

CHAPTER 2

IMPACT OF CLIMATE CHANGE ON THE RIGHTS TO HEALTH AND LIFE OF PERSONS WITH ALBINISM: WHAT ARE SOUTH AFRICA'S OBLIGATIONS?

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Summary

Climate change significantly threatens the health and lives of people with albinism, affecting both their physical and mental well-being. Elevated ultraviolet radiation increases visual impairments and susceptibility to skin cancer, while climate-related disasters further limit access to healthcare. Despite these multifaceted challenges, states in their capacity as duty-bearers are obligated under human rights and climate change frameworks to not only uphold their climate change mitigation and adaptation duties but also their duty to respect, protect, promote, and fulfil the individual's rights. These obligations as the article submits are related – with the climate change obligations influencing the human rights ones. Heeding the clarion call that 'no one is left behind', South Africa has established legal mechanisms to mitigate the impacts of climate change on the rights of persons with albinism, ensuring that they adapt to climate change by undertaking practical measures, such as the provision of protection packages. However, the state's efforts fall short of achieving full disability inclusivity for persons with albinism in climate related decision-making processes, leading to their marginalisation.

1 Introduction

The link between human rights and climate change gained prominence in the mid-2000s, becoming the focal point of discussion amongst scholars¹

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1 J Knox 'Human rights principles and climate change' in P Cinnamon and others (eds) *International climate change law* (2016) 213. See also P Cullet 'Human rights and climate change: Broadening the right to environment' in P Cinnamon and others (eds) *International climate change law* (2016) 495.

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and the international community. In 2008, the United Nations Human Rights Council (HRC) requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) and others to conduct a study on this relationship.² Subsequently, several resolutions have been adopted in this regard. Perhaps the most significant resolution for the purposes of this article is the HRC resolution adopted in 2011 which emphasised the impacts of climate change on the enjoyment of human rights.³ The HRC accurately observed that although the impacts of climate change are felt by all beings collectively, vulnerable groups are severely affected.⁴ Nevertheless, the HRC recognised that states' involvement in the climate change crisis reduces the adverse effects of climate change on the enjoyment of rights. Thus, it affirmed that human rights obligations, standards, and principles could inform and improve international policymaking around climate change.

This article addresses two aspects: while the interference of climate change with human rights is acknowledged, debates arise regarding the nature of states' human rights obligations concerning climate change. Atapattu examines how the human rights obligations of states pan out in relation to mitigation and adaptation measures as states decide how to implement their Nationally Determined Contributions (NDC) under the Paris Agreement.⁵ Knox observed various state obligations such as assessing the environmental impacts of proposed projects within their jurisdiction, disseminating information, and ensuring remedies for environmental interferences with human rights enjoyment.⁶ What distinguishes the present article is that it focuses on a specific rights bearer. Limited legal research has been conducted on the impacts of climate change on persons with disabilities let alone persons with albinism.

This article addresses the following question: what are South Africa's obligations under international, or regional human rights law regarding climate change impacts on persons with albinism? The article demonstrates that the international instruments applicable to the discourse seem to implicitly outline these obligations. However, how has the South African government fared in fulfilling these obligations?

To address these issues, the article adopts a human rights based approach, a conceptual framework intended for mainstreaming human rights norms, standards, and principles into legislation, policies, and

2 Human Rights Council, Resolution 7/23: Human rights and climate change, 28 March 2008, UN Doc A/HRC/RES/7/23 (2008).

3 Human Rights Council, Resolution 18/22: Human rights and climate change, 17 October 2011, UN Doc A/HRC/RES/18/22 (2011) 2.

4 As above.

5 S Atapattu 'The right to a healthy environment and climate change mismatch or harmony' in J Knox & R Pejan (eds) *The human right to a healthy environment* (2018) 253.

6 Knox (n 1) 220-232.

planning to ensure that peoples' interests are always protected.⁷ Since the call made by the UN Secretary-General to the UN entities during the launch of the UN Programme for Reform in 1997 to mainstream human rights norms into their respective mandates and activities,⁸ various agencies began to integrate human rights principles within their operations.

Choosing the human rights based approach also seems befitting due to its unproblematic legal basis. Thus, most parties to the core human rights treaties including South Africa are also parties to the international climate change regime. As such these countries have obligations under international law to respect human rights and to address climate change. The human rights based approach provides a holistic framework through which parties can meet their obligations under both regimes. The framework allows states to respect, protect, and fulfil human rights while meeting their climate change obligations. It does not seek to impose new obligations other than those which parties have already agreed to under international human rights law.

This article's primary focus is on the obligations of states, in particular South Africa's in relation to the impacts of climate change on persons with albinism. The article consists of three sections. The first section is the introduction. Section two lays the groundwork by analysing the effects of climate change on persons with albinism and examining the fundamental concepts of climate change, albinism, and the link between the two. It also examines fundamental rights of people with albinism that are impacted by climate change. Section three discusses South Africa's general and procedural obligations as derived from treaties directly applicable to this discussion. Additionally, it assesses the government's efforts to fulfil its international and regional obligations before concluding.

2 Effects of climate change on albinism

Climate change presents unique challenges for individuals with albinism, and this section explores the connection between these two issues, emphasising how people with albinism, who are recognised as having disabilities, are disproportionately affected by climate change. It begins by

7 See UN Sustainable Development Group 'The human rights based approach to development cooperation towards a common understanding among UN agencies' (2003) https://unsdg.un.org/sites/default/files/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf (accessed 18 October 2023). See further UN Sustainable Development '2030 Agenda: Universal values – Principle one: human rights-based approach' <https://unsdg.un.org/2030-agenda/universal-values/human-rights-based-approach> (accessed 18 October 2023)

8 Report of the Secretary General, *Renewing the United Nations: A program for reform*, 14 July 1997, UN Doc A/51/950 (1997) para 274. D Olawuyi *The human rights-based approach to carbon finance* (2016) 145.

defining climate change and examining the social framing of albinism as a disability to ensure that individuals with albinism receive equal protection as those with disabilities in the face of climate change. The discussion then transitions to the broader relationship between climate change and human rights, followed by a more detailed analysis of how climate-related challenges impact the rights to health and life of people with albinism.

2.1 Climate change

The United Nations Framework Convention on Climate Change (UNFCCC) and the South African Climate Change Act (CCA) define climate change as a

change in climate which is attributed directly or indirectly to human activity that alters the composition of the global atmosphere and which is in addition to natural climate variability observed over comparable time periods.⁹

In essence, it refers to long-term shifts in global temperatures and weather patterns, which can result from natural climate variations or, as the UNFCCC and the CCA accurately highlighted, from human-induced activities. Since the first industrial revolution, human activities, particularly the destruction of rainforests and the burning of fossil fuels such as coal, oil, and natural gas, have been the primary contributors to climate change. These fossil fuels generate greenhouse gas emissions which form a blanket around the Earth, trapping the sun's heat, and raising temperatures.¹⁰ According to the Intergovernmental Panel on Climate Change (IPCC) AR6 2023 synthesis report, global surface temperatures have increased by 1.1°C above 1850-1900 in 2011-2020.¹¹ This rise affects global weather and climate, resulting in widespread adverse climate change impacts on nature and people. Global assessments indicate that these adverse impacts have a range of implications for the full enjoyment of human rights with vulnerable groups, including persons with disabilities experiencing the impacts most acutely.

9 Art 1 of the United Nations General Assembly, United Nations Framework Convention on Climate Change, 9 May 1992 / 1771 United Nations Treaty Series (UNTS) 107. See also Chapter 1 of the South African Climate Change Act 22 of 2024.

