



**Access to Healthcare Services for People with Albinism in South Africa: A
Human Rights Perspective**

A mini dissertation submitted in fulfilment of the requirements for the degree of
Master of Laws in Human Rights at the School of Law, Faculty of Management,
Commerce and Law, University of Venda

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2024

Declaration

I, **MUDAU BENNI AVHATAKALI**, hereby declare that this mini-dissertation for Master of Laws in Human Rights titled “**Access to Healthcare Services for People with Albinism in South Africa: A Human Rights Perspective**” hereby submitted by me at the University of Venda, has not been submitted previously for a degree at this or any other institution and that it is my own work in design and execution, and that all reference material contained therein has been duly acknowledged.

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ACKNOWLEDGMENT

God: I would like to extend my deepest gratitude to God for His unwavering support throughout this challenging journey. Witnessing the fulfilment of His promise has been an incredible blessing, and I am in awe of His perfect timing and provision. Embarking on this arduous path without funding required immense courage, perseverance, self-determination, and bravery. I commend myself for overcoming the odds and staying resilient in the face of adversity.

Dr Chiedza Simbo: Special thanks go to the remarkable Dr Chiedza Simbo, whose kindness and wisdom have been instrumental in my achievements this year. I am profoundly indebted to you for being a dedicated supervisor, mentor, and mother figure throughout my LLM studies. Your unwavering support, opportunities, and the wealth of knowledge you imparted have left an indelible mark on my academic journey. You have done everything that a supervisor could have done for me. May the universe reciprocate all your efforts!

Adv. Tshepo Cyril Phanyane: I am grateful to my co-supervisor, Adv. Tshepo Cyril Phanyane, for his insightful comments and suggestions that enriched my dissertation. Your expertise has significantly strengthened the quality of my work, and I am deeply appreciative of your contributions.

Prof Ademola Jegede and Prof Tharien Van der Walt: My heartfelt thanks go to Prof Ademola Jegede and Prof Tharien Van der Walt for their relentless efforts in securing funding for LLM students. Your support and commitment to students' success are commendable.

My Parents: To my parents, Mudau Khathutshelo and Jeffrey Shika, your sacrifices and unwavering support have been the bedrock of my journey. Despite limited resources, your patience, love, and perseverance have seen me through the toughest times. Thank you for standing by me and believing in my dreams.

Mukumela Mudau: I also express my gratitude to my grandmother, Mukumela Mudau. Your love, strength, and guidance have shaped me into the person I am today. Your teachings were invaluable, and I am forever grateful.

Mavhungu Zwannda: To my partner, Mavhungu Zwannda, your unwavering love and support have been a constant source of strength and motivation during my Master of Laws studies. You have stood by me through every challenge, offering words of encouragement and a shoulder to lean on. I am grateful for your presence in my life. May we enjoy the fruits of our hard work together and share countless bright moments ahead.

Abstract

The Albinism Society of South Africa found that the national healthcare system is failing to meet the needs of people with albinism. People with albinism face significant health challenges, including skin damage from ultraviolet (hereafter referred to as UV) rays and vision problems, primarily due to a lack of melanin. Research shows that many people with albinism die young, often from skin cancer in their 30s or 40s. Regular annual skin tests and eye check-ups are essential for early detection and treatment of these health issues.

In South Africa, the right to access healthcare services for people with albinism is protected by the Constitution of the Republic of South Africa, 1996 (hereafter referred to as the Constitution). The Constitution is read with various international laws and agreements, including the Universal Declaration of Human Rights (hereafter referred to as the UDHR), the International Covenant on Economic, Social and Cultural Rights (hereafter referred to as the ICESCR), the International Convention on the Elimination of All Forms of Racial Discrimination (hereafter referred to as the ICERD), the Convention on the Elimination of All Forms of Discrimination Against Women (hereafter referred to as the CEDAW), the United Nations Convention on the Rights of the Child (hereafter referred to as the UNCRC), the Convention on the Rights of Persons with Disabilities (hereafter referred to as the CRPD), the African Charter on Human and Peoples' Rights (hereafter referred to as the ACHPR), the African Charter on the Rights and Welfare of the Child (hereafter referred to as the ACRWC), and the SADC Declaration on the Protection of Persons with Albinism (hereafter referred to as the DPPA), all of which provide for the right to health. However, despite these international and constitutional provisions, there is no specific case law or health legislation in South Africa that clearly defines the state's obligations in providing access to healthcare services for people with albinism.

This lack of case law and legislation that defines the state's internationally and constitutionally compliant obligations creates significant challenges for people with albinism in enforcing their right to access healthcare services. Clarifying these legal obligations is crucial to establish the health demands of people with albinism as legally enforceable claims, facilitating effective advocacy grounded in rights-based language. Advocacy based on international and constitutional entitlements empowers people with albinism to assert their health needs as rights rather than mere service requests.

This approach provides a stronger foundation for holding the state accountable and ensuring that people with albinism have access to healthcare services they are entitled to.

Through a doctrinal method, this study aims to clarify South Africa's specific international obligations which are also protected by the Constitution in section 27. It evaluates South Africa's legislative framework and measures to ensure healthcare access for people with albinism, identifies gaps, and concludes with recommendations to persuade the government to adopt internationally and constitutionally compliant health laws that guarantee full access to necessary healthcare services for this population.

Keywords: Albinism, right of access to healthcare services, obligations.

List of abbreviations

1. ACHPR: African Charter on Human and Peoples' Rights
2. ACHPR: African Commission on Human and Peoples' Rights
3. ACRWC: African Charter on the Rights and Welfare of the Child
4. CEDAW: Committee on the Elimination of Discrimination Against Women
5. CEDAW: Convention on the Elimination of All Forms of Discrimination Against Women
6. CERD: Committee on the Elimination of Racial Discrimination
7. CESCR: Committee on Economic, Social and Cultural Rights
8. CRC: Committee on the Rights of the Child
9. CRPD: Committee on the Rights of Persons with Disabilities
10. CRPD: Convention on the Rights of Persons with Disabilities
11. DPPA: SADC Declaration on the Protection of Persons with Albinism
12. ICESCR: International Covenant on Economic, Social and Cultural Rights
13. ICERD: International Convention on the Elimination of All Forms of Racial Discrimination
14. NHI: National Health Insurance
15. PEPUDA: Promotion of Equality and Prevention of Unfair Discrimination Act
16. SADC: Southern African Development Community
17. UDHR: Universal Declaration of Human Rights
18. UNCRC: United Nations Convention on the Rights of the Child

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CHAPTER ONE

INTRODUCTION AND BACKGROUND

1.1. INTRODUCTION

People with albinism have long faced human rights challenges that have been overlooked for generations.¹ One of the human rights challenges they face is the lack of access to healthcare services that meet their specific needs.² Albinism is a genetic condition that affects the production of skin pigmentation, resulting in a lack of pigmentation in the skin. It can affect humans of all races, as well as mammals, birds, fish, reptiles, and amphibians.³ The National Organisation for Albinism and Hypopigmentation, a South African organisation states that globally, approximately one in 17,000 individuals are affected by some form of albinism.⁴ In South Africa, the incidence of albinism is about 1 in every 3,900 among Black individuals and 1 in every 15,000 among the White population.⁵ It is estimated that there are around 11,500 individuals with albinism in South Africa, based on current statistics.⁶

In South Africa, people with albinism within the Black population have faced human rights challenges with deep historical roots dating back to the apartheid era.⁷ This period characterised by systematic racial segregation, and the marginalisation of Black people placed persons with albinism within the broader context of human rights violations.⁸ People with albinism have lacked special recognition and access to healthcare services both during apartheid and to date.⁹ However, after the end of

¹ Kwame Andrews Daklo, 'Human Rights-Based Approach to Advocacy for Children with Albinism in Africa' (presented at the 43rd Ordinary Session of ACERWC, 17 April 2024) <<https://africaalbinismnetwork.org/wp-content/uploads/2024/04/Panel-4.-Presentation-on-Human-Rights-Based-Approach-to-Advocacy-on-CWA-by-Kwame-Andrews-Daklo-1.pdf>> accessed 20 June 2024.

