 DOI: 10.1080/02560040085310081 at 29-30.

20 K April (ed) *Narratives of racism in South Africa* (2021).

21 See Mswela & Nöthling-Slabbert (n 2).

22 D Gabriel *Layers of Blackness: Colourism in the African diaspora* (2007) 11.

Literature provides considerable evidence that colourism affects persons with albinism in most aspects of their lives.²³ Because persons with albinism lack pigmentation, their skin colour has led to a number of damaging social constructions towards this group, for instance, the association of fair tanned skin colour with curses, stereotypes, false notions, and harmful myths.²⁴ Intra-racial colourism in the context of albinism manifests in several different ways, for example, as capital, where the skin colour of persons with albinism is a mark, which easily identifies persons with albinism for ritual killings and violent attacks, placing their colour as the basis of various crimes. Intra-racial colourism in the context of albinism is also presented by teasing, name-calling and derogatory statements and ignorant questions regarding the condition.

23 J Burke 'Colourism as an interracial phenomenon: The case of Tanzania' African Studies Association of Australasia and the Pacific (AFSAAP) 37th Annual Conference – Dunedin – New Zealand – 25-26 November 2014. Mswela (n 7) 1-76.

24 Mswela (n 7) 91.

3

Discrimination Based on Race & Colour in Relation to Persons with Albinism

3.1 Challenging social determinants of race _____

Historically, South African society has used colour as an instantaneous means of recognising racial affiliation.²⁵ In South Africa, race and racialism is largely reliant on a dual conception of black versus white and one's physical appearance, particularly skin colour, is relied upon heavily to classify people within racial categories.²⁶ However, for persons with albinism, having white skin does not qualify them to be white. In fact, persons with albinism themselves generally identify with the black communities into which they were born rather than white communities, in spite of their fair skin colour.²⁷ Phatoli submits that because of their difference in looks, persons with albinism do not fit neatly in the black or white racial groups.²⁸ Persons with albinism are regarded as crossing the border between black and white, defying the binary

25 Mswela & Slabbert (n 2).

26 Blankenberg (n 18) 36.

27 R Phatoli, N Bila & E Ross 'Being black in white skin: Beliefs and stereotypes around albinism at a South African University' (2015) 4 *African Journal of Disability* 106.

28 As above.

code and threatening established racialised identities.²⁹ Legally, the race of persons with albinism was never in doubt, but socially the controversy lay in being an African in white skin living in a society that discriminated against Africans in black skin. Skin colour is therefore not the only determining factor for racial classification of persons with albinism. Albinism thus challenges traditional forms of racial classification.³⁰

Research shows that most black persons with albinism identify their race by referring to the race of their parents.³¹ Thus, ancestry and lineage play a role where skin colour contradicts race. Provided the parents are of the same race, this way of identification is logical.³² However, not everyone in society accepts such self-identification.³³ In South Africa, racial identity is imposed rather than discovered. Lyotard asserts that reality is constructed through a social contract, that is, through a collective agreement on what constitutes reality.³⁴ Hence, identity is not simply a matter of self-identification.³⁵ A crucial element of identity is how one is perceived and accepted by others.³⁶ Responding to a question on racial classification of persons with albinism during apartheid, Rhodes states that accepting persons with albinism within the category of white would raise hatred between the racial groups and subject persons with albinism to discrimination in social situations where

29 Prof Rhodes 'How would albino Black-Africans be treated in apartheid-era South Africa?' https://www.reddit.com/r/AskHistorians/comments/32wsje/how_would_albino_blackafricans_be_treated_in/ (accessed 6 May 2023).

30 Blankenberg (n 18).

31 Blankenberg (n 18) 19-20.

32 As above.

33 As above.

34 Blankenberg (n 18) 33.

35 As above.

36 As above.

race created divisions.³⁷ Therefore, black persons with albinism were treated exactly the same as all other black people and denied various privileges and rights.³⁸ Classified as black, persons with albinism experienced systematic racism that included forced removals, racial inequality, discrimination, and marginalisation. Just like any other black person, they were barred from sharing or gaining privilege and power. In modern times, despite black persons with albinism identifying as black because of their lineage, some members of the black community reject them, creating an identity crisis.

3.2 Complex nature of race and colour-based discrimination against persons with albinism

In contemporary South Africa, there is an alarming emergence of race and colour-based discrimination against persons with albinism including hate speech, violence and provocation of violence. Often, the discrimination manifests in a complex manner. On the one hand, because of their white skin tone, black persons with albinism are associated with the white race and it is assumed that they benefit from the privileges that come with being white and having fair skin.³⁹ This perception can attract retribution from members of the black community. On the other hand, persons with albinism are perceived as either sub-human or super human as evidenced by the name-calling, myths and misconceptions about them.⁴⁰ For example, during the COVID-19 pandemic, persons with albinism were perceived as the source of the virus, which was considered

37 Rhodes (n 28).

38 As above.

39 T Corinne 'Albinism in Africa: Examining identity formulation' Honours Thesis, University of Chattanooga, 2021.

40 As above.

as a disease of the 'white man' thereby exposing them to further violence and hatred. Race and colour-based discrimination against persons with albinism is therefore complex, making it necessary to study its occurrence and impact.