10 UN Climate Action 'Causes and effects of climate change' <https://www.un.org/en/climatechange/science/causes-effects-climate-change> (accessed on 17 September 2024).

11 See IPCC 'Climate change: 2023 Synthesis report' (2023) 42 https://www.ipcc.ch/report/ar6/syr/downloads/report/IPCC_AR6_SYR_LongerReport.pdf (accessed 27 October 2023).

2.2 Albinism as a disability

Albinism is a rare, genetic condition affecting melanin synthesis, causing skin, hair, and eye colour loss due to a deficiency in melanin.¹² There are different types of albinism: ocular and oculocutaneous. The latter manifests when there is reduced melanin synthesis in the melanocytes of the hair, skin, and eyes, while ocular albinism involves hypopigmentation primarily involving the retinal pigment epithelium of the eyes.¹³ In Africa, statistics on albinism prevalence vary widely, with an estimated occurrence of one in 5 000-15 000 people, and selected populations having estimates as high as one in 1 000.¹⁴ In South Africa, specifically in Soweto, one in 3 900 out of a size sample of 803 511 has albinism.¹⁵

Determining who qualifies as a disabled person can be challenging because the notion of disability is an evolving concept with unclear and flexible boundaries.¹⁶ However, with regards to albinism there is a consensus that it qualifies as a disability. According to the Convention on the Rights of Persons with Disability (CRPD) and the Protocol to the African Charter on Human and Peoples' Rights of Persons with Disabilities (African Disability Protocol),¹⁷ disability encompasses various impairments. Individuals with long-term physical, mental, intellectual, neurological or sensory impairments are considered persons with disability.¹⁸ These impairments hinder them from participating in society fully and effectively on an equal basis with others.¹⁹

Internationally and regionally the CRPD and the African Disability Protocol are the most significant instruments relating to disability, with the

12 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond: Climate change and persons with albinism, 13 July 2023, UN Doc A/ 78/167 (2023) para 14. Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism: Report of the Independent Expert on the enjoyment of human rights by persons with albinism, 14 July 2017, UN Doc A/72/131 (2017) para 2.

13 RA King & WS Oetting 'Oculocutaneous albinism' in J Nordlund and others (eds) *The pigmentary system: Physiology and pathophysiology* 2nd ed (2006) 600.

14 Report of the Office of the United Nations High Commissioner for Human Rights: Persons with albinism, 12 September 2013, A/HRC/24/57 (2013) para 14.

15 JGT Kromberg & R Kerr 'Oculocutaneous albinism in Southern Africa: Historical background, genetic, clinical and psychosocial issues' (2022) 11 *African Journal of Disability* 3.

16 Preamble (e) of the United Nations General Assembly, Convention on the Right of Persons with Disabilities: Resolution/adopted by the General Assembly, 24 January 2007, UN Doc A/RES/61/106/ (2007) (CRPD).

17 AU, Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018) (African Disability Protocol) https://au.int/sites/default/files/treaties/36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf (accessed 27 October 2023). It is important to take note that during the process of writing this article the African Disability Protocol entered into force on 3 May 2024, following the receipt of the 15th instrument of ratification, in accordance with art 38 of the Protocol.

18 Art 1 of the CRPD. See also Art 1 of the African Disability Protocol.

19 As above.

purpose of protecting the fundamental rights and dignity of persons with disability. Although the CRPD does not specifically mention albinism, its broad definition of disability encompasses it. Additionally, the Preamble of the African Disability Protocol explicitly affirms that individuals with albinism fall within the category of persons with disabilities.²⁰ Furthermore, a report on the human rights enjoyment of persons with albinism notes that persons with albinism are a constituent of persons with disabilities.²¹ Having said that several other scholars such as Mswela, Astel, and Franklin and others also agree that persons with albinism are indeed disabled.²² However, access to the protection of their rights offered by the international and regional disability instruments is often granted to them based solely on their visual impairments.²³ While this observation holds, I submit that skin physiology should also be taken into account when defining disability.²⁴

2.3 The relationship between climate change and persons with albinism

What effect does climate change have on the enjoyment of human rights by persons with albinism? Answering this question requires stepping back to unveil the layers within climate change and human rights discourse. In my view, it is necessary to engage in a three-stage process, namely: a brief general examination of the connection between climate change and human rights; an analysis of the link between climate change and disability; and a more focused approach when examining the nexus between climate change and albinism.

2.3.1 *The intersection between climate change and human rights*

The application of human rights to climate change is still in its early developmental stages, however, the connection between climate change and human rights is undeniable. Knox for instance, examined whether the effects of climate change interfered with the full enjoyment of human rights recognised in international law.²⁵ Drawing from the livelihood of the Inuit

20 Para 18 of the Preamble to the African Disability Protocol.

21 Report of the Independent Expert on albinism (n 12) para 8.

22 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 the US non-discrimination laws' (2018) 21 *Potchefstroom Electronical Law Journal* 1. B Astle and others 'Global impact of climate change on persons with albinism: A human rights issue' (2023) 9 *The Journal of Climate Change and Health* 100190 at 2. A Franklin and others 'Children with albinism in African Regions: Their rights to "being" and "doing"' (2018) 18 *BMC International Health and Human Rights* 2. See also Kromberg & Kerr (n 15) 1.

23 Report of the Independent Expert on albinism (n 12) para 8.

24 To corroborate this view, see the Report of the Independent Expert on albinism (n 12) para 14.

25 Knox (n 1) 215-220.

Indigenous peoples living in the Arctic region (classified as a vulnerable community) he observed that rising temperatures in the Arctic due to climate change infringed on the Inuit's human rights such as life, property, and health.²⁶ Cullet, on the other hand examined the extent to which the climate change regime has addressed the human rights dimension of climate change.²⁷ He explored the human right to a clean, healthy and sustainable environment as an underlying conceptual framework for considering the link between human rights and climate change, acknowledging climate change as part of the corpus of international environmental law. Cullet observed that despite the obvious intersection between the two regimes, the foundational framework of the climate change regime (the 1992 UNFCCC and 1997 Kyoto Protocol) refrained from addressing human rights directly.²⁸

In 2007, the Male Declaration on the Human Dimension of Global Climate Change marked the first occasion climate change was linked to human rights. In the declaration, representatives of the small island states recognised climate change as a threat multiplier, posing harm to the environment, individuals, and global communities. The declaration observed that 'climate change has clear and immediate implications for the full enjoyment of human rights'.²⁹ To corroborate this observation, the HRC has since adopted several resolutions highlighting the link between climate change and human rights.³⁰ A common feature in these resolutions is the Council's observation that the adverse effects of climate change have a range of implications for the enjoyment of a wide range of human rights such as the right to life, food, water, and adequate housing. The Council also noted that the effects of climate change are felt most acutely by vulnerable groups such as children, Indigenous peoples, elderly people, women, and persons with disability. Importantly, the council

26 Knox (n 1) 220.

27 Cullet (n 1) 496-501.

28 See the Kyoto Protocol to the United Nations Framework Convention of Climate Change 2303 UNTS 148 (Kyoto Protocol). Cullet (n 1) 499.

29 'Male' Declaration on the Human Dimension of Global Climate Change: Adopted 14 November 2007' (2007) 2 https://www.ciel.org/Publications/Male_Declaration_Nov07.pdf (accessed 28 October 2023).