² Ikponwosa Ero, Samer Muscati, Anne-Rachelle Boulanger and India Annamanthadoo, *People with Albinism Worldwide: A Human Rights Perspective* (UN Human Rights Office, 2021) <https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf> accessed 8 August 2024.

³ Cancer Association of South Africa, 'Fact Sheet on Albinism and its Implications' (January 2021) <<https://www.cansa.org.za/files/2021/01/Fact-Sheet-on-Albinism-and-its-Implications-January-2021.pdf>> accessed 07 May 2024.

⁴ National Organization for Albinism and Hypopigmentation, 'Information Bulletin – What is Albinism?' (NOAH, 2023) <https://albinism.org/information-bulletin-what-is-albinism/> accessed 21 August 2024.

⁵ Cancer Association of South Africa (n 3 above).

⁶ Ibid.

⁷ Centre for Human Rights, 'The Impact of Race and Colour on the Enjoyment of Human Rights and Fundamental Freedoms by Persons with Albinism in South Africa' (2023) University of Pretoria.

⁸ Ibid.

⁹ Ikponwosa Ero et al (n 2 above).

apartheid and with the establishment of constitutional democracy in South Africa, hope for access to healthcare services for people with albinism should have been restored.¹⁰

The new South African democratic government promised the creation of a more equitable system that would serve all its citizens, regardless of race or condition, such as albinism.¹¹ The Constitution was enacted and laws were introduced such as the National Healthcare Act 61 of 2003,¹² and later the National Health Insurance Act¹³ which aimed at improving the availability, affordability, and acceptability of healthcare services. The expansion of the public healthcare system was a promise followed by the introduction of primary healthcare services at facilities such as clinics and hospitals and overall efforts to improve healthcare infrastructure.¹⁴ Primary health care services mean the health services that the Minister designates as primary health care services, according to the National Health Act,¹⁵ which was a significant step towards achieving healthcare equity.¹⁶

Although the provision of basic healthcare at no cost was legislated in the National Health Act in section 4(3), it excludes a certain number of vulnerable groups such as some people with albinism who are not covered by this section.¹⁷ According to the section, certain groups of people are entitled to free healthcare services at government clinics and hospitals if they do not have medical aid such as pregnant and lactating women, children below six years of age, and all persons receiving compensation for compensable occupational diseases, excluding members of medical aid schemes and their dependents.¹⁸ For people with albinism who do not fall within these categories, this means that they are not automatically entitled to free healthcare services under the current Act but are only entitled to free primary health services according to section 4(3)(b).¹⁹

¹⁰ René Burger and Catherine Christian, 'Access to healthcare in post-apartheid South Africa: availability, affordability, acceptability' (2018) 15 Health Economics, Policy and Law 43, 11.

¹¹ Ibid, 44.

¹² Act 61 of 2003.

¹³ Act 20 of 2023.

¹⁴ Abrahams Gavin Leonard, Thani Xolani Christopher, and Kahn Shireen Bibi, 'South African Public Primary Healthcare Services and Challenges' (2021) 30 Journal of Public Administration 2.

¹⁵ Act 61 of 2003, sec 1.

¹⁶ Ibid.

¹⁷ Ibid, sec 4(3).

¹⁸ Act 61 of 2003.

¹⁹ Ibid.

Meanwhile, within the above interpretation of the right to access health care in South Africa, people with albinism are in urgent need of free preventative medication as they are more likely to be affected by lifetime physical health problems, such as visual impairment and sensitivity to UV radiation from the sun which often damage the skin leading to death or cancer.²⁰ Studies disturbingly indicate that the risks of developing skin cancer and skin disorders are extremely high, with most people with albinism dying from skin cancer between the ages of 30 and 40.²¹ The vulnerability of people with albinism necessitates the enabling internationally and constitutionally compliant legislative frameworks that mandate the provision of specific types of health protection, such as eye surgery, visual aids, regular skin cancer check-ups, and sunglasses with high UV protection at no cost.²²

However, the South African government seems to have failed to provide enabling legal frameworks that comply with international law and the Constitution and are aimed at addressing the health concerns of people with albinism.²³ Petitions, interviews, and campaigns led by the Chairperson of the Albinism Society of South Africa have highlighted that the national health system has inadequately addressed the health needs of people with albinism.²⁴ Very few people with albinism have access to sunglasses with UV protection, preventative healthcare services like dermatological and eye examinations, and corrective measures.²⁵ The highlighted health challenges faced by people with albinism that are distinct from those experienced by the general population²⁶ motivates the focus of this study.

²⁰ Peter Martin Lund and Jacqueline Susan, 'Lack of adequate sun protection for children with oculocutaneous albinism in South Africa' (2008) 8(225) < <http://www.biomedcentral.com/1471-2458/8/225> > accessed 22 April 2024.

²¹ Ikponwosa Ero, Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (UN Human Rights Council, 2015) <https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/A_HRC_28_75_ENG.doc> accessed 8 August 2024.

²² Mphoeng Maureen Mswela 'A Selection of Legal Issues Relating to Persons Living with Albinism', Published LLD Dissertation, University of South Africa, 2016.

²³ Ibid.

²⁴ Mphoeng Maureen Mswela, 'Living with albinism in South Africa: uncovering the health challenges from a legal perspective' (2022) 43 Obiter 1.

²⁵ Ibid.

²⁶ UNESCO, 'Albinism is part of human diversity' (2023) United Nations in Namibia <<https://namibia.un.org/en/254652-albinism-part-human-diversity>> accessed 8 August 2024.

In South Africa, the right of access to health is a fundamental right protected under national,²⁷ regional,²⁸ and international laws.²⁹ The cornerstone of this protection is found in the Constitution, specifically in section 27(1)(a), which affirms that every person has the right to access healthcare services.³⁰ However, this right is subject to qualifiers such as ‘reasonable legislative and other measures’, ‘within state available resources’, and through ‘progressive realisation’ under section 27(2).³¹ These qualifiers are regarded by this dissertation as crucial in understanding the practical implementation of the right of access to healthcare services for people with albinism. ‘Reasonable legislative and other measures’ implies that the state must take appropriate and effective steps to ensure access to healthcare, but these steps must be sensible and achievable within the given context.³²

‘Within state available resources’ acknowledges that the state’s obligation to provide healthcare is limited by the resources it has at its disposal.³³ This means that while the state must strive to provide healthcare services, it can only do so to the extent that its financial and material resources allow. ‘Progressive realisation’ indicates that the state is expected to improve access to healthcare services over time, rather than immediately.³⁴ However, the Constitution like many other Constitutions, does not specify the obligations of the South African government to ensure access to healthcare services for people with albinism. Section 27 of the Constitution is further reinforced

²⁷ The Constitution of the Republic of South Africa, 1996, section 27(1)(a).

²⁸ African Union, ‘African Charter on Human and Peoples’ Rights’ (1981) ratified by South Africa on 9 July 1996, African Union, ‘Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa’ (2003) ratified by South Africa on 17 December 2004, African Union, ‘African Charter on the Rights and Welfare of the Child’ (1990) ratified by South Africa on 7 January 2000. <<http://hrlibrary.umn.edu/research/ratification-southafrica.html>> accessed 21 August 2024

²⁹ International Covenant on Economic, Social and Cultural Rights, 16 December 1966, 993 UNTS 3, ratified on 3 October 1994, International Covenant on Civil and Political Rights, 16 December 1966, 999 UNTS 171. Ratified on 3 October 1994, Optional Protocol to the International Covenant on Civil and Political Rights, 16 December 1966, 999 UNTS 302, ratified on 28 August 2002, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, 1249, UNTS 13. Ratified on 15 December 1995, Convention on the Rights of the Child, 20 November 1989, 1577, UNTS 3. Ratified on 16 June 1995, Convention on the Rights of Persons with Disabilities, 13 December 2006, 2515, UNTS 3, ratified on 30 November 2007. <<http://hrlibrary.umn.edu/research/ratification-southafrica.html>> accessed 21 August 2024

³⁰ The Constitution of the Republic of South Africa, 1996.