4

The Impact of Race & Colour-based Discrimination

The research study found that race and colour-based discrimination against persons with albinism impacts them in two dimensions, the social dimension and the human rights dimension. The following section explores each of these in turn.

4.1 The social impact of race and colour-based discrimination against persons with albinism_____

The social impact of race and colour-based discrimination against persons with albinism affects how they identify their own race, how others identify their race and the significance of the different perceptions.

4.1.1 How persons with albinism identify their race

The majority of South Africans with albinism interviewed during the focus group discussion identified their race in relation to that of their parents, their ancestry, lineage, and tribe and did not view their fair or white skin as a core determinant of their race.⁴¹ A few mentioned that they identify as white, despite being of black

41 It is important to note that a small minority of persons with albinism from black ancestry who participated in the research choose to identify as white based on the colour of their skin believing that physical characteristics are the most important determinant of race.

heritage.⁴² Many, however, acknowledged that they struggled with formulating their racial identity particularly in their earlier years and some continue to struggle because other members of their racial group often question and contest their racial identity.

4.1.2 How society perceives the race of persons with albinism

Society's perception and treatment of persons with albinism, has a significant effect on their inclusion and participation and influences their sense of belonging to a racial group. In an environment where most of the black population have darker pigmentation, persons with albinism appear starkly different from their families and communities, causing confusion and raising questions about their racial identity, particularly in communities with little understanding about albinism. Persons with albinism are often confronted with the question, 'how are you black when your skin colour is white?' In many black societies in South Africa persons with albinism are thus perceived and treated as outsiders who do not fit into the norms of their social group and are labelled as 'others'. Their identity is often questioned and they are sometimes rejected as members of the racial group from birth and throughout their entire lives.

Other members of the black community reject persons with albinism for two reasons. First, they perceive them as belonging to the white race. Persons with albinism are sometimes referred to as '*lekgoa*' meaning white person. One participant shared the following experience:

I did not know I was different until I was 12. When we relocated there was a group of people in the new community where we moved who started touching me, asking me what language I spoke and trying to speak with me in English and here I was also learning English myself. They were speaking with me like I am a white person, trying to speak to me with an accent. That is when I started to feel different.

42 See section 4.1.3 below.

In another incident a young man with albinism became a target of a hijacking because the hijackers thought he was white. On realising he was not, they abandoned their plan.

I was driving in Bree. There is a KFC/Chicken Licken there. There is guy who came there with a gun. I don't know if he wanted to hijack me or take the car but because of the nature of me I don't believe that something like that was going to happen. I opened the window and asked him what are you doing (in vernacular). Then he responded surprised a 'uyakhuluma' (oh you speak vernacular) and left.

Second, they are rejected as members of the black community because they are regarded as sub-human as exemplified by the use of names such as '*inkawu*', meaning monkey. In some cases, they are regarded as curses as exemplified by the use of the name '*isishawa*', meaning a curse. Having a child with albinism is frowned upon, and often, the mother is blamed for bringing a curse on the family. As a result, mothers are often abandoned by their partners or spouses and face hostility and exclusion from community members on the grounds that they had a child with albinism because they were unfaithful.⁴³ Three of the narratives shared by the participants on the reactions to their birth illustrate this point:

I was told my great grandmother had albinism. When I was born, my maternal family were familiar with the condition or knew about it even though they did not really understand it. So, it was not something they had never seen before. My father's side however struggled to accept me. My mother was living with her in-laws when she passed away. After her death they said we cannot take care of this child, we know nothing about this condition. So, my mother's side took me back and raised me.

43 Women impacted by albinism.

Another participant shared the following experience:

I was born in Venda 1999, my mom is from Polokwane, it was a surprise for her even though she was a nurse herself and yet knew nothing about albinism. The doctor explained to her that no, it is just a condition. When she got home my father's family said you have brought us a curse, you must throw away the child. Then my mother decided to move back to her home.

A third participant stated the following:

My mother also was a nurse she was in her second year as a nurse when she had me. When she delivered me, she developed a condition where her body was swelling. Then I was forced to stay in hospital the rest of the time she was in hospital until she passed on. After she passed on the hospital decided to keep me in honour of her, they said we cannot take him home now because there is no one to take care of him. So, the hospital had a nursery and they decided to keep me. But what I heard was that whilst I was kept in hospital, there was such a fierce fight between my grandparents from my mother's side and my father's side. From my mother's side they were blaming my father's side that, look you married our daughter and now she has given birth to something we have never seen in the world. I was four years when my father fetched me from the hospital then I went home.