30 Report of the Human Rights Council on its Seventh Special Session: Vice-President and Rapporteur: Mr Alejandro Artucio (Uruguay): Resolution adopted by the council at its seventh special session, 17 July 2008, UN Doc A/HRC/S-7/2 (2008) on the negative impacts of the worsening of the world food crisis on the realisation of the right to food for all; See also Human Rights Council, Resolution 10/4: Human rights and climate change, 25 March 2009, UN Doc A/HRC/Res/10/4 (2009); Human Rights Council, Resolution 18/22: Human rights and climate change, 17 October 2011, UN Doc A/HRC/Res/18/22 (2011); Human Rights Council, Resolution 26/27: Human rights and climate change, 15 July 2014, UN Doc A/HRC/Res/26/27 (2014); and Human Rights Council, Resolution 29/15: Human rights and climate change, 22 July 2015, UN Doc A/HRC/Res 29/15 (2015).

stressed states' obligations to protect human rights from the harmful effects of climate change,³¹ a matter addressed in section three.

Over the years, OHCHR has organised annual HRC panel discussions on climate change, covering diverse subjects such as climate change and the rights of the child;³² climate change and migration;³³ climate change and the right to health;³⁴ and the impacts of climate change on the rights of persons with disabilities³⁵ which is the focus of this article.

2.3.2 Climate change and disability

Climate change has widespread impacts on human rights. However, for an estimated one billion people globally living with some form of disability, nearly 200 million of whom face significant challenges in daily functioning,³⁶ adverse effects of climate change are experienced differently and more severely. Consequently, the HRC requested the OHCHR to prepare 'an analytical study on the promotion and the protection of the rights of persons with disabilities in the context of climate change'³⁷ to better understand their plight. The study observed that sudden-onset natural disasters and slow-onset events seriously affect persons with disability's access to food, safe drinking water, sanitation, healthcare services, education, adequate housing, and access to decent work.³⁸

31 See Human Rights Council, Report of the Office of the United Nations High Commissioner for Human Rights on the relationship between climate change and human rights, 15 January 2009, UN Doc A/HRC/10/61 (2009).

32 See Human Rights Council, Analytical study on the relationship between climate change and the full and effective enjoyment of the rights of the child – Report of the Office of the United Nations High Commissioner for Human Rights, 4 May 2017, UN Doc A/HRC/35/13 (2017).

33 See Human Rights Council, Annual report of the United Nations High Commissioner for Human Rights and reports of the Office of the High Commissioner and the Secretary-General: The Slow onset effects of climate change and human rights protection for cross-border migrants, UN Doc A/HRC/37.CRP.4 (2018); See also Human Rights Council, Addressing human rights protection gaps in the context of migration and displacement of persons across international borders resulting from the adverse effects of climate change and supporting the adaptation and mitigation plans of developing countries to bridge the protection gaps - Report of the United Nations High Commissioner for Human Rights, 23 April 2018, UN Doc A/HRC/38/21(2018).

34 See Human Rights Council, Report of the Office of the United Nations High Commissioner for Human Rights: Analytical study on the relationship between climate change and the human right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 6 May 2016, UN Doc A/HRC/32/23 (2016).

35 See Human Rights Council, Analytical study on the promotion and protection of the rights of persons with disabilities in the context of climate change: Report of the Office of the United Nations High Commissioner for Human Rights, 22 April 2020, UN Doc A/HRC/44/30 (2020).

36 World Health Organisation (WHO) and the World Bank *World Report on Disability* (2011) xi.

37 See the request in Human Rights Council, Resolution 41/21: Human rights and climate change, 23 July 2019, UN Doc A/HRC/Res/41/21 (2019) para 10.

38 Analytical study on the promotion and protection of the rights of persons with disabilities in the context of climate change (n 35) paras 8-23.

Furthermore, persons with disabilities were identified amongst the most adversely affected in emergencies, sustaining disproportionately higher rates of morbidity and mortality, while being among those least able to access emergency support.³⁹

2.3.3 *Climate change and albinism*

One impact of climate change on persons with albinism's health is increased global temperatures. According to the IPCC climate change synthesis report of March 2023⁴⁰ in all regions weather and climate extremes have become more widespread and pronounced. Projected increases in average seasonal temperature and the frequency and intensity of heatwaves contribute to heat-related illness.⁴¹ Heatwaves increase the incidents of respiratory, cardiovascular diseases, and clinical heatstroke. Furthermore, during a heatwave, the levels of ultraviolet (UV) radiation also increase,⁴² and this is detrimental to persons with albinism. It has been observed that as average global temperatures rise, so do human mortality and morbidity,⁴³ and persons with albinism bear the brunt of deadly heatwaves fuelled by climate change.

2.3.4 *The right to health and life of persons with albinism*

Climate change poses a great threat to a wide variety of rights. These include the indivisible and interdependent rights to health, food, water, housing, and life. The interdependent nature of these rights is especially visible in the context of the rights to health and life. The enjoyment of the right to life is contingent upon good health. The right to life is supreme, with no derogation permitted even in situations of environmental degradation due to climate change.⁴⁴ Equally, the right to health is a fundamental human right and everyone is 'entitled to the enjoyment of the

39 See Analytical study on the promotion and protection of the rights of persons with disabilities in the context of climate change (n 35) paras 10-12.

40 IPCC 'Climate change 2023: Synthesis Report – Summary for Policymakers' https://www.ipcc.ch/report/ar6/syr/downloads/report/IPCC_AR6_SYR_SPM.pdf (accessed 29 October 2023).

41 See WHO 'Fact sheet on heat and health' (28 May 2024) <https://www.who.int/news-room/fact-sheets/detail/climate-change-heat-and-health> (accessed 15 November 2023).

42 JC Van der Leun and others 'Climate change and human skin cancer' (2008) 7 *Photochemical & Photobiological Sciences* 730. They observed that UV radiation could increase by 2% for every degree Celsius of temperature rise.

43 Human Rights Council, Report by the special rapporteur on the issue of human rights obligations relating to the enjoyment of a safe, clean, healthy environment and sustainable environment, 1 February 2016, UN Doc A/HRC/31/52 (2016) para 24.

44 United Nations Human Rights Committee, General Comment 36: Art 6: Right to life, 3 September 2019, UN Doc CCPR/C/GC/35 (2019) paras 2, 26 and 62.

highest attainable standard of health conducive for living a life in dignity'.⁴⁵

The right to life is inherent to every individual and is protected by several human rights instruments.⁴⁶ Concerning disabled persons, article 10 of the CRPD reaffirms the inherent nature of the right to life and states' duty to ensure its effective enjoyment by persons with disability on an equal basis with others. Analogously, article 8 of the African Disability Protocol provides for the right to life and elaborates in article 8(2)(b) that persons with disability must be guaranteed access to services, facilities, and devices enabling them to realise their right to life and live in a dignified manner. In view of this article, it can be interpreted that the services that are referred to include healthcare services. This leads us to the interconnected right to health.

Like the right to life, the right to health is recognised in several international instruments.⁴⁷ Nevertheless, the Preamble of the CRPD recognises the importance of the right to health in enabling persons with disabilities to fully enjoy rights and fundamental freedoms. Additionally, article 17(1) of the African Disability Protocol affirms that '[e]very person with a disability has the right to the highest attainable standard of health'.⁴⁸ The Constitution of the World Health Organisation (WHO) conceptualises health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.⁴⁹ The reference in article 17(1) to 'the right to the highest attainable standard of health' in the African Disability Protocol is not confined to the right to healthcare. The right to health, as well as the right to life, embrace a wide range of socio-economic and environmental factors that promote the realisation of the rights.

Thus, both rights are dependent upon the availability of safe drinking water, food, quality healthcare, and a healthy environment amongst other things.⁵⁰ A healthy environment is *inter alia* non-toxic, free of pollutants,

45 United Nations Committee on Economic Social and Cultural Rights, General Comment 14. Art 12: Right to the highest attainable standard of health, 11 August 2000, UN Doc e/c.12/2000/4 (2000) para 1.