³¹ The Constitution of the Republic of South Africa, 1996 section 27(2).

³² Lilian Manka Chenwi ‘Unpacking “progressive realisation”, its relation to resources, minimum core and reasonableness, and some methodological considerations for assessing compliance (2010) 46(3) Studies in Poverty and Inequality Institute 756.

³³ Daniel McLaren, ‘Socio-Economic Rights and the National Budget’ (2016) Studies in Poverty and Inequality Institute <<http://spii.org.za/wp-content/uploads/2016/02/SPII-Policy-Brief-2016-1.pdf>> accessed 8 August 2024.

³⁴ Chenwi (n 32 above) 747.

by national legislation, such as the National Health Act³⁵ which also provides a framework for a structured uniform health system within the Republic. This legislation also fails to define South Africa's obligations to ensure access to healthcare services for people with albinism.

Internationally, South Africa is a signatory to several treaties that protect the right to health which include the right of access to healthcare services.³⁶ Section 231 of the Constitution provides that international agreements become binding to South Africa after they have been ratified and contains an exception to those agreements that do not need ratification.³⁷ In the case of *S v Makwanyane*, the Constitutional Court clarified that international law that the court must consider includes both binding and non-binding law.³⁸ International instruments such as the UDHR,³⁹ the ICESCR,⁴⁰ the ICERD,⁴¹ the CEDAW,⁴² the UNCRC,⁴³ the CRPD,⁴⁴ and African regional instruments such as the ACHPR,⁴⁵ the ACRWC⁴⁶ and the SADC DPPA⁴⁷ provide for the right to health, which includes access to healthcare services for all, including people with albinism.

This study is important because it clarifies the international and constitutional obligations that South Africa must ensure access to healthcare services for people with albinism. It lays the groundwork for advocacy, enabling individuals with albinism to claim their rights as entitlements and obligations that the state must respect, protect, promote, and fulfil the rights. The study further evaluates the current legislative and

³⁵ Act 61 of 2003.

³⁶ Chukwudi C Ajibo, 'Market Exclusivity and the Right to Health in South Africa: A Primer for Tackling the Paradox' (2020) 64 *Journal of African Law* 53.

³⁷ The Constitution of the Republic of South Africa, 1996.

³⁸ *S v Makwanyane and Another* [1995] ZACC 3, 1995 (3) SA 391 (CC), para 35.

³⁹ United Nations. Universal Declaration of Human Rights. General Assembly Resolution 217A, 10 December 1948.

⁴⁰ International Covenant on Economic, Social and Cultural Rights, 16 December 1966, 993 UNTS 3.

⁴¹ United Nations, 'International Convention on the Elimination of All Forms of Racial Discrimination' (adopted 21 December 1965, entered into force 4 January 1969) 660 UNTS 195.

⁴² Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, 1249, UNTS 13.

⁴³ Convention on the Rights of the Child, 20 November 1989, 1577, UNTS 3.

⁴⁴ Convention on the Rights of Persons with Disabilities, 13 December 2006, 2515, UNTS 3

⁴⁵ Organization of African Unity. African Charter on Human and Peoples' Rights. Adopted June 27, 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), entered into force October 21, 1986.

⁴⁶ Organization of African Unity, African Charter on the Rights and Welfare of the Child (adopted 1 July 1990, entered into force 29 November 1999) OAU Doc CAB/LEG/24.9/49 (1990).

⁴⁷ Southern African Development Community, 'Declaration on the Protection of Persons with Albinism' (17 August 2024) <<https://www.sadc.int/latest-news/declaration-protection-persons-albinism-17-august-2024>> accessed 3 September 2024.

other measures taken by the South African government to ensure access to healthcare services for people with albinism, identifying areas needing legislative improvement to meet international and constitutional obligations, and provides recommendations to persuade the government to adopt internationally and constitutionally compliant health laws that guarantee full access to necessary healthcare services for this population.

1.2. PROBLEM STATEMENT

Despite extensive scholarship on the health challenges faced by people with albinism and the barriers they encounter in accessing healthcare services,⁴⁸ there remains a significant problem which is the gap in legal research and specific documentation that clarifies South Africa's international and constitutional obligations regarding their right to access healthcare services. This gap disenfranchises people with albinism as well as advocates who seek to root their claims in international and constitutional law, which provides for legal entitlements for people with albinism.

International instruments such as the UDHR,⁴⁹ the ICESCR,⁵⁰ the ICERD,⁵¹ the CEDAW,⁵² the CRC,⁵³ the CRPD,⁵⁴ and African regional instruments such as the ACHPR,⁵⁵ the ACRWC,⁵⁶ and the SADC DPPA⁵⁷ provide for the right to health, which includes the right of access to healthcare services for all, including people with albinism. Section 27(1) of the South African Constitution further provides for everyone's right to access healthcare services,⁵⁸ although like many Constitutions it does not specify the access to healthcare services obligations of the government about people with albinism. Legislation such as the National Health Act, which is supposed to enunciate both international and Constitutional obligations incumbent on South Africa relating to persons with albinism also fails to cover these obligations, meaning there is no legal instrument in South Africa that clarifies South Africa's legal obligations.

⁴⁸ Ero et al (n 2 above).

⁴⁹ UDHR (n 39 above).

⁵⁰ ICESCR (n 40 above).

⁵¹ ICERD (n 41 above).

⁵² CEDAW (n 42 above).

⁵³ UNCRC (n 43 above).

⁵⁴ CRPD (n 44 above).

⁵⁵ ACHPR (n 45 above).

⁵⁶ ACRWC (n 47 above).

⁵⁷ DPPA (n 46 above).

⁵⁸ The Constitution of the Republic of South Africa, 1996.

It is of note that, some progress has been made with the adoption of the Ekurhuleni Declaration on the Rights of Persons with Albinism which aims to state aspirations about the provision of healthcare needs for persons with albinism.⁵⁹ However, this declaration is non-binding, which maintains the point of this dissertation that the lack of legislated and binding obligations poses a problem for individuals with albinism in South Africa who seek to enforce their right of access to healthcare services. Clarifying these legal obligations is important because it lays the foundation for effective legal advocacy. Advocacy rooted in international and constitutional entitlements is essential as it enables people with albinism to claim their health needs as entitlements rather than mere service delivery claims. This approach ensures that their rights are recognised and enforced, and it provides a stronger basis for holding the state accountable and ensuring that people with albinism receive the healthcare services they are entitled to.

1.3. AIMS AND OBJECTIVES

1.3.1. Aims

This study aims to clarify South Africa's international and constitutional obligations to provide access to healthcare services for people with albinism.

1.3.2. Objectives

To meet the above aim, the objectives of this study are as follows:

- a) To clarify South Africa's obligations under the international and regional instruments to provide people with albinism with access to healthcare services.
- b) To clarify South Africa's obligations under the Constitution to provide people with albinism with access to healthcare services.
- c) To assess South Africa's legislative and other efforts to ensure access to healthcare services for people with albinism, identifying areas needing improvement to meet international and constitutional obligations.
- d) To develop recommendations to ensure the full realisation of the right of access to healthcare services for individuals with albinism in South Africa.

⁵⁹ South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (27 October 2013) <<https://www.gov.za/news/media-statements/ekurhuleni-declaration-rights-persons-albinism-27-oct-2013>> accessed 6 October 2024.

1.4. RESEARCH QUESTIONS

The main research question to be answered in this study is:

- (a) What are South Africa's international and constitutional obligations to ensure access to healthcare services for people with albinism, the legislative and other measures in place, and areas that need improvement to meet these obligations?

To answer this question adequately, the following sub-questions are dealt with:

- (a) What are the international and regional norms and standards on access to health care services for persons with albinism?
- (b) What are South Africa's obligations under the Constitution to provide people with albinism with access to healthcare services?
- (c) What measures have been taken by the South African government to ensure access to healthcare services for people with albinism and areas that need improvement to meet international and constitutional obligations?
- (d) What recommendations can be proposed to ensure full access to healthcare services for individuals with albinism in South Africa?