Society's rejection of persons with albinism as fellow members of the black race can be explained by the lack of knowledge and information about the genetic causes of albinism. It is therefore important to educate communities and raise awareness about albinism.

4.1.3 The effect of racial segregation on individuals with albinism

The rejection that persons with albinism experience negatively impacts them in three ways. First, it leads to a fragmented sense of identity due to the inability to fully identify with any racial groups. They thus suffer from a state of ‘in-between-ness’ in which they feel (and are perceived) as not black or melanated enough to belong to the black race, yet not white enough to be considered a white person. A participant described her experience as follows:

I personally identify as a black woman but when I am around other black people, I get the sense that maybe I am not black enough and around white people I feel like I am not a white person.

Concurring, another participant stated as follows:

This question comes up when filling in forms that require you to identify your race and there is often total confusion. Some persons with albinism identify as ‘other’ partly as a rejection to racial categories and how they were used during apartheid and their struggle to fit into these (cut and dry) categories. Some just leave it blank.

In other instances, it has resulted in some persons with albinism choosing to distance themselves from the black race and opting to identify as white because of the discrimination they experienced from black people. One participant speaking on her choice to identify as a white person said:

I am black, my forefathers are African, but I am called ‘lekgoa’ (white person) because of my skin so now I identify as white.

There are those who are also hesitant to identify as black fearing that this creates expectations on them to do things typically done by black people, which they will not be able to do, such as staying out in the sun for long periods of time.

Some persons with albinism have internalised the erroneous identities ascribed by communities from when they were young. One participant explained that:

[When] I was in sub-A and 10 years old, whenever I passed a group of children, they called me 'lekgoa' (white person) so I accepted that I am white.

Those who accepted they were white often did so as a way of coping with the rejection and trying not to let the labels affect them. Many of those in turn internalised negative stereotypes about the abilities and intrinsic worth of persons with albinism.

Second, the rejection inflicts psychological scars. In a number of cases, the negative experiences have affected how persons with albinism perceive themselves, their sense of self-worth and their confidence, leading to feelings of shame, self-blame and worthlessness.⁴⁴ Studies conducted in South Africa show that children and adults with albinism have a lower self-image and a higher level of anxiety than their peers.⁴⁵

Reflecting on his own experience, a young participant shared that

the effect on a young person of contradictory views about their identity is the creation of an identity crisis, of not knowing where one belongs.

Another participant who had a similar experience described the trauma he experienced at the hands of the community he grew up in as follows:

44 Similar findings in attitudinal barrier report.

45 AC Rielly 'Mental health of children with albinism: Associated risk and resilience factors' Master of Education dissertation, University of Johannesburg, 2020 <https://ujcontent.uj.ac.za/esploro/outputs/graduate/Mental-health-of-children-with-albinism/9913602407691> (accessed 20 May 2023).

They experimented on me, touched me, and made me feel like I had fallen from somewhere. I felt anger, inferiority, frustration, closeted isolation, my self-esteem was low. I lost the dignity of my identity. I questioned why I am like this, who am I. Am I black, white?

Persons with albinism often have to explain their identity to others, particularly when they are black, which takes an emotional toll.

Third, the consequences can be calamitous particularly where the colour of persons with albinism is linked with harmful myths and superstitions. One participant explained this as follows:

I did a lot of research on that. Most of the families where there is a child with albinism they normally do not accept and for your information in Limpopo even as we speak chances are that a child with albinism to survive must be born to these modernised families. Otherwise, if not is gonna be killed. You know how they kill them? Simple. You take you know these water basins, put the child under a water basin until they suffocate and die (drown). Then they will call people and say 'hai' the child was playing and got covered with water (drowned). It's so easy. When we went to the national albinism conference last year, we had a case a day before [and] went to Mpumalanga. I was called in and we had a case where this lady gave birth to a child with albinism and the mother-in-law called her and said I want you to go to town buy the child clothes and all that and then when the lady was about to take a taxi into town somebody went to her and said do you know why they are sending you away? They want to kill your child because they think it is a curse. So that lady ... get off the taxi just less than a km away, went back to the house and found that there was an 'inyanga' (witch doctor) there who wanted to perform rituals to kill the child. Then she took the child away and her marriage is broken as we speak as she protected her child. So, these are the kinds of things we are experiencing as activist[s].

In another incident, a young boy with albinism who often played at his neighbour's house, was blamed for causing the neighbour's child to be born with albinism. The neighbour banned the boy from visiting his home threatening to beat him if he ever came back.