46 Art 6 of the International Covenant on Civil and Political Rights (ICCPR), United Nations Treaty Series, Vol 999, 171; art 6 of the Convention on the Rights of Children (CRC) United Nations, United Nations Treaty Series (UNTS), Vol 1577, 3; art 4 of the African Charter on Human and Peoples Rights (ACHPR), 27 June 1981, 1520, UNTS 217.

47 Art 25(1) of the 1948 Universal Declaration of Human Rights (UDHR) GA Res 217A (III), UN Doc A/810 at 71; art 12(1) of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) 993 UNTS 3; art 12 of the 1979 Convention on the Elimination of All Forms of Racial Discrimination against Women 1249 UNTS 13; art 24 CRC (n 46) UNTS 3. On a regional level, we have art 16 ACHPR (n 46).

48 Art 17(1) of the African Disability Protocol.

49 See the 1946 Constitution of the World Health Organisation https://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf#page=6 (accessed 30 October 2023).

50 General Comment 36 (n 44) para 26. See also General Comment 14 (n 45) para 4.

and has a safe and stable climate.⁵¹ Climate change contributes to the increased frequency of extreme weather events such as rising sea water levels, droughts, floods, and heatwaves. These extremes impact the right holders' rights to health and subsequent life. All things considered, the UN Human Rights Committee observed that climate change constitutes one of the 'most pressing and serious threats to the ability of the present and future generations to enjoy the right to life'.⁵² Correspondingly, WHO observed that climate change has adverse impacts on the enjoyment of the highest attainable standards of mental and physical health.⁵³

Certain population groups are particularly vulnerable to the health effects of climate change due to physiological factors. Albinism, for instance, leads to a heightened susceptibility to skin cancer that is fatal if left untreated, and climate change further elevates this risk amongst persons with albinism. Their susceptibility to skin cancer is due to a lack of or inefficient protection against harsh UV rays or sun exposure because of low skin pigmentation. In Africa skin cancer is a significant cause of deaths for persons with albinism.⁵⁴ Ninety-eight (98) per cent of persons with albinism do not live beyond the age of 40 because of sun exposure, with skin cancer responsible for at least four-fifths of these deaths.⁵⁵ A sub-Saharan African study indicated that in addition to the skin cancer, persons with albinism may suffer sunburn and skin photoaging, which can lead to lentigines (small, flat, brown spots), freckles and heavy wrinkling of the skin.⁵⁶

Apart from increasing the risk of fatal skin cancer for most persons with albinism, climate change directly impacts their eye health. Visual impairment is another physiological consequence of albinism common to individuals who have ocular albinism. This impairment varies from mild to severe, with many persons with albinism considered legally blind.⁵⁷

51 Human Rights Council, Report of the special rapporteur on the issue of human rights obligations relating to the enjoyment of a safe, clean, healthy and sustainable environment, 30 December 2019, UN Doc A/ HRC/43/53 (2019) paras 38-112. See also the Information note by the United Nations Development Programme (UNDP), the United Nations Environment Programme (UNEP) and the OHCHR 'What is a right to a healthy environment' (2023) <https://www.undp.org/publications/what-right-healthy-environment> (accessed 16 January 2024).

52 General Comment 36 (n 44) para 62.

53 WHO 'Climate change and health' <https://www.who.int/news-room/fact-sheets/detail/climate-change-and-health> (accessed 10 November 2023).

54 Human Rights Council, visit to South Africa: Report of the independent expert on the enjoyment of human rights by persons with albinism, 9 January 2020, UN Doc A/ HRC/43/42/Add.1 (2020) para 11.

55 E Nakkazi 'People with albinism in Africa: contending with skin cancer' (2019) 394 *The Lancet* 553.

56 Y Caradee and others 'Oculocutaneous albinism in Sub-Saharan Africa: adverse sun-associated health effects and photoprotection' (2015) 91 *Photochemistry and Photobiology* 27.

57 Mswela (n 22) 24.

UV radiation has been linked to the increase of ocular tumours and cataracts,⁵⁸ along with increased risk of retinal detachment.⁵⁹ Clearly, exposure to extreme sunlight rays affects persons with albinism's eye health as they are more sensitive to bright light and experience a lot of discomfort from sunlight exposure.

Beyond the direct impacts on the eyes and skin, climate change can also overwhelmingly affect the mental health of persons with albinism⁶⁰ through direct impact on their physiological well-being. Those residing in the warmer geographical regions with less adaptive measures face higher risks of stress, anxiety, and depression during climate induced weather extremes such as heatwaves. Because climate change exacerbates their existing genetic defects and threatens their mortality, people with albinism are more conscious of their physiological conditions. They are more apprehensive about being outdoors and about being exposed to the sun for longer periods because this could be a life-threatening situation. Also, they may worry about procuring quality sunscreen and protective gear, which is expensive for many persons with albinism who live in poverty.⁶¹

As highlighted, climate change has direct adverse effects on the physiology and mental state of people with albinism. However, it is important to recognise its indirect effect on their access to essential resources. One of the key elements of the right to health is the right holders' entitlements and determinants to health.⁶² Thus the right contains entitlements such as access to essential medicine,⁶³ and the determinants include adequate housing amongst other things. In the event of a climate change disaster, for example, flooding, landslides, and wildfires, persons with albinism may struggle due to disrupted healthcare access. During extreme weather events, accessing sunscreen, protective wear, visual aids, and essential medicines or treatment becomes challenging. Additionally, lack of proper shelter and infrastructure, and disruption to transport

58 L Echevarria-Lucas and others 'Impacts of climate change on eyes disease and associated economical cost' (2021) 18 *International Journal of Environmental Research and Public Health* 2. AP Cullen 'Ozone depletion and solar ultraviolet radiation: Ocular effects – A United Nations Environment Programme perspective' (2011) 37 *Eye Contact Lens Science and Clinical Practice* 185.

59 N Auger and others 'Climate and the eye: Case-crossover analysis of retinal detachment after exposure to ambient heat' (2017) 157 *Environmental Research* 103.

60 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond (n 12) paras 34 and 39. See also, Report of the Office of the United Nations High Commissioner for Human Rights (n 34) para 21.

61 See Report of the Office of the United Nations High Commissioner for Human Rights (n 35) para 6. See also I Ero and others 'People with albinism worldwide: A human rights perspective' (2021) 2 https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf (accessed 18 January 2024). Ero observed that although people with albinism represent a relatively small segment of people globally, they are disproportionately affected by poverty, particularly in least developing countries.

62 See WHO 'The right to health: Factsheet 31' <https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf> (accessed 11 November 2023)

63 As above.

networks means persons with albinism may spend significantly more time exposed to the sun, thus increasing their risk of skin cancer. To corroborate this view during Muluka-Anne Miti-Drummond's mandate as the independent expert on the enjoyment of human rights by persons with albinism she received reports that the care packages for those affected by tropical Cyclone Freddy (in Madagascar, Malawi, Mozambique, South Africa, and Zimbabwe) lacked sun protection products. In Mozambique, an organisation working on issues concerning persons with albinism visiting resettlement centres for the victims of Cyclones Eloise and Idai identified cases where children and adolescents with albinism were 'housed in humanitarian tents that were not appropriate for their condition owing to the heat accumulating inside, causing discomfort and skin damage'.⁶⁴

3 The legal normative framework establishing state obligations under the disability and climate change discourse

An important premise of this article is that climate change interferes with the enjoyment of persons with albinism's rights to health along with life and this triggers numerous obligations. These obligations are primarily imposed on states, and other duty bearers such as businesses, to promote, protect, respect, and fulfil as would be appropriate, human rights, including those of persons with albinism, when taking action to address the adverse effects of climate change.⁶⁵ Additionally, states are obligated to ensure that persons with albinism receive information on climate change and its effects and participate in climate change policy making.