1.5. HYPOTHESIS

This study assumes that South Africa has international and constitutional obligations to ensure access to healthcare services for people with albinism. Still, its current legislative and policy measures are insufficient to fully meet such obligations, and improvement is needed in the areas of legislation and policies.

1.6. LITERATURE REVIEW

In South Africa, extensive research has been conducted on the health challenges faced by people with albinism and the barriers they encounter in accessing healthcare services. Despite this, there remains a significant gap in the literature that studies the international and constitutional obligations that South Africa must ensure access to healthcare services. Scholars such as Ikponwosa, Muscati, Boulanger, and Annamanthadoo have highlighted numerous barriers that people with albinism face globally. These include inaccessible healthcare facilities, where many are not equipped to meet the specific needs of people with albinism, making it difficult for them to receive appropriate care. According to these scholars, there is often a lack of

training and awareness among healthcare providers about the unique health needs of people with albinism, leading to misdiagnosis or inadequate treatment. They further indicate that governments frequently fail to implement policies and programs that specifically address the healthcare needs of people with albinism. These scholars emphasise the need for more inclusive healthcare policies and practices that recognise and address the specific challenges faced by people with albinism.⁶⁰ They call for increased training for healthcare providers, better-equipped facilities, and stronger government commitment to ensuring equitable access to healthcare services.⁶¹

However, it is essential to note that these scholars do not specifically clarify South Africa's international and constitutional obligations to the right of access to healthcare services for people with albinism. Available limited scholarship does not show the legislative and other measures mandated by the Constitution which are taken by the South African government to ensure access to healthcare services for this marginalised group. Evaluating measures is important as it opens room for improvements suggestions. Scholars such as Ikponwosa, Muscati, Boulanger, and Annamanthadoo further emphasise that people with albinism face multiple and intersecting forms of discrimination due to their color, disability, and gender, which can lead to social exclusion and barriers to accessing healthcare services.⁶² The concept of economic accessibility is another crucial aspect that they highlight. They emphasise that health facilities, goods, and services must be affordable for all.⁶³ These scholars' study differs from this one because it does not include other causes of lack of access to healthcare services such as discrimination, social exclusion, and economic accessibility.

Durojaye and Nabaneh argue that while there has been a great deal of attention on ritual killings of people with albinism, other human rights challenges faced by this community have been overlooked, including their right to access healthcare services. According to these scholars, discrimination hinders access to healthcare for people with albinism, particularly affecting women in terms of their sexual and reproductive health. They also indicate that women with albinism often face discrimination by

⁶⁰ Ero et al (n 2 above) 76.

⁶¹ Ibid.

⁶² Ero et al (n 2 above) 77, 78.

⁶³ Ibid, 79, 80.

medical healthcare practitioners in public hospitals.⁶⁴ While Durojaye and Nabaneh do not focus on South Africa's international and constitutional obligations to provide healthcare services to people with albinism, they do discuss international instruments such as the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa to determine the protection of the right to healthcare services for people with albinism.⁶⁵ This study will also include the discussion of other important international instruments that define the right of access to healthcare services, encompassing all genders to clarify South Africa's international obligations regarding the right of access to healthcare services for people with albinism.

In her thesis, Mswela argues that many governments, including the South African government, have not ensured "access and affordability" of healthcare services for people with albinism.⁶⁶ She highlights that the South African healthcare system does not address the health needs of people with albinism due to false notions and stereotypes surrounding the condition.⁶⁷ Mswela asserts that individuals with albinism should receive the same level of attention in healthcare provision as those with HIV/AIDS.⁶⁸ She notes that people with albinism have the right to challenge the government's failure to provide skin protection for the prevention of skin cancer, sunglasses, and low vision, citing the right of access to healthcare services in the South African Constitution.⁶⁹

Mswela emphasises the state's duty to provide necessary healthcare services for people with albinism.⁷⁰ While Mswela's study focuses on the violation of the rights of people with albinism in general without specifically addressing the right of access to healthcare services,⁷¹ This study complements Mswela's findings by analysing international instruments, the Constitution, and the measures taken by the South African government in complying with the state's obligations toward international and regional instruments and the Constitution, with a focus on the right of access to healthcare services. This study will also identify the areas that need improvement in

⁶⁴ Ebenezer Durojaye and Satang Nabaneh, "Human Rights and Access to Healthcare for Persons with Albinism in Africa," (2019) 7 African Disability Rights Yearbook 35-58.

⁶⁵ Ibid.

⁶⁶ Mswela (n 22 above).

⁶⁷ Ibid.

⁶⁸ Ibid.

⁶⁹ Ibid.

⁷⁰ Ibid.

⁷¹ Ibid.

measures taken by the South African government to ensure access to healthcare services for people with albinism.

In his dissertation, Daklo highlights the challenges faced by individuals with albinism in accessing appropriate healthcare in Ghana. He argues that structural and systemic discrimination, along with stigma and a lack of knowledge about the condition, have resulted in a significant lack of access to healthcare services tailored to the specific health needs of individuals with albinism. According to him, these social factors not only hinder their ability to receive necessary medical care but also constitute a violation of their right to achieve the highest attainable standard of physical and mental health.⁷²

Daklo emphasised that individuals with albinism commonly face impaired vision, nystagmus, strabismus, and progressive vision deterioration due to the lack of natural eye protection. Surgeries and corrective lenses are necessary for improved vision, and protective measures such as sunglasses and hats are essential. However, access to these services is limited in terms of availability, affordability, and quality. Discrimination, stigma, harmful cultural beliefs, and lack of awareness hinder individuals with albinism from accessing necessary healthcare services. The absence of data, policies, and legal frameworks addressing the rights of individuals with albinism contributes to their marginalisation and exclusion from essential healthcare services. This situation violates their right to the highest attainable standard of physical and mental health as outlined in international human rights law.⁷³ Daklo addressed Ghana's international obligations to ensure access to healthcare services for people with albinism and further analysed how Ghana's Constitution reflects the international human rights law standards concluding by identifying the best practices in other jurisdictions that can guide Ghana as to how to best solve the problem of access to healthcare services for people with albinism in Ghana.⁷⁴

Daklo's study resonates with this study despite that this study will focus on South Africa. This study clarifies South Africa's international and constitutional obligations to provide access to healthcare services for people with albinism and assesses the legislative and other efforts in place, identifying areas needing improvement to meet

⁷² Andrews Kwame Daklo 'Access to Healthcare for Persons with Albinism in Ghana A Human Rights Approach' published LLM dissertation, University of Pretoria, 2021.

⁷³ Ibid.

⁷⁴ Ibid.

these obligations. This study will further provide recommendations to ensure full access to healthcare services for individuals with albinism in South Africa

1.7. RESEARCH METHODOLOGY

The research method adopted for this study is the doctrinal methodology. This method includes the analysis of primary legal sources such as the Constitution, legislation, treaties, and case laws. It also includes the analysis of secondary legal sources such as textbooks, journal articles, online journals, internet websites, and case studies.⁷⁵ Given the nature of the research questions, which require an in-depth analysis of legal principles, statutes, journal articles, academic literature, and case laws, the empirical method is not deemed necessary. The questions of this study can be effectively addressed through a doctrinal methodology and as such, the doctrinal method is deemed appropriate and sufficient for addressing the research questions in this study.

1.8. DEFINITION OF KEY CONCEPTS

1.8.1. Albinism

Human albinism is a disorder when there is a genetic mutation that affects the skin's ability to produce melanin, leaving the skin lacking colour. All racial groups of people as well as fish, amphibians, birds, mammals, and reptiles can be affected by albinism. Albinism is a genetic disorder, however, in most cases, there may not be a family history of the affliction.⁷⁶ Albinism is regarded as a form of disability. This is according to the African Disability Rights Protocol which recognises the risk of violence and abuse, particularly for those with albinism in its preamble.⁷⁷ By this recognition, the Protocol, therefore, makes it clear that persons with albinism are within the treaty's conceptualisation of persons with disabilities.