As shown above, the community's rejection of persons with albinism has a negative impact on them feeling rejected, excluded and alienated from their own communities.

The impact of colour-based discrimination against persons with albinism transcends the social sphere and impacts the enjoyment of human rights and fundamental freedoms as outlined in the next section.

4.2 The human rights impact of race and colour-based discrimination against persons with albinism _____

This study found that colour-based discrimination adversely affects the enjoyment of human rights and fundamental freedoms by persons with albinism in South Africa. Chief amongst these are the rights to employment, education, health, freedom from abuse and violence and access to justice.

4.2.1 *The right to employment*

Generally, the unemployment rate in South Africa is high. South Africa's unemployment rate in the first quarter of 2023 was recorded at 32,9 per cent. This study revealed that unemployment is higher among persons with albinism compared to persons without albinism. Employers and potential employers often underestimate the capacities and abilities of persons with albinism believing them to be intellectually inferior to and less competent than persons without albinism. A participant who had been hired as a sound engineer for a big concert featuring a popular local artist quit the job after overhearing the other crew members questioning his ability to do the job given his albinism. He later returned to complete the job after the manager apologised. In another incident, a casting agent told an actor with albinism auditioning for a role in a movie that required a person with albinism that persons with albinism could

not act and were only cast because of their albinism. An academic with albinism commented that:

People are surprised I hold a Master's Degree from University of Pretoria. They do not see us as thinkers. They even ask, the University of Pretoria?

This discrimination results in low employment rates amongst South Africans with albinism. Those who do procure employment are often employed in low paid minimum wage jobs that are not commensurate with their qualifications and they work under unjust and unfavourable conditions. Moreover, they are often employed on a part-time basis, or as daily wage labourers, working seasonally or under contract as opposed to receiving long-term full-time employment. A young female economics graduate shared her struggle to secure permanent employment after graduating as follows:

After graduating I went to work for a small start-up company. They are like a management consulting company. So, I did a learnership there. Before I completed my learnership I got a job where I am currently working. I started as an intern and then I noticed after my internship ended, they kept giving me temporary contracts. 3 month temporary contracts. The only reason for this was my albinism. I had two other people who I started the internship with at the same time. One became permanently employed after the internship contract ended and the other was let go. I just kept getting these recurring temporary contracts for 3 months, 6 months. Then I realised that in the beginning I had been hired to fill up the quota for disability. But I was convinced that I had shown that I am good at the job, that I can do it. They even kept commending me telling me 'You are adding value.' So where was my permanent contract? I told my manager; 'I am going to look for a job elsewhere. I studied economics and would like to grow in the area I studied. I am basically doing the same thing I was doing as an intern two years ago.' Then after the conversation with my manager they suddenly offered me a contract but my duties were administrative. I told them that is not in

line with what I studied nor is it in line with where I want to go so I cannot accept it and then there was a meeting with the CEO to reiterate how much they valued my contribution and currently that's the only role there is for me. My response was ok, but I can't take that job, I am not going to accept that contract because I noticed with the person that I started the internship with even though they tell us we can't discuss contracts its confidential we do talk as people, as colleagues and friends. This person studied a general degree, I studied economics and the organisation had specifically said they were looking for an economics expert she was offered a permanent position and was doing things in line with her qualification, and I was not. I felt the only difference is I have albinism and she does not. It raised some issues with the company where I was now being labelled as difficult but, in the end, they agreed to a promotion more aligned with what I wanted to do and had studied to do. But it was a situation where because of the colour of my skin, they felt I was more aligned to administrative work, call centre kind of work and it's very limiting and discouraging.

Another participant who had a similar experience described how she secured an internship at a courier company when she graduated from university with a degree in logistics and transport. During the internship, the only work she was allocated to do was photocopying, filing, and collecting documents. She eventually complained that she, unlike the other interns, was not getting the experience she needed and gave the company an ultimatum to either let her go or give her work. The manager's justification for giving her basic administrative tasks was that she could not see and was thus more suited to menial tasks. It often takes strong self-advocacy for one to be employed on equal basis with others. Participants expressed frustration at the fact that many employees seemed to expect persons with albinism to thrive in jobs that were administrative in nature and thus hired them only for such posts notwithstanding their qualifications and aptitude.

Participants further stated that in some cases, persons with albinism are hired simply to meet employment equity quotas with no genuine intention to give them meaningful responsibilities and build their capacity. Some of the participants opined that organisations prefer to hire persons with albinism over persons with other types of disabilities because they perceive persons with albinism as having lesser reasonable accommodation and support needs and thus, as one participant put it, are ‘a lesser evil or having a better level of disability’. Such approaches undermine the intention behind affirmative action measures that are aimed at enhancing equality in the workplace.