3.1 State's general obligations

When a state becomes a party to a treaty, it assumes various obligations under international law. Within the context of this article, there is a combination of state obligations: (a) those emanating from international climate change laws (obligation to mitigate and adapt to climate change);⁶⁶ and (b) those under international human rights law, but also applicable in climate change law (respect, protect, promote, and fulfil). I submit that obligations from the former influence those of the latter. For example, there is an overarching obligation requiring states as primary duty bearers to actively prevent and curb the increase in global

64 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond (n 12) para 29.

65 HRC, Resolution 41/21: Human rights and climate change adopted on 12 July 2019, 23 July 2019, UN Doc A/HRC/Res/41/21 (2019) Preamble.

66 The obligation to mitigate and adapt to climate change is in line with the 2015 United Nations Sustainable Development Goal (SDG) 13.

temperatures (by avoiding and reducing greenhouse gas emissions) to minimise the human rights impacts of climate change. In so doing, it respects individuals' rights thereby upholding its human rights obligations. Also, states have a positive obligation under climate change laws to take adaptive measures. Climate change adaptation involves acclimatising to the impacts of climate change. This could encompass building climate change resilient housing and protecting people from extreme heat amongst other things. While upholding its adaptation obligations, the state simultaneously satisfies its obligation to fulfil.⁶⁷ Although the obligations to mitigate and adapt to climate change arise from climate change laws, this article demonstrates how they intersect with states' general obligations under human rights law concerning persons with albinism impacted by climate change. Under the international human rights regime, several instruments, including the international Bill of Rights enjoin states to uphold their respective human rights obligations.⁶⁸ However, a discussion of these conventions falls outside the remit of this research.

Under the CRPD and African Disability Protocol, article 4 of the instruments in their respective capacity outline the states' general obligations. It stipulates that within their policy, legislative, administrative, and institutional endeavours state parties are to undertake the duty of ensuring, respecting, promoting, and fulfilling the rights of persons with disability including persons with albinism.⁶⁹ This entails that South Africa which ratified the CRPD⁷⁰ and signed the African Disability Protocol has a combination of positive and negative duties.

Regarding climate change instruments, it is notable that like the legal framework protecting the rights of persons with albinism, no mention is made of the link between climate change and persons with albinism in the primary legal framework governing climate change matters. Thus, the UNFCCC and its Kyoto Protocol do not refer to the adverse effects of climate change on the enjoyment of human rights. This could be because, for a long time, the fields of human rights and environmental law developed in parallel. The first direct reference to human rights in the context of the UNFCCC was made in a decision adopted by the Conference of the Parties in 2010.⁷¹ The parties referred to HRC Resolution 10/4, which recognised the link between human rights and climate change, and reiterated the importance of states ensuring respect for human rights in their climate actions.⁷² The Preamble to the Paris

67 For more detail on this topic refer to the discussion in sec 3.1.4 below.

68 See the Preamble of the UDHR and ICESCR (n 47) and the Preamble of the ICCPR (n 46) which recognises the obligation of states to respect human rights and freedoms.

69 Art 4 of the CRPD; art 4 of the African Disability Protocol.

70 South Africa ratified the CRPD on the 30 November 2007. For ratification status see https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD (accessed 15 November 2023).

71 Report of the Conference of the Parties at its 16th session, held in Cancun from 29 November to 10 December 2010, UN Doc FCCC/ CP/2010/7/Add. 1 (2010).

72 Preamble to Report of the Conference of Parties (n 71).

Agreement to the UNFCCC developed upon this notion calling on states, when taking action to address climate change, to ‘respect, promote and consider their respective obligations on human rights, the right to health, the rights of ... persons with disabilities and people in vulnerable situations’.⁷³ The Paris Agreement is the first climate agreement, and one of the first environmental agreements of any kind, to explicitly recognise the relevance of human rights, recognising that climate change poses unacceptable threats to the full enjoyment of persons with disabilities rights and that actions to address climate change must comply with human rights obligations.

While international legal frameworks governing human rights and climate change establish obligations that states are bound to uphold, the specific articulation of these obligations lacks clarity. However, the African Commission on Human and Peoples’ Rights in the *Social and Economic Rights Action Centre (SERAC) and the Centre for Economic and Social Rights (CESR) v Nigeria* case⁷⁴ took an occasion to examine various state obligations. Although the case was decided outside the framework of disability rights or climate change issues, it recognised that all social, economic, civil, and political rights generate at least four distinct levels of responsibility for a state that undertakes to adhere to a human rights regime, namely the duties to respect, protect, promote, and fulfil.⁷⁵ Furthermore, the case provided clarity on the specific responsibilities associated with each obligation. In this regard, this article expounds, and augments each obligation, while considering the impacts of climate change on persons with albinism.

3.1.1 *Obligation to mitigate climate change and respect human rights*

South Africa is among the world’s largest greenhouse gas emission emitters. Its emissions mainly stem from heavy reliance on coal for electricity generation, potentially indicating a failure in its mitigation duties. On the one hand, the obligation to mitigate entails the avoidance and reduction of heat trapping greenhouse gas emissions in the atmosphere to prevent the planet from warming to more extreme temperatures. Article 3 of the UNFCCC notes that states ‘should take precautionary measures to ... minimise the cause of climate change and mitigate its adverse effects’. On the other hand, the obligation to respect fundamental rights dictates that states must refrain from interfering with or limiting the enjoyment of rights.⁷⁶ While these obligations appear unrelated, I submit that states

73 Paris Agreement to the United Nations Framework Convention on Climate Change, 12 December 2015, Treaties and Other International Acts Series (TIAS) No 16-1104.

74 *Social and Economic Rights Action Centre (SERAC) v Nigeria* (2001) AHRLR 60 (*SERAC* case).

75 *SERAC* case (n 74) para 44.

76 *SERAC* case (n 74) para 45.

obligation to mitigate climate change has a bearing on the obligation to respect human rights.

Under international law a state may violate a right through its acts, or omissions.⁷⁷ In the context of climate change, a state's action or inaction can therefore violate human rights. When addressing climate change, a state simultaneously executes its human rights obligation to respect. Conversely, when a state fails to reduce its greenhouse gas emissions it will interfere with and therefore will not respect individuals' rights. To successfully tackle climate change, South Africa must refrain from interfering in the enjoyment of persons with albinism's rights by avoiding activities contributing to climate change. Mitigating climate change may involve inter alia decreasing its reliance on fossil fuels and transitioning to renewable energy sources. While the State's mitigation duties are directed at enhancing its commitment to reducing climate change, its obligation to respect human rights is centred toward bearers of right.

Regarding an omission, article 4(1)(b) of the UNFCCC notes that:

All parties, taking into account their common but differentiated responsibilities ... shall formulate, implement ... national programmes containing measures to mitigate climate change by addressing anthropogenic emissions.

In this regard, South Africa will be deemed to be in breach of its climate change obligations if it fails to implement legislative measures aimed at achieving its nationally determined contributions.⁷⁸

Mitigating climate change is not only an environmental responsibility, but also a human rights obligation. The obligation to mitigate and respect are interrelated, addressing climate change is essential for respecting and protecting human rights.