1.8.2. The right of access to healthcare services

The term "right of access to healthcare services" in South Africa refers to the unalienable right of every person to receive medical attention and treatment. Section

⁷⁵ P. Ishwara Bhat, 'Doctrinal Legal Research as a Means of Synthesising Facts, Thoughts, and Legal Principles' in *Idea and Methods of Legal Research* (Oxford University Press 2019) <<https://academic.oup.com/book/41749/chapter/354157753>> accessed 09 June 2024.

⁷⁶ Cancer Association of South Africa (n 3 above).

⁷⁷ Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (adopted 29 January 2018, entered into force 17 June 2020) AU Doc CAB/LEG/24.12/18.

27 of the Constitution guarantees this right. It includes treatment for a variety of medical diseases, emergency medical services, and access to healthcare for reproductive health.⁷⁸

1.9. ETHICAL CONSIDERATIONS

I am aware of the university's policies on plagiarism and ethics, and I commit to adhering to them. I will ensure that all the sources I have used or cited are fully acknowledged with proper references.

1.10. OVERVIEW OF CHAPTERS

Chapter one serves as an introductory section of the study, offering a context and overview of the study. It includes a background of the research topic, presents the problem statement, outlines the research questions, details the research methodology, and includes a literature review. This chapter further includes the chapter outline of the study.

Chapter two discusses the international and regional norms on access to health care services for persons with albinism.

Chapter three is the clarification of South Africa's obligations under the Constitution to provide people with albinism with access to healthcare services. These include positive and negative obligations. South African case laws where these obligations were clarified are also discussed.

Chapter four assesses South Africa's legislative and other efforts in place to ensure access to healthcare services for people with albinism, identifying areas needing improvement to meet international and constitutional obligations.

In Chapter five, the research is concluded and provides recommendations to improve the legislative and other measures taken by the South African government. These recommendations aim to improve access for people with albinism ensuring that South Africa fulfils its international and constitutional obligations.

1.11. LIMITATIONS OF STUDY

This research employs the doctrinal research method and draws on existing literature. It is crucial to acknowledge that certain measures taken by the South African

⁷⁸ The Constitution of the Republic of South Africa, 1996, sec 27(1)(a).

government to ensure access to healthcare services may not be documented in the existing literature and may not be fully disclosed. This lack of information could potentially influence the overall findings and conclusions of the research.

One limitation of this study is that it does not utilise other research methods that could provide additional insights. For example, some measures taken by the government may require empirical research methods, such as interviews or surveys, to be accurately captured and understood. Another limitation is the absence of primary data collection, such as speaking to people with albinism directly. Engaging with this community could improve the findings and recommendations of the study by providing firsthand accounts and perspectives that are not available in the existing literature.

1.12. CONCLUSION

This chapter has laid the foundation for this dissertation by providing a comprehensive overview of the research topic. It has highlighted the significant health challenges faced by people with albinism in South Africa. The chapter has established the importance of clarifying South Africa's international and constitutional obligations to ensure access to healthcare services for people with albinism. The problem statement has identified the lack of specific legal frameworks and case law defining these obligations, which poses a challenge for individuals with albinism seeking to enforce their healthcare rights. The aims and objectives of the study have been outlined, focusing on clarifying these obligations and assessing current legislative efforts. The research questions and hypothesis have been formulated to guide the study's investigation.

The literature review has provided insights into existing research on the right of access to healthcare services for people with albinism. It has also identified the gap in legal research regarding South Africa's obligations. The research methodology has been detailed, emphasising the doctrinal approach to analysing legal sources. Key concepts have been defined, and ethical considerations have been addressed. Finally, the chapter has presented an overview of the subsequent chapters, the research schedule, and the limitations of the study. This comprehensive chapter sets the stage for the detailed analysis and recommendations that follows in the subsequent chapters, aiming to ensure that people with albinism in South Africa can fully realise their right to access healthcare services. The following chapter explores South Africa's

international obligations to provide healthcare access for people with albinism, discussing relevant general comments and recommendations by treaty bodies to clarify these obligations.

CHAPTER TWO

AN ANALYSIS OF SOUTH AFRICA'S OBLIGATIONS UNDER THE INTERNATIONAL HUMAN RIGHTS INSTRUMENTS TO PROVIDE PEOPLE WITH ALBINISM WITH ACCESS TO HEALTHCARE SERVICES

2.1. INTRODUCTION

The previous chapter introduced the study. It covered the background of the research topic, presented the problem statement, outlined the research questions, detailed the research methodology, and included a literature review. It also provided an outline of the study's chapters. This chapter explores South Africa's international obligations to provide healthcare access for people with albinism, discussing relevant general comments and recommendations by treaty bodies for clarification of such obligations.

Section 231 of the Constitution stipulates that an international agreement becomes binding on South Africa only after it has been approved by both the National Assembly and the National Council of Provinces.⁷⁹ Exceptions exist for agreements of a technical, administrative, or executive nature, or those that do not require ratification or accession. These agreements, entered by the national executive, do not need prior approval from the National Assembly and the National Council of Provinces but must be presented to both bodies within a reasonable time.⁸⁰ These provisions ensure that international law is binding in South Africa.

Section 233 of the Constitution mandates that South African courts must prefer any reasonable interpretation of legislation that aligns with international law over any alternative interpretation that does not.⁸¹ The right of access to healthcare services, as provided by section 27(1)(a) of the Constitution,⁸² is recognised by international human rights law. Although this right is not included word for word in international instruments, such instruments contain provisions that include the right of access to healthcare services and obligations of member states to ensure the realisation of this

⁷⁹ The Constitution of the Republic of South Africa, 1996, sec 231(2).

⁸⁰ The Constitution of the Republic of South Africa, 1996, sec 231(3).

⁸¹ The Constitution of the Republic of South Africa, 1996.

⁸² Ibid.

right.⁸³ This chapter ends with a conclusion that summarises the whole discussion made in this chapter.

2.2. THE MEANING OF THE RIGHT TO HEALTH

The most comprehensive meaning of the right to health was provided by the World Health Organisation (WHO).⁸⁴ According to the WHO, the right to health is a fundamental human right that guarantees everyone the highest attainable standard of physical and mental health.⁸⁵ This right is enshrined in several international legal instruments which I discuss in the following sections of this chapter. It encompasses both freedoms and entitlements.⁸⁶ Freedoms include the right to control one's health and body, such as sexual and reproductive rights, and the right to be free from interference, including non-consensual medical treatment and experimentation, which is particularly relevant for persons with disabilities. Entitlements include the right to access quality health services without discrimination.⁸⁷

According to WHO, a human rights-based approach to health commits countries to develop rights-compliant, effective, gender-transformative, integrated, and accountable health systems.⁸⁸ It also involves implementing public health measures that improve the underlying determinants of health, such as access to water and sanitation.⁸⁹

WHO indicates that right to health includes four essential, interrelated elements: availability, accessibility, acceptability, and quality.⁹⁰ Availability refers to the need for a sufficient quantity of functioning health facilities, goods, and services for all. Accessibility requires that health facilities, goods, and services must be accessible to everyone, considering physical, geographical, financial, and other barriers that may affect marginalized people. Acceptability relates to respect for medical ethics, cultural appropriateness, and sensitivity to gender. Quality extends to the underlying determinants of health, such as safe and potable water and sanitation, and requires

⁸³ n 28 above.

⁸⁴ World Health Organisation, 'Newsroom fact sheet' 1 December 2023. <<https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health>> accessed on 23 March 2025.

⁸⁵ Ibid.

⁸⁶ Ibid.

⁸⁷ Ibid.

⁸⁸ Ibid.

⁸⁹ Ibid.