Participants also stated that employers perceive hiring persons with albinism as a benevolent act and treat them in a condescending manner. A participant recounted how one of his managers treated him like a child, rather than a professional colleague.

Some employers in South Africa are unwilling to provide reasonable accommodation that employees with albinism may require in order to perform their jobs, seeing such requests as proof that the employee with albinism is not suited for the job. Organisations of persons with albinism regularly receive complaints from persons with albinism who have been unfairly dismissed from their jobs or have been labelled as incompetent after requesting reasonable accommodations to do their work.

The participants added that discrimination in employment does not always come from employers but from clients too. One of the participants who had trained as a nurse left the profession because of patients’ reluctance to be assisted by her. Similarly, a teacher with albinism who applied to be the principal of his school

was not given the position because some of the parents objected to his appointment.

Moreover, employees with albinism are not considered for promotions because of misconceptions about their abilities.

Although disability quotas are in place in South Africa to encourage the employment of persons with disabilities, including persons with albinism, these are not always respected even by government departments. A participant who worked in a local municipality in his province reported that most of the time when his municipality was recruiting for a new post, persons with albinism were not given a chance to interview for the post. Some are shortlisted for the recruitment to look inclusive but never called to the interview. The total population of persons with albinism that live in poverty thus remains high due to this institutionalised racial discrimination in the country's labour market.

Persons with albinism who are self-employed reported that they experienced similar types of discrimination. Many felt they were side-lined from business opportunities because of the colour of their skin. A participant with albinism who runs an event organising and catering company relayed a number of incidents in which he had been hired to cater or do the décor for an event telephonically or over email only for the client to change their mind after they met him and realised that he had albinism. He explained this as follows:

A couple reached out to me telephonically for a quote to organise their wedding. They were happy with the quote and wanted to engage my services. I organised for them to come and see a demonstration of how their venue would be set up. The parents of the groom who came together with the couple expressed they were not comfortable at having someone like me (with albinism) organise the wedding. I did not get the contract.

In instances where they collaborated with other businesses some felt their contribution in the business partnership was not as valued and partners treated them in a condescending manner, expecting them to be grateful that they had partnered with them in the first place.

4.2.2 *The right to education*

Persons with albinism face discrimination at both special and mainstream educational institutions and at all levels. The colour-based discrimination faced by persons with albinism in their communities has led to parents of learners with albinism predominantly placing them in special schools with boarding facilities where they believe they will integrate better, and have their learning needs met. Whilst special boarding schools may indeed provide a more accommodating environment for learners with albinism, they also reinforce the marginalisation of these learners. Removing children with albinism from their communities at an early age and for prolonged periods, results in them missing opportunities to build relationships within their communities and participating in the community. Some of the participants at the focus group discussion were opposed to the idea of placing learners with albinism in special schools, citing the fact that they are often forced to learn Braille even though many are able to read if provided with the right assistive devices. Moreover, special schools tend not to teach certain subjects offered in mainstream schools which limits career options of learners enrolled in these schools.

Mainstream schools also have their problems. Participants who had attended mainstream schools reported facing challenges including the discriminatory attitudes and behaviours of teachers and peers alike such as bullying, physical assaults, name-calling,

and segregation. Sadly, this was also the case at pre-school level where children experienced isolation and marginalisation. Parents often had to fight schools for their child to be fully included and provided with the necessary support. The difficulties are also present as tertiary level. Some of the participants who have attended University said they had been excluded from group work by their peers. Moreover, students with albinism were usually only permitted to actively participate and speak on topics related to albinism and disability and not on other academic topics. In some cases, their fellow students assumed that they only passed because they got preferential treatment from the faculty. Some students saw the extra time given to students with albinism during exams as favouritism. As one participant put it:

We were revising a past test paper before an exam and one of the other students said we know you are going to pass because they give you answers.

This discrimination adversely impacts the enjoyment of the right to education by persons with albinism.

4.2.3 *The right to health*

South Africans with albinism also experience discrimination in accessing healthcare services in public hospitals. Participants narrated experiences in which healthcare providers exhibited hostile attitudes towards them, thereby compromising their ability to receive quality healthcare on an equal basis with others. Participants reported that healthcare providers treated them inhumanely, ignoring them, refusing to attend to them or doing so reluctantly. This is attributable to deep-seated prejudices and stereotypes about persons with albinism. One participant who

narrated his recent admission at a local hospital in Pretoria had the following to say:

I broke my ankle some years ago, despite many operations it did not heal properly. I had to go to hospital in March for a third operation to try and fix it. The interaction with nurses and ward attendees inside the ward made me question whether it was me or did they treat patients generally this way. The nurse who attended to me was rough. When she inserted a drip, she was not careful or gentle. I was in a lot of pain. Whereas with other patients the nurses used to chat and talk about family. With me it was just hello then getting to the medical part. I would sometimes overhear them talking about me in hushed tones. I was meant to be in hospital for a week for an emergency operation. I spent two weeks as they kept prioritising other patients before me.