3.1.2 Obligation to protect

The obligation to protect requires states to safeguard individuals and groups from human rights abuses. In the CRPD and the African Disability Protocol, under articles 11 and 12(a) respectively, states are obliged to protect persons with disabilities, including those with albinism, in situations of risk and humanitarian emergencies. These situations according to the CRPD and African Disability Protocol include 'armed conflict, forced displacements, humanitarian emergencies and natural

77 See Art 2 of the International Law Commission Draft Articles on Responsibility of States for Internationally Wrongful Acts, with Commentaries (2001) II Yearbook of International Law Commission (ILC DARSIIWA).

78 Art 4(2) of the Paris Agreement.

disasters'.⁷⁹ Since climate change is deemed a humanitarian crisis, its impact can be classified as a humanitarian emergency or natural disaster. The *SERAC* case aptly noted that the obligation to protect 'requires the state to take measures to protect beneficiaries of the protected rights against political, economic, social, [and to add on the list environmental] interferences'.⁸⁰ Thus, for example, in the case of an extreme heatwave the government must take all necessary measures to ensure the protection and safety of persons with albinism in situations of risk to life and health. Articles 11 and 12(a) provide a HRBA entry point to humanitarian responses and ultimately ensure that climate change programmes and policies, as well as prevention, planning, and responses, are fully inclusive of persons with albinism.⁸¹

The obligation to protect also means that states have a responsibility to protect persons with albinism rights from third parties, like private businesses. In this regard, states must take measures to protect persons with albinism against harmful environmental interferences detrimental to their well-being. This entails the creation and maintenance of an atmosphere or framework by an effective interplay of laws and regulations so that persons with albinism can freely realise their rights. To this end, South Africa must therefore regulate the activities of private businesses emitting greenhouse gas emissions. In a joint statement with four other treaty monitoring bodies, the CRPD committee stressed states' obligations to regulate private actors and hold them accountable for climate harm occurring domestically and extra-territorially. It warned that 'failure to ... regulate activities contributing to such harm, could constitute a violation of states' human rights obligations'.⁸²

3.1.3 *Obligation to promote*

Articles 1 and 4 of the CRPD, and Preamble, and article 4 of the African Disability Protocol, collectively note that state parties are to promote the rights of all individuals, which includes persons with albinism, to enable them to fully enjoy their human rights and fundamental freedoms. In the *SERAC* case the court opined that to promote the enjoyment of all human rights

79 Art 11 of the CRPD; art 12 of the African Disability Protocol.

80 *SERAC* case, para 46.

81 Fulfilling art 4(b) of the African Disability Protocol which obligates states to mainstream disability into policies, legislation, development plans and programmes and activities and in all other spheres of life.

82 United Nations Human Rights Commission for Human Rights, joint statement on 'Human rights and climate change' by the Committee on the Elimination of Discrimination against Women, Committee on Economic, Social and Cultural Rights, Committee on the Rights of Children, Committee on the Protection of the Rights of All Migrant Workers and Members of their Families of (September 2019) in States' Human Rights Obligations in the Context of Climate Change 2020 update 6 https://www.ciel.org/wp-content/uploads/2020/03/States-Human-Rights-Obligations-in-the-Context-of-Climate-Change_2020-Update.pdf (accessed 27 January 2024).

[s]tates should make sure that individuals are able to exercise their rights and freedoms, for example, by promoting tolerance, raising awareness, and even building infrastructures [which can include legal infrastructure].⁸³

The idea of raising awareness regarding persons with albinism at various levels of society is widely canvassed in the CRPD. Article 8(1) of the CRPD stipulates that state parties assume the responsibility to

adopt immediate, effective and appropriate measures: (a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities.

Recently it was reported that there is a lack of awareness among persons with albinism about their physiological state, how climate change exacerbates their health condition and how to protect themselves against UV radiation.⁸⁴ Furthermore, other key stakeholders such as health practitioners lack awareness about the health needs of persons with albinism, especially concerning their skin condition.⁸⁵ There are records capturing cases where persons with albinism with skin cancer have been misdiagnosed and discharged based on the belief that their skin condition was a normal part of their condition.⁸⁶ To this end, the government is duty bound and recommended to promote the training of health professionals and staff working with persons with disabilities to protect the rights recognised in the present Conventions so as to better provide the assistance and services guaranteed by those rights.⁸⁷

3.1.4 Obligation to adapt to climate change and fulfil human rights

States often find themselves in a realm of greatly enhanced environmental uncertainty with extreme unpredictable weather patterns. As climate change impacts continue to emerge, states must respond either by mitigating⁸⁸ or adapting. Climate change adaptation involves acclimatising, and as noted by Voight, it can either be anticipatory or responsive.⁸⁹ Anticipatory action involves implementing measures before the occurrence of an extreme event, such as constructing climate-resilient structures. This includes building shelters friendly to persons with albinism, featuring thermal insulation on the walls and roof, as well as

83 *SERAC* case (n 74) para 46.

84 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond (n 12) para 28

85 As above. See also Astle (n 22).

86 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond (n 12) para 28.

87 Report of the independent expert on the enjoyment of human rights by persons with albinism (n 54) para 112.

88 For more detail on this topic, refer to discussion in sec 3.1.1 above.

89 C Voight 'Climate change and damages' in P Cinnamon and others (eds) *The Oxford handbook of international climate change law* (2016) 476.

ultraviolet-protective window film. Voight also notes that responsive action ‘requires the capacity to react once the extreme event takes place’.⁹⁰ However, I submit that responsive adaptation need not be taken as a responsive strategy to a singular catastrophic event, it may be action taken in response to conditions that have already changed, namely a climate crisis, considering the specific needs of persons with albinism.

Recognising that adaptation can significantly reduce vulnerabilities to the impacts of climate change, parties to the UNFCCC in article 4(1)(b) committed to implementing national programmes containing measures to facilitate adequate adaptation to climate change. Additionally, in article 7 of the Paris Agreement, parties established global goals on adaptation. In terms of article 7(5) parties recognised that ‘adaptation action should follow a ... participatory and fully transparent approach, taking into consideration vulnerable groups’. This means that states that ratified the agreement such as South Africa,⁹¹ are obliged to ensure that appropriate adaptation measures are established to reduce human vulnerability to climate change especially those greatly affected by its negative impacts such as persons with albinism.⁹² When a state executes its national adaptation measures in an anticipatory or responsive manner, it subsequently meets its obligation to fulfil persons with albinism’s rights and freedoms under the disability and climate change instruments. Like the obligation to adapt, the obligation to fulfil creates a positive obligation on the part of the state to move its machinery towards the actual realisation of the rights.⁹³ As noted above, this could include the direct provision of basic needs such as shelters designed for persons with albinism which incorporate high-quality insulation materials in the building to minimise heat transfer. Additionally, the state must increase the availability of affordable and quality healthcare for persons with albinism, providing sunscreen with a high sun protection factor (SPF), and protective clothing such as long trousers, long-sleeved tops, and hats made from dense ultraviolet-resistant material.⁹⁴ All these essentials, which I term a ‘persons with albinism protection package’ are vital to ensure they enjoy the highest attainable standard of health and ultimately right to life. The government must also make certain that persons with albinism have access to dermatologists to treat skin lesions, and oncologist practitioners who will

90 As above.

91 South Africa ratified the Paris Agreement on 1 November 2016 https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=XXVII-7-d&chapter=27&clang=_en (accessed 21 March 2024).

92 See art 7 of the Paris Agreement which stipulates that adaptation is a key component of and contributes to the long-term global response to climate change to protect people, livelihoods, and ecosystems, taking into account the urgent and immediate needs of those developing country Parties that are particularly vulnerable to the adverse effects of climate change.

93 *SERAC* case (n 74) para 47.

94 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond (n 12) para 26. See also Report of the independent expert on the enjoyment of human rights by persons with albinism (n 54) para 111.

be available for the treatment of cancer. All these actions will ultimately enable persons with albinism to fully realise their right to health enshrined in article 17(1) and recognised in the Preamble of the African Disability Protocol and the CRPD respectively.