⁹⁰ Ibid.

that health facilities, goods, and services are scientifically and medically approved. These elements are discussed in detail in this chapter of this dissertation.⁹¹

The comprehensive meaning of the right to health provided by the WHO has significant implications for persons with albinism. Given their unique health challenges, such as visual impairments and a high susceptibility to skin cancer, the right to health for persons with albinism means ensuring they have equal access to health services, including specialised care tailored to their needs. This includes regular eye examinations, provision of visual aids, dermatological services, and access to sunscreen and protective clothing. It also involves educating health care providers to reduce stigma and improve care quality and implementing legal and policy frameworks that protect their health rights, including anti-discrimination measures. Furthermore, addressing the underlying determinants of health, such as access to safe water and sanitation, is crucial for persons with albinism to achieve the highest attainable standard of health.

2.3. OBLIGATIONS TO RESPECT, PROTECT AND FULFIL

State obligations fall into three categories: the obligations to respect, protect, and fulfil rights.⁹² These obligations are rooted in foundational documents such as the UDHR⁹³ and the International Covenants on Civil and Political Rights (hereafter referred to as the ICCPR)⁹⁴ and ICESCR.⁹⁵ These obligations are as follows:

2.3.1. Obligation to respect

This obligation requires states to refrain from interfering with or curtailing the enjoyment of human rights including the health rights of vulnerable people like those with albinism.⁹⁶ As outlined by the CESCR in General Comment No. 14, the obligation to respect the right to health requires states to avoid actions that directly or indirectly harm individuals' health rights.⁹⁷ According to this General Comment, the obligation to

⁹¹ Ibid.

⁹² Office of the United Nations High Commissioner for Human Rights, International Human Rights Law (OHCHR) <<https://www.ohchr.org/en/instruments-and-mechanisms/international-human-rights-law>> accessed 2 September 2024.

⁹³ UDHR (n 39 above).

⁹⁴ International Covenant on Civil and Political Rights, 16 December 1966, 999 UNTS 171.

⁹⁵ ICESCR (n 40 above).

⁹⁶ Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the International Covenant on Economic, Social and Cultural Rights)' (2000) UN Doc E/C.12/2000/4.

⁹⁷ Ibid, para 34.

respect mandates states to refrain from denying or limiting equal access to preventive, curative, and palliative health services for all persons, including prisoners, detainees, minorities, asylum seekers, and illegal immigrants.⁹⁸ States must also abstain from enforcing discriminatory practices as state policy and avoid imposing discriminatory practices related to women's health needs and status.⁹⁹

For people with albinism in South Africa, this dissertation opines that the explanation provided in General Comment No. 14 would mean that the state has an obligation to ensure they have the same access to healthcare services as everyone else and avoid making any policies or actions that could result in limited or denied access to necessary health services for individuals with albinism.¹⁰⁰ Failure to do so would mean that South Africa has failed to comply with its obligation to respect the right of access to healthcare services for people with albinism which is provided by section 27(1) of the South African Constitution¹⁰¹ and encompassed by the right to health in the ICESCR which South Africa has ratified.¹⁰²

Violations of the obligation to respect the right to health, as outlined by the CESCR in General Comment No. 14, occur when state actions, policies, or laws fail to meet the standards set by Article 12 of the ICESCR which are discussed later in this dissertation, leading to potential harm.¹⁰³ This would mean that if the South African government or its policies result in the denial of access to healthcare services for people with albinism, it constitutes a violation. This includes any discriminatory practices, whether explicit or implicit, that prevent individuals with albinism from receiving necessary medical care.¹⁰⁴

The Committee further states that if the governments of member states deliberately withhold or misrepresent crucial information needed for health protection or treatment for people with albinism, it constitutes a violation¹⁰⁵ which would mean that if the South African government by virtue of being a state party to the ICESCR, withholds or misrepresents crucial health information, such as the importance of UV protection or

⁹⁸ Ibid.

⁹⁹ Ibid.

¹⁰⁰ Ibid.

¹⁰¹ The Constitution of the Republic of South Africa, 1996.

¹⁰² ICESCR (n 40 above).

¹⁰³ General Comment No. 14 (n 87 above), para 50.

¹⁰⁴ Ibid.

¹⁰⁵ Ibid.

the availability of dermatological treatments, it is failing its obligation. Furthermore, the Committee explained that any suspension of legislation or the adoption of new laws that negatively impact the health rights of people with albinism would be a violation¹⁰⁶ hence, it is reasoned by this dissertation that if new policies were to reduce funding for skin cancer treatments in South Africa, it would disproportionately affect individuals with albinism, and this would mean that the state would have violated the obligation to respect the right to health.¹⁰⁷

2.3.2. Obligation to protect

In its General Comment No. 14, the CESCR elaborates on the obligations of states to protect the right to health.¹⁰⁸ According to the CESCR, this obligation includes adopting legislation or taking measures to ensure equal access to healthcare services provided by third parties, ensuring that privatisation does not compromise the availability, accessibility, acceptability, and quality of healthcare, regulating the marketing of medical equipment and medicines, and ensuring that medical practitioners meet appropriate standards of education, skill, and ethical conduct.¹⁰⁹ The concepts of availability, accessibility, acceptability, and quality of healthcare quality are defined later in this dissertation.

For South Africa as a state party to the ICESCR, this dissertation reasons that the explanation given by the CESCR of the obligation to protect the right to health¹¹⁰ would mean that the government enacts legislation that would enable vulnerable populations like people with albinism to have access to healthcare services that meet their needs. It must ensure that people with albinism in South Africa, have equal access to healthcare services and are not disadvantaged by privatisation or inadequate regulation. It also means that healthcare providers must be properly trained and adhere to ethical standards to provide the necessary care for people with albinism.

According to General Comment No. 14 by CESCR, violations of the obligation to protect occur when a state fails to take all necessary measures to safeguard persons within its jurisdiction from infringements on their right to health by third parties.¹¹¹ This

¹⁰⁶ Ibid.

¹⁰⁷ Ibid.

¹⁰⁸ General Comment No. 14 (n 87 above), para 35.

¹⁰⁹ Ibid.

¹¹⁰ Ibid.

¹¹¹ General Comment No. 14 (n 87 above), para 51.

includes failures to regulate the activities of individuals, groups, or corporations to prevent them from violating the right to health of others.¹¹² This would mean that if South Africa fails to take all necessary measures to safeguard the individuals with albinism in its jurisdiction from infringements by third parties would constitute a violation of the obligation to protect. Also failing to enact and enforce such regulations on the activities of individuals, groups, or corporations to prevent them from violating the right to health of people with albinism would constitute a violation of the obligation to protect, as it would allow third parties to infringe upon the health rights of people with albinism.

2.3.3. Obligation to fulfil

The obligation to fulfil is also explained by the CESCR in its General Comment No. 14.¹¹³ According to the Committee, the obligation to fulfil the right to health requires states to take specific actions to realise this right.¹¹⁴ The Committee explained that states must recognise the right to health within their national legal and political systems, preferably through legislative measures.¹¹⁵ They must adopt comprehensive national health policies with detailed plans for achieving the right to health.¹¹⁶ This includes ensuring the appropriate training of medical professionals, providing sufficient healthcare facilities, and promoting mental health services with equitable distribution across the state.¹¹⁷

For South Africa as a state party to the ICESCR, the explanation given by the CESCR of the obligation to fulfil the right to health would mean that the government has a responsibility to implement laws and policies that ensure people with albinism have access to necessary healthcare services.¹¹⁸ This includes training healthcare providers to meet their specific needs, ensuring that enough hospitals and clinics are available, and supporting institutions offering the population counselling and mental health services. The explanation by the Committee would also mean that the South African government must take positive steps to assist individuals and communities in enjoying the right to health, particularly when they are unable to do so on their own,

¹¹² Ibid.

¹¹³ General Comment No. 14 (n 87 above), paras 36 and 37.

¹¹⁴ Ibid, para 36.

¹¹⁵ Ibid.

¹¹⁶ Ibid.

¹¹⁷ General Comment No. 14 (n 87 above), para 37.

¹¹⁸ General Comment No. 14 (n 87 above), 36 and 37.

and should also promote health by fostering research, providing information, and ensuring healthcare services are culturally appropriate and responsive to the needs of vulnerable and marginalised groups like people with albinism.