Participants therefore, noted that because of the attitudinal barriers on the part of healthcare workers, the healthcare needs of persons with albinism were accorded low priority. Other challenges, such as the inconsistent availability of sunscreen lotions in public hospitals across the country and the availability of sunscreen lotions that are not appropriate for persons with albinism, also contribute to the lack of access to health care services.

4.2.4 The right to freedom from exploitation, violence, and abuse

The study found that women with albinism are particularly vulnerable to various forms of violence and abuse including sexual harassment and violence, assault, and exploitation. Although these are systemic issues affecting women and girls in South Africa generally, this violence is exacerbated in relation to women with albinism who are doubly marginalised on the basis of gender and disability. The women interviewed for this research all agreed that it was not uncommon for a stranger to walk up to them and tell

them they had never had sexual intercourse with a woman with albinism or ask to touch them, making them feel violated, unsafe and fearful.

Men with albinism also reported receiving indecent and unwanted proposals from members of the opposite sex who are curious to experience sexual intercourse with a person with albinism. One male participant related such an encounter as follows:

I remember whilst I was starting teaching, whilst we were sitting in the staff room here. You know teachers. They talk, talk too much. There was a certain lady she just said hey, I want to sleep with an albinism man like you. I want to see whether they are real men. And when that lady talked like that all the other staff members the teachers they were laughing. They said if you taste him come and tell us how is he performing. Then I just said no, I am not a cabbage where everyone come to taste.

A member of a non-governmental organisation representing persons with albinism stated that they received a request for intervention from a 24-year-old man with albinism who was being sexually exploited by an older woman in exchange for financial benefits. He felt trapped and unable to leave the relationship. When the organisation approached his family for assistance, the family was unwilling to help, stating that he had sold himself to her. The participants indicated that when persons with albinism reject such sexual advances, they are often publicly humiliated and met with responses such as, 'who does she think she is, I was just doing her a favour, she is not in my league or class. I know her she has been longing for attention', which the participants find deeply humiliating. In the majority of cases, these incidence and crimes go unreported due to the fear of stigma and retaliation.

4.2.5 *The right to political and public participation*

Colour-based discrimination against persons with albinism also limits their participation in public and political life to such an extent that there are few persons with albinism in public office and in politics. One participant described the hostility and intimidation, which he experienced when he attempted to join a political party as follows:

In 1990, I wanted to join Umkondo weSizwe liberation struggle. I went to Botswana via Zerust to Daisy Camp with 24 others but was the only one turned away and told 'we won't make it with you, your colour and who you are, go and get an education'.

These negative attitudes still persist and continue to prevent persons with albinism from participating in the public and political life of the country.

4.2.6 *The right to access justice*

Many of the participants said they did not report the incidents of discrimination that they experienced. One of the reasons cited for not reporting was feeling uncertain about whether their experience amounted to discrimination or not. Participants were often worried that others would not view their experiences as discriminatory treatment but instead think they were being overly sensitive. This resulted in many downplaying and minimising their experiences.

Another reason for the failure to report is that many said they did not know where to report. Whilst some were aware of the existence of institutions such as the SAHRC where they could lodge a complaint, they were unsure how to go about making the complaint and decided not to do so.

Furthermore, participants expressed little confidence in the ability of the justice system to deal with complaints timeously and decisively. Their perception was that although colour-based discrimination was a component of racial discrimination, it did not elicit the same indignant response as racial discrimination. As one participant put it:

[I]f a person calls someone with albinism inkawu nothing happens, but if a white person calls a black person the 'k' word all hell breaks loose.

The outcome of the highly publicised case concerning Commissioner Nomasonto Mazibuko, a Commissioner at the Commission for Gender Equality and a woman with albinism, illustrates the poor handling of cases of colour-based discrimination against persons with albinism by the justice system.⁴⁶ In that case, a senior official from the Commission for Gender Equality allegedly made derogatory comments about Commissioner Mazibuko's albinism during one of the Commission's plenary sessions. He was initially suspended by the Commission but the suspension was over-ruled by the High Court. The High Court's decision was based on the finding that the Commission did not have the power to suspend a Commissioner, but only the President could do so, according to the Constitution. However, many from the albinism community saw this decision as a failure of the justice system to protect persons with albinism from colour-based discrimination. As one participant put it:

46 Z Venter 'Court overturns suspension of Gender Equality senior official Mbuyiselo Botha' *IOL* 1 March 2023 <https://www.iol.co.za/pretoria-news/news/court-overturns-suspension-of-gender-equality-senior-official-mbuyiselo-botha-a7c69ed6-ecf5-4df9-aede-94408ff5714c> (accessed 15 March 2023); *Botha v Commission For Gender Equality* [2023] 6 BLLR 598 (GJ).