Some may however argue that the suggested protection package and free specialised healthcare lie beyond government's available resources, and climate change affects everyone hence, everybody needs protection. It is crucial to acknowledge people with albinism peculiar vulnerabilities that are exacerbated by climate change. In this regard, the government is obligated to provide services that meet their survival needs, and it must do so in a manner that is reasonable in both conception and implementation.⁹⁵ Additionally, the state must take into account available resources, and the urgency of the need of vulnerable groups as emphasised in *Grootboom* and subsequent cases.⁹⁶ Vulnerable groups' interests or those whose needs are most urgent are of greater importance and require a higher level of protection,⁹⁷ and there is none so vulnerable as persons with albinism whose very survival is threatened by climate change's adverse impacts.

In essence, the obligation to adapt is interlinked with the obligation to fulfil human rights, creating a comprehensive approach to addressing the impact on vulnerable groups like persons with albinism. Although providing essential services to persons with albinism may stretch the government's available resources, the reasonableness standard dictates that the government acknowledge their unique vulnerabilities, which are exacerbated by climate change, and take appropriate measures to address their needs in a timely and effective manner.

3.2 South Africa's normative framework and its efforts

Against this backdrop, it is important to acknowledge South Africa's commendable efforts in fulfilling its obligations. Beyond ratifying the CRPD, African Disability Protocol,⁹⁸ and having signed the Paris Agreement,⁹⁹ the State has incorporated and implemented treaty obligations at a national level. Meaning within its jurisdiction, the Republic has established an institutional and legal framework that can be

95 *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46 (CC) para 42.

96 *Grootboom* (n 95) para 44. *Minister of Health v Treatment Action Campaign (No 2)* 2002 (5) SA 721 (CC) paras 26-36, 68,78.

97 *Grootboom* (n 95) para 44.

98 It is also important to note that these international human rights treaties apply in South Africa to the extent provided by the Constitution of the Republic of South Africa, 1996 sec 39(1)(b) and sec 233.

99 See the list of states that have signed the Paris Agreement <https://www.un.org/sustainabledevelopment/blog/2016/04/parisagreementsingatures/> (accessed 17 October 2023).

extended to promote the rights of persons with albinism impacted by climate change.

The South African Constitution of the Republic of South Africa, 1996, for instance, provides a comprehensive Bill of Rights enshrining the rights of all people. Section 9 on equality prohibits discrimination on several grounds including disability. Also, section 27 enshrines *inter alia* the right to health for everyone, and section 11 the right to life. Perhaps the most important is section 24(a) which provides that everyone has the right 'to an environment that is not harmful to their health or well-being'. Although the provision does not explicitly recognise the existence of intersections between persons with albinism and climate change, the term 'everyone' patently includes persons with albinism and the right to a healthy environment can by extension cover climate change.¹⁰⁰

In addition to the Constitution, in 2013, the South African government also adopted the Ekurhuleni Declaration on the Rights of Persons with Albinism aimed at *inter alia* eliminating all forms of discrimination against persons with albinism and improving access to free healthcare services and assistive devices.¹⁰¹ On the former matter, the delegates recognised that free access to healthcare services for persons with disability should be detached from disability grants and made available to all persons with disability, including persons with albinism. The free healthcare services were to be non-discriminatory, and made available to all especially those in the rural areas where the department of health had to build medical infrastructure.¹⁰² To guarantee free healthcare services, it was observed that the department of health should also provide free access to adequate sunscreen protection.¹⁰³ Moreover, the department would have to accelerate the roll-out of free eye tests and issue spectacles across all nine provinces.¹⁰⁴ The Declaration was hailed as a key achievement, not only for raising the aspirations of persons with albinism, but also that it prompted further dialogue and awareness about the needs of persons with albinism. However, the question one must ask is how much dialogue and awareness has been done since, for example, on climate change and people with albinism. Article 12 of the Paris Agreement encourages states to take appropriate measures in enhancing *inter alia* climate change awareness¹⁰⁵

100 See R Lavanya 'Human rights in the climate change regime from Rio to Paris and beyond' in Knox & Pejan (eds) (n 5) 237 and 243. See also the Preamble of the CCA which notes that 'everyone has the Constitutional right to an environment that is not harmful to their health and well-being, and to have the environment protected'.

101 See South African Government 'Ekurhuleni Declaration on the rights of persons with albinism' (2013) <https://www.gov.za/ekurhuleni-declaration-rights-persons-albinism#> (accessed 19 October 2023).

102 Ekurhuleni Declaration (n 101) item 29.

103 Ekurhuleni Declaration (n 101) item 25.

104 Ekurhuleni Declaration (n 101) item 26.

105 Paris Agreement art 12 notes that '[p]arties shall cooperate in taking measures, as appropriate, to enhance climate change education, training, public awareness, public participation and public access to information, recognising the importance of these steps with respect to enhancing actions under this Agreement'.

which is critical to ensure that persons with albinism are educated about current and future climate-related impacts. This will enable them to make a concerted effort to ensure their safety. The South African government may have missed an opportunity to raise climate change awareness, and effectively engage with persons with albinism during Climate Change Bill (CCB) public hearings (as discussed in section 3.3).

South Africa has taken steps to address climate change through legislation. One significant piece of legislation is the latest CCA which is a critical legal instrument, establishing a comprehensive framework for managing climate change and ensuring the country meets its international obligations, including those under the UNFCCC and the Paris Agreement. The Act includes provisions for reducing greenhouse gas emissions, developing adaptation strategies, and integrating climate change considerations across different sectors of the economy.¹⁰⁶ Additionally, in a bid to protect rights holders by mitigating the impacts of climate change the South African government enacted the Carbon Tax Act 15 of 2019 that enables it to tax greenhouse gas emissions. Carbon tax follows the polluter-pay principle since it requires large greenhouse producers to pay for the damage they cause. It is hoped that attaching a fee to emissions will incentivise individuals and corporate companies to emit less. This in turn leverages the country's climate change mitigation strategies and reverses the slow onset effects of climate change such as increases in global temperatures that adversely affect persons with albinism.

To further demonstrate the commendable efforts in fulfilling its obligations, to promote the rights of persons with albinism the government raises awareness of persons with albinism rights. September is designated as an albinism awareness month.¹⁰⁷ Additionally, the government distributes sunscreen lotions free of charge to persons with albinism to safeguard their right to health and life. However, some challenges persist. There have been reports about the poor quality of the sunscreens. In some cases, sunscreens are not consistently available and people in rural areas complain about the accessibility of the product.¹⁰⁸ Furthermore, health professionals such as dermatologists lack sufficient training, and obtaining optical devices remains problematic.¹⁰⁹ All these issues persist despite the commitments outlined in the Ekurhuleni Declaration.¹¹⁰

3.3 State procedural obligations

Apart from the obligations to respect, protect, promote, and fulfil discussed above, states must adhere to their procedural obligations. These include

106 See the CCA chaps 4 and 5.

107 Report of the independent expert on albinism (n 54) para 27.

108 Report of the independent expert on albinism (n 54) para 48.

109 Report of the independent expert on albinism (n 54) para 49.

110 See the Ekurhuleni Declaration (n 101) discussion on access to healthcare services.

facilitating public participation, providing access to justice, and sharing environmental information. Knox in his capacity as the special rapporteur, recognised that ‘these obligations have bases in civil and political rights’.¹¹¹ They also extend to social, economic, and cultural rights, the CRPD and the African Disability Protocol have provisions to that end.¹¹² Furthermore, these obligations find support in international environmental¹¹³ and specifically climate change instruments.¹¹⁴

This discussion focuses on the State’s obligation to facilitate public participation in decision-making in connection with the CCB public hearing sessions. Evidence from hearing footage demonstrates that the public participation processes may not have been disability inclusive.¹¹⁵ The public turnout was extremely poor and persons with albinism who are disproportionately affected by climate change, homogenised as climate ‘victims’, were excluded in the hearings, perpetuating the ‘participation disconnect narrative’ highlighted by the independent expert.¹¹⁶ To ensure inclusivity and prevent anyone from being left behind, the government should have created a space for effective participation for all, particularly persons with albinism who are seriously affected by climate change. Including their voices would have contributed to the creation of effective and sound climate change legislation.