According to General Comment No. 14 by the CESCR, violations of the obligation to fulfil occur when a state fails to take all necessary steps to ensure the realisation of the right to health.¹¹⁹ This includes failing to adopt or implement a national health policy designed to ensure the right to health for everyone.¹²⁰ In South Africa, this would mean that if the government does not have a comprehensive health policy that includes specific provisions for the needs of people with albinism, it would have failed to meet its obligation to fulfil the right to health. According to the Committee, insufficient expenditure or misallocation of public resources that results in the non-enjoyment of the right to health by vulnerable groups constitutes a violation.¹²¹ This would mean that the South African government is failing to fulfil its obligation if it does not allocate sufficient funds to provide dermatological care, UV protection, and other necessary health services for people with albinism.

According to the CESCR, the failure to monitor the realisation of the right to health at the national level is another example.¹²² This would mean that if South Africa does not establish and track health indicators and benchmarks specific to people with albinism, it cannot effectively ensure that their right to health is being met. Also failing to take measures to reduce the inequitable distribution of health facilities, goods, and services would be a violation according to the Committee.¹²³ In South Africa, this would mean that, if people with albinism in rural or underserved areas do not have access to the same quality of healthcare as those in urban areas, the government is failing to meet its obligation to fulfil the right to health.

2.4. INTERNATIONAL DECLARATIONS

2.4.1. Universal Declaration on Human Rights (UDHR)

The UDHR, a foundational document adopted by the United Nations General Assembly in 1948 outlines fundamental human rights to be universally protected.

¹¹⁹ General Comment No. 14 (n 87 above), para 52.

¹²⁰ Ibid.

¹²¹ Ibid.

¹²² Ibid.

¹²³ Ibid.

Although not legally binding, it serves as a guiding framework for human rights standards globally.¹²⁴ Countries do not need to ratify the UDHR, but its principles have been incorporated into legally binding international treaties¹²⁵ and national laws.¹²⁶

Article 25, paragraph 1 of the UDHR emphasises that every individual is entitled to a living standard that ensures their health and well-being. This includes access to essential needs such as food, clothing, housing, medical care, and necessary social services. It also guarantees security in situations like unemployment, illness, disability, widowhood, old age, or any other circumstances that prevent earning a livelihood.¹²⁷ This article is inclusive as it goes beyond mere access to healthcare services to encompass a holistic approach to well-being.¹²⁸ This includes ensuring that individuals have access to the basic necessities that contribute to a healthy life.¹²⁹ The provision recognises that health is influenced by various social determinants, including living conditions, nutrition, and social support systems.¹³⁰ This article contains the right of access to healthcare services because the mandates of this article cannot be fulfilled without access to healthcare services.¹³¹ South Africa has integrated the principles of the UDHR¹³² into its Constitution, which guarantees the right to access healthcare services.¹³³ This incorporation obligates South Africa to ensure that all individuals, including vulnerable groups like those with albinism, have access to healthcare services.

2.5. UNITED NATIONS TREATIES

2.5.1. International Covenant on Economic, Social, and Cultural Rights (ICESCR)

The ICESCR is a treaty that aims to ensure the enjoyment of economic, social, and cultural rights, including the rights to education, health, and an adequate standard of

¹²⁴ UDHR (n 39 above).

¹²⁵ n 28 above.

¹²⁶ The Constitution of the Republic of South Africa, 1996.

¹²⁷ UDHR (n 39 above), article 25(1).

¹²⁸ Ibid.

¹²⁹ Ibid.

¹³⁰ Ibid.

¹³¹ Ibid.

¹³² Ibid.

¹³³ The Constitution of the Republic of South Africa, 1996, sec 27(1).

living, for all individuals.¹³⁴ South Africa ratified the ICESCR in 2015¹³⁵ meaning that its provisions are binding to South Africa.

Article 12 of the ICESCR provides that:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:
 - (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases.¹³⁶

Article 12(1) of the ICESCR establishes a broad framework for the right to health, recognising the right of everyone to the highest attainable standard of physical and mental health.¹³⁷ In South Africa, recognising the right to the highest attainable standard of health means that the government must ensure that all individuals have access to quality healthcare services.¹³⁸ This includes people with albinism. People with albinism are more susceptible to certain diseases, such as skin cancer, due to their lack of melanin.¹³⁹ Article 12(2)(c) of the ICESCR obliges South Africa to implement measures for the prevention, treatment, and control of such diseases.¹⁴⁰ According to Mswela, people with albinism need to have regular skin checks, access to sunscreen, and dermatological care to prevent, treat, and manage skin cancer.¹⁴¹ Therefore, South Africa must provide these necessary services to effectively address the health needs of individuals with albinism.

Under the ICESCR, the right to health is subject to the qualifiers of 'progressive realisation' and 'states available resources'.¹⁴² Article 2, paragraph 1 of the ICESCR mandates that each State Party commits to taking necessary actions, both independently and through international cooperation, particularly in economic and

¹³⁴ ICESCR (n 40 above).

¹³⁵ Ibid.

¹³⁶ ICESCR (n 40 above).

¹³⁷ Ibid.

¹³⁸ General Comment No. 14 (n 87 above), para 12.

¹³⁹ Mswela (n 22 above), 114.

¹⁴⁰ ICESCR (n 40 above).

¹⁴¹ Mswela (n 22 above), 115.

¹⁴² ICESCR (n 40 above), Article 2(1).

technical areas.¹⁴³ These actions should use the maximum available resources to progressively achieve the full realisation of the rights outlined in the Covenant.¹⁴⁴ This includes, but is not limited to, the implementation of legislative measures.¹⁴⁵

The progression towards fully realising health rights should commence within a reasonable timeframe following the ratification and enforcement of the ICESCR.¹⁴⁶ These measures must be intentional, specific, and focused on enhancing the health rights of the most vulnerable members of society, including individuals with albinism.¹⁴⁷ Essential actions encompass healthcare legal reforms and the provision of sufficient resources to establish and maintain healthcare facilities, goods, and services.¹⁴⁸ This may be achieved at the national level or through international aid and cooperation.¹⁴⁹

State Reporting Obligations under the International Covenant on Economic, Social, and Cultural Rights

Under the ICESCR, state parties are obligated to report on their compliance with the Covenant to the CESCR.¹⁵⁰ This obligation is outlined in Article 16 of the ICESCR, which requires states to submit reports on the measures they have adopted, and the progress made in achieving the observance of the rights recognised in the Covenant.¹⁵¹ The regulatory body of the ICESCR is the Committee on the Economic, Social, and Cultural Rights (hereafter referred to as the CESCR) which reviews reports submitted by State parties on the measures they have adopted, and the progress made in achieving the rights outlined in the ICESCR including the health rights for people with albinism.¹⁵² It engages with state parties to assess how well the Covenant's norms are being applied and to provide recommendations for improvement.¹⁵³

¹⁴³ Ibid.

¹⁴⁴ Ibid.

¹⁴⁵ Ibid.

¹⁴⁶ Committee on Economic Social and Cultural Rights, 'General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1 of the Covenant)' (1990) E/1991/23, para 2.

¹⁴⁷ Ibid para 3.

¹⁴⁸ Ibid, para 13.

¹⁴⁹ Ibid.

¹⁵⁰ ICESCR (n 40 above), Article 16.

¹⁵¹ Ibid.

¹⁵² Office of the United Nations High Commissioner for Human Rights (OHCHR), 'Reporting guidelines' (OHCHR, 2023) <<https://www.ohchr.org/en/treaty-bodies/cescr/reporting-guidelines>> accessed 03 November 2024.

¹⁵³ Ibid.