If something like this could happen to a Commissioner who is in public office and nothing happens to the perpetrator, what more of me, a nobody.

Incidence of colour-based discrimination against persons with albinism therefore remain under reported.

In many instances, persons with albinism turn to organisations of persons with albinism for assistance and intervention. However, these organisations tend to have limited capacity to handle these complaints as they are often staffed by volunteers with little or no operational budget and limited legal knowledge. Consequently, persons with albinism rarely access justice.

5

Legal Protection Against Race & Colour- based Discrimination

Having highlighted the negative impact of discrimination based on race and colour, it is important to note that the law, at national, regional and global levels, prohibits this discrimination. These laws provide recourse for persons with albinism who have experienced discrimination on the basis of race and colour.

5.1 Laws prohibiting discrimination at national level

At national level, section 9 of the Constitution of South Africa guarantees the right to equality and equal protection and benefit of the law. Section 9(3) prohibits unfair discrimination on a number of grounds including race and colour.

The Employment Equity Act prohibits discrimination in the employment sphere including discrimination based on race and colour.⁴⁷

The Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA)⁴⁸ seeks to address systemic discrimination by eradicating social and economic inequalities.⁴⁹ PEPUDA prohibits discrimination on the basis of race making

⁴⁷ Section 6(1) Employment Equity Act 55 of 1998.

⁴⁸ Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (PEPUDA).

⁴⁹ Section 4(2)(a) & (b) of PEPUDA.

it possible for persons with albinism to rely on this provision to obtain redress for discrimination based on colour.⁵⁰ PEPUDA goes a step further and establishes Equality Courts⁵¹ to adjudicate cases involving unfair discrimination, harassment, and hate speech.⁵² Equality Courts eliminate barriers to judicial access by making it easier for complainants to navigate the courts without legal representation. A clerk of an Equality Court guides complainants through the procedure of filing a complaint and offers any advice needed by litigants.⁵³ The Equality Court clerk together with the presiding officer provide guidance on how to advance the case, the kind of evidence to present, they question witnesses themselves, and have authority to call witnesses. Equality Courts hear cases in an 'expeditious and informal manner which enables and encourages participation by the parties'.⁵⁴ Therefore, persons with albinism seeking redress and remedy for unfair discrimination, harassment and hate speech based on colour may approach the Equality Court closest to them.

At policy level, the National Action Plan to Combat Racism, Racial Discrimination, Xenophobia and Related Intolerance calls for the development of an Integrated National Strategy to Protect, Promote and Uphold the Rights of Persons with Albinism using a participatory approach.⁵⁵ The deadline for the development of

50 Section 7(2)(a) & (b) of PEPUDA.

51 Section 16(1)(a) of PEPUDA.

52 Sections 3, 4, 5 & 16 of PEPUDA.

53 Section 20(1)-(3) and regulation 6(1) of the Regulations relating to the Promotion of Equality and Prevention of Unfair Discrimination published under Government Notice 764, Government Gazette 25065 of 13 June 2003 (the Regulations).

54 Section 4(1)(a) and (b). Also see *Maharaj v Gold Circle* [2018] 1 All SA760 (KZP).

55 Republic of South Africa 'National Action Plan to combat racism, racial discrimination, xenophobia and related intolerance' (2019) 60.

the strategic framework (by 2024) is fast-approaching and it is hoped that it will address race and colour discrimination against persons with albinism in South Africa. The outcome of this strategic framework will assist South Africa in attaining its targets towards the Regional Action Plan on Albinism, which aims to end racial and colour discrimination as well as violent attacks against persons with albinism by 2030.

Persons with albinism also have the option of registering a complaint with the SAHRC, which recently (2022) reiterated its commitment to register complaints by persons with albinism for investigation in order to provide the necessary redress.

5.2 International human rights instruments prohibiting discrimination at regional level _____

Several human rights instruments, at regional level, prohibit discrimination based on race and colour. The African Charter on Human and Peoples' Rights (African Charter) protects the right to equality and non-discrimination and prohibits discrimination on various grounds including race and colour.⁵⁶ This provision, and indeed, the whole Charter, applies to 'every individual' including persons with albinism.