3.3.1 *Obligation to facilitate effective public participation*

The state’s obligation to facilitate the effective participation of persons within its jurisdiction in decision-making and policies stems from the right to participate in public affairs. Both article 29(b) of the CRPD and article 21 of the African Disability Protocol acknowledge the right of persons with disability to participate in public life. States are tasked with actively

111 Report by the special rapporteur on the issue of human rights obligations relating to the enjoyment of a safe, clean, healthy environment and sustainable environment (n 43) para 56. See also S Apatattu *Human rights and the environmental key issues* (2019) 129. Apatattu corroborates Knox’s view when he notes that these rights were established under international human rights law. However, they crept into the environmental protection discourse through the environmental impact assessment process at the national level.

112 Art 13 of the CRPD on access to justice; art 21 on freedom of expression and opinion, and access to information; and art 24 of the African Disability Protocol on access to information.

113 Arts 4 and 5 of the Convention on Access to Information, Public Participation in Decision Making and Access to Justice in Environmental Matters 25 June 1998, 2161, UNTS 447 (Aarhus Convention) on access to environmental information; arts 6-8 on public participation; art 9 on access to justice. Rio Declaration on the Environment and Development, 13 June 1992, UN DOC. A/CONF.151/26. Rev.1 (1992), Principle 10.

114 See arts 4(1)(i) and 6(a)(iii) of the UNFCCC. See further the Preamble, arts 7(5) and 12 of the Paris Agreement.

115 See Climate Change Bill: Public Hearing in Free State, Bloemfontein; Cape Town Metropolitan, available on You Tube https://youtu.be/5eRSht_W23E (accessed 19 January 2024).

116 Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond (n 12) para 57.

promoting an inclusive environment where individuals with disabilities can fully participate in public affairs without discrimination. The term public affair ‘covers all aspects of public administration and formulation and implementation of policy at international, national, regional, and local levels’.¹¹⁷ It is unquestionable that this duty encompasses decision-making in relation to climate policy.

In the climate change regime, states have long emphasised the importance of facilitating an effective public participation process in addressing climate change. This facilitation is crucial for safeguarding a broad spectrum of rights against environmental harm. Moreover, public participation serves as a mechanism for integrating public concerns and knowledge into policies and decision-making affecting the environment.¹¹⁸ The UNFCCC article 4(1)(i) as read with article 6(a)(iii) notes that state parties shall encourage, promote, and facilitate public participation in addressing climate change and its effects and developing adequate responses. Similarly, the Paris Agreement requires state parties to collaborate on implementing measures that enhance public participation.¹¹⁹ South Africa having ratified both instruments¹²⁰ has implemented laws that provide for public participation in legislative processes.

South Africa upholds participatory rights in terms of sections 59(1)(a) and 72(1)(a) of the Constitution which imposes a duty on the government to facilitate public involvement in decision-making. Drawing on the *Doctors for Life* case¹²¹ in the *South African Iron and Steel Institute* case,¹²² the Constitutional Court clarified that the primary purpose of public participation is to influence decision-making processes affecting individuals. Institutions with decision-making powers must involve those likely to be affected by national policies.¹²³ In the context of this discussion, any decisions on climate change should follow a participatory approach, considering the view of vulnerable groups such as persons with

117 United Nations Human Rights Committee, General Comment 25: Art 25: Participation in public affairs and right to vote, 12 July 1996, UN Doc CCPR/C/21/Rev.1/Add.7 (1996) para 5.

118 *The Environment and Human Rights (State Obligations in Relation to the Environment in the Context of the Protection and Guarantee of the Right to Life and to Personal Integrity: Interpretation and Scope of Articles 4(1) and 5(1) in Relation to Articles 1 (1) and 2 of the American Convention on Human Rights)* Advisory Opinion OC-23/17, 15 November 2017 para 228.

119 Art 12 of the Paris Agreement.

120 South Africa ratified the UNFCCC on 29 August 1997 and the Paris Agreement on 1 November 2016. See the list of countries that have actioned on the treaties <https://unfccc.int/process/parties-non-party-stakeholders/parties-convention-and-observer-states> (accessed 21 October 2023).

121 *Doctors for Life International v Speaker of the National Assembly* 2006 (6) SA 416 (CC).

122 *South African Iron and Steel Institute v Speaker of the National Assembly* 2023 (10) BCLR 1232 (CC).

123 *South African Iron and Steel Institute* case (n 122) para 28.

albinism, with a view of integrating adaptation measures into relevant socio-economic and environmental policies and actions.

To uphold effective participation standards, the public must be informed, educated, and given a meaningful opportunity to participate in decisions-making. Hence, persons with albinism need awareness on climate change, education on its consequences and related adaptive measure thereof. The CCB underwent public consultations and generated modest public interest, with approximately 13 200 written submissions received by Parliament.¹²⁴ On the face of it, it may appear as though the legislature took steps to afford concerned citizens a reasonable opportunity to participate effectively in the law-making process. After all the CCB has a provision to this end. Article 3 which was retained in the CCA notes that the interpretation and application of the Act must be guided by

[the] need for decision-making to consider the special needs and circumstances of localities and people that are particularly vulnerable to the adverse effects of climate change, including vulnerable workers and groups such as women, especially poor and rural women, children, especially infants and child-headed families, the aged, the poor, the sick and *persons with disability*.

However, the article suggests, based on the public hearing footage, there may not have been enough substantive engagement, particularly from those significantly affected by climate change. Top of Form

4 Conclusion

A substantive body of evidence has substantiated with a considerable degree of certainty that climate change significantly undermines the rights to health and life of persons with albinism. Unfortunately, their plight will not improve unless the global community takes urgent action to combat climate change and its impact. The global pledge to 'leave no one behind' is not a futile oath. It is a highly esteemed universal value, placing an unequivocal commitment on states to reduce the impacts of climate change, especially on vulnerable groups such as persons with albinism. States as duty-bearers are bound by international climate change and human rights laws that they have voluntarily accepted, requiring them not to only mitigate and adapt to climate change, but also to uphold the four specific human rights obligations outlined in this article. The article observed and submitted that climate change and human rights obligations are in part interrelated. When acting to address climate change obligations, states will simultaneously satisfy their human rights obligations. Using South Africa as an example, the article observed that it has endeavoured to

124 N Fumba 'Climate change and parliament' https://static.pmg.org.za/Climate_change_research_piece.pdf (accessed 3 November 2023).

implement legal and practical measures to ensure inclusivity. However, more can be done to ensure that the lived realities of persons with albinism who are impacted by climate change are less brutal. Going forward, South Africa should prioritise both climate change mitigation actions to address the root cause of climate change and strengthen adaptation measures to mitigate its impacts. Additionally, prioritising the healthcare of persons with albinism as an adaptation strategy is crucial. Most importantly, empowering persons with albinism to participate in climate dialogue and policymaking is essential for nothing can be effectively done for them without their involvement.