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol) prohibits all forms of discrimination against persons with disabilities, including persons with albinism.⁵⁷

56 Article 2 African Charter on Human and Peoples' Rights.

57 Article 5 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol), also prohibits discrimination against women with albinism. The Maputo Protocol requires member states to eliminate discrimination against women, including women with albinism who often face discrimination on the basis of gender, colour, and disability.⁵⁸

In terms of policy, the Regional Action Plan on Albinism in Africa, adopted by the African Union with the objective of combatting human rights violations against persons with albinism by 2030 is also pertinent.⁵⁹ The Regional Action Plan's second pillar on protection is particularly important because it includes colour as a ground upon which discrimination is prohibited.⁶⁰ The remaining three pillars on prevention, accountability and equality, and non-discrimination are also relevant.⁶¹

5.3 International human rights instruments prohibiting discrimination at global level _____

Several International Human Rights Law instruments prohibit discrimination at global level as outlined below.

The Convention on the Elimination of all Forms of Racial Discrimination (CERD), was specifically adopted to combat

58 Article 2 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.

59 Action on Albinism 'Towards an inclusive world for persons with albinism' (2020) https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/RegionalAction_Plan_on_albinism_EN.docx (accessed 18 July 2023).

60 As above.

61 As above.

racial discrimination.⁶² It prohibits various forms of discrimination including discrimination based on race and colour.⁶³

The Special Rapporteur on Racism, together with other Rapporteurs, issued a Statement on the attacks against persons with albinism. In the Statement, the Special Rapporteur on Minorities stated:

People living with albinism do not fall under the internationally accepted definition of minorities. However, their stigma, the lifelong social exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour.

The Special Rapporteur on racism, Mutuma Ruteree, added:

Regardless of whether one has a lighter or a darker skin compared to the majority population in a country or a community, everyone is entitled to the same rights, dignity and treatment. It must be ensured that people living with albinism enjoy their human rights without distinction and have the same opportunities as anyone else.

Both rapporteurs emphasised the fact that discrimination based on colour contravenes international law.

The Convention on the Rights of Persons with Disabilities (CRPD), prohibits discrimination against persons with disabilities, including persons with albinism.⁶⁴

62 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 (1965).

63 Article 1 of the Convention on the Elimination of All Forms of Racial Discrimination.

64 Articles 3, 4 and 5 of the UN General Assembly, Convention on the Rights of Persons with Disabilities: Resolution adopted by the General Assembly, 24 January 2007, A/RES/61/106 (2007). The provisions of the present Convention shall extend to all parts of federal states without any limitations.

The International Covenant on Civil and Political Rights (ICCPR) protects everyone, including persons with albinism, from all forms of discrimination, including race and colour-based discrimination.⁶⁵ In General Comment 18,⁶⁶ The Human Rights Committee declares that states have an obligation to attempt to rectify historical trends of discrimination against members of minority groups by implementing affirmative action.⁶⁷

Similarly, the International Covenant on Economic, Social and Cultural Rights (ICESCR) guarantees equality and non-discrimination for everyone in relation to economic, social and cultural rights such as the right to health and the right to education.

Other instruments that also prohibit all forms of discrimination on various grounds including race and colour are, the Universal Declaration on Human Rights (UDHR),⁶⁸ the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)⁶⁹

65 Article 26 of the UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations, Treaty Series, vol 999, p 171 (1966).

66 Section 10 of the United Nations, General Assembly, General Comment 18: Non-discrimination, 29 July 1994, UN Doc HRI/GEN/1/Rev.1 (1994).

67 Committee on Economic, Social and Cultural Rights, Vienna Declaration and Programme of Action, adopted by the World Conference on Human Rights, Vienna, 25 June 1993.

68 Article 2 of the UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III) (1948).

69 Article 1 of the UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, United Nations, Treaty Series, vol 1249, p 13 (1979).

There is therefore, a strong legislative framework that can be used to protect persons with albinism from discrimination based on race and colour.



Conclusion & Recommendations

This study demonstrated the adverse impact that discrimination based on race and colour has on persons with albinism in the social sphere and in terms of the enjoyment of human rights. Socially, this form of discrimination creates alienates persons with albinism from their community, leaving them feeling isolated and unwanted. It also prevents them from being able to enjoy human rights and fundamental freedoms, such as education, employment, health, freedom from violence and abuse as well as access to justice. The study found that lack of knowledge and awareness about albinism in the community fuels discrimination and harmful myths and practices. In spite of the enabling legislative framework at national, regional and global levels, discrimination based on race and colour persists. In response to these findings, the following responses are recommended:

- 1 Raise awareness about albinism in the community to combat the lack of knowledge that fuels discrimination.
- 2 Conduct albinism sensitisation amongst key sectors including, education, employment, health, and justice.
- 3 Raise awareness amongst persons with albinism about their right to equality and the legal resources available to them.

- 4 Conduct further research on examples of measures and initiatives that have been initiated in other parts of the world to combat race and colour-based discrimination that would benefit persons with albinism in South Africa.
- 5 Involve media in human rights education and in countering hate speech. The media has an important role to play in countering hate speech and challenging myths and misconceptions.