South Africa's report on the right to health, submitted to the CESCR, provides a comprehensive overview of the state's efforts to ensure access to health care for its population.¹⁵⁴ The report addresses various aspects of the right to health, including implementing a universal healthcare plan, improvements in health indicators, and measures to support vulnerable populations such as the elderly and people with disabilities.¹⁵⁵ However, it does not specifically address the health needs of people with albinism, focusing instead on the general right to health care, which includes the right of access to healthcare services. In its concluding observations, the CESCR recommended that South Africa take further steps to ensure that all individuals, including those with albinism, have access to healthcare services.¹⁵⁶

The CESCR issues general comments to provide authoritative guidance on the provisions of the ICESCR.¹⁵⁷ Such general comments are as follows:

General Comment No. 14 of the Committee on the Economic, Social, and Cultural Rights

General Comment No. 14 of the CESCR identifies key elements of the right to health, tailored to each state's circumstances: availability, accessibility, acceptability, and quality.¹⁵⁸ According to the CESCR, availability means that sufficient healthcare facilities, goods, and services must be present, including hospitals, clinics, and trained medical staff.¹⁵⁹ In the context of South Africa, the explanation of the availability of the CESCR¹⁶⁰ requires the government to ensure healthcare services for people with albinism, such as sunscreens, regular skin checks, and access to dermatological care, are readily available in sufficient quantity. This also includes the availability of hospitals and clinics.

¹⁵⁴ Paula Knipe, 'CESCR Concluding Observations on the Initial Report of South Africa' (2020) 21(4) ESR Review <<https://journals.co.za/doi/pdf/10.10520/ejc-esrrev-v21-n4-a8>> accessed 2 September 2024.

¹⁵⁵ Ibid.

¹⁵⁶ Paula Knipe, 'CESCR Concluding Observations on the Initial Report of South Africa' (2020) 21(4) ESR Review <<https://journals.co.za/doi/pdf/10.10520/ejc-esrrev-v21-n4-a8>> accessed 2 September 2024.

¹⁵⁷ Office of the United Nations High Commissioner for Human Rights, Committee on Economic, Social and Cultural Rights (OHCHR) <<https://www.ohchr.org/en/treaty-bodies/cescr>> accessed 2 September 2024.

¹⁵⁸ General Comment No. 14 (n 87 above), para 12.

¹⁵⁹ Ibid.

¹⁶⁰ Ibid.

According to the CESCR in its General Comment No.14, accessibility ensures that health services are accessible to all without discrimination, covering non-discrimination, physical, economic, and information accessibility.¹⁶¹ For South Africa, this explanation of the CESCR¹⁶² means healthcare must be physically accessible, even in rural areas, affordable, and inclusive of information on managing albinism. Acceptability involves health services being culturally appropriate and respecting medical ethics.¹⁶³ For South Africa, this means providing respectful and sensitive care to all individuals including those with albinism. Quality necessitates that health services are scientifically and medically appropriate.¹⁶⁴ This means that South Africa must ensure high standards of care, including skilled dermatologists and quality treatments, for individuals with albinism as a way of upholding the right to health.

General Comment No. 3 of the Committee on the Economic, Social, and Cultural Rights

The CESCR has emphasised in its General Comment No. 3 that states have a fundamental obligation to fulfil minimum essential levels of each right under the ICESCR.¹⁶⁵ While these essential levels can be dependent on resources, they should be prioritised by the state in its efforts to realise the rights under the ICESCR.¹⁶⁶ Drawing from over a decade of reviewing state reports, the CESCR asserts that every state party must ensure at least the minimum essential levels of each right.¹⁶⁷ For example, if a significant number of people in a state lack essential food, healthcare, basic shelter, housing, or fundamental education, the state is failing its obligations under the Covenant.¹⁶⁸ The Covenant would lose its purpose if it did not establish these minimum core obligations.¹⁶⁹ However, any evaluation of whether a state has met these obligations must consider the state's resource constraints.¹⁷⁰ Article 2(2) of the ICESCR requires states to take necessary steps to the maximum of their available resources.¹⁷¹ If a State claims it cannot meet its minimum core obligations due to

¹⁶¹ Ibid.

¹⁶² Ibid.

¹⁶³ Ibid.

¹⁶⁴ Ibid.

¹⁶⁵ General Comment No. 3 (n 137 above).

¹⁶⁶ Ibid.

¹⁶⁷ Ibid.

¹⁶⁸ Ibid.

¹⁶⁹ Ibid.

¹⁷⁰ Ibid.

¹⁷¹ ICESCR (n 40 above).

resource limitations, it must show that it has made every effort to use all available resources to prioritise these obligations.¹⁷²

In the *Social and Economic Rights Action Center v Nigeria*¹⁷³ case, the African Commission on Human and Peoples' Rights (hereafter referred to as ACHPR) adopted the concept of minimum duties concerning the state's obligations to "respect" and "protect" human rights. The Commission held that the Nigerian Government's actions had violated these duties by destroying food sources through its security forces and the State Oil Company, allowing private oil companies to do the same, and creating significant obstacles for the Ogoni communities through terror, thus preventing their efforts to feed themselves.¹⁷⁴

However, in the context of South Africa, courts have historically been reluctant to adopt the "minimum core" obligation principle,¹⁷⁵ particularly before the ICESCR was ratified in 2015.¹⁷⁶ Consequently, it remains uncertain whether this principle will be adopted and what the minimum core of the right to access healthcare services for people with albinism would entail. The government's efforts must reflect a commitment to fulfilling these minimum core obligations, ensuring that all individuals, including those with albinism, receive the necessary healthcare services and support to lead healthy, dignified lives.

2.5.2. The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)

The ICERD is a treaty that aims to eliminate racial discrimination in all its forms and promote understanding among all races.¹⁷⁷ South Africa ratified the ICERD on 10 December 1998, making this treaty binding to South Africa.¹⁷⁸ Article 5(e)(iv) of the

¹⁷² General Comment No. 3 (n 137 above).

¹⁷³ *Social and Economic Rights Action Centre and the Centre for Economic and Social Rights v Nigeria Communication* 155/96 (2001) AHRLR 60.

¹⁷⁴ Ibid, para 66.

¹⁷⁵ *Government of the Republic of South Africa v Grootboom and Others* [2000] ZACC 19, 2001 (1) SA 46 (CC), 2000 (11) BCLR 1169 (CC), para 33; *Minister of Health and Others v Treatment Action Campaign and Others* [2002] ZACC 16, 2002 (5) SA 703 (CC), 2002 (10) BCLR 1075 (CC), para 34; *Mazibuko and Others v City of Johannesburg and Others* [2009] ZACC 28, 2009 (4) SA 1 (CC), 2009 (7) BCLR 637 (CC).

¹⁷⁶ ICESCR (n 40 above).

¹⁷⁷ ICERD (n 41 above).

¹⁷⁸ SAnews, 'Cabinet approves UN ICERD periodic report' (SAnews, 26 February 2021) <<https://www.sanews.gov.za/south-africa/cabinet-approves-un-icerd-periodic-report>> accessed 3 September 2024.

ICERD addresses the right to public health, medical care, social security, and social services. It obligates state parties to ensure that everyone, regardless of race, colour, or national or ethnic origin, has equal access to these essential services.¹⁷⁹ South Africa's ratification of ICERD obligates it to ensure that all individuals, including those with albinism, have equal access to healthcare services.

State Reporting Obligations under the International Convention on the Elimination of All Forms of Racial Discrimination

The regulatory body of the ICERD is the Committee on the Elimination of Racial Discrimination (hereafter referred to as the CERD), which monitors the implementation of ICERD by its state parties. CERD reviews periodic reports submitted by states, provides recommendations, and issues general comments to guide states in fulfilling their obligations under the Convention.¹⁸⁰ The CERD reviewed South Africa's combined ninth to eleventh periodic reports during its meetings in early December 2023.¹⁸¹ In its concluding observations, the Committee highlighted several recommendations regarding persons with albinism in South Africa.¹⁸² The Committee noted a lack of detailed information on the current situation of persons with albinism.¹⁸³ The Committee recommended that it is important to ensure that persons with albinism have equal access to education, healthcare, and employment.¹⁸⁴ Regarding the right of access to healthcare services, the CERD recommended that there is a need for persons with albinism to have access to necessary healthcare services without discrimination.¹⁸⁵ This includes providing specialised healthcare services that address their unique needs, such as skincare and vision support.¹⁸⁶

¹⁷⁹ ICERD (n 40 above).

¹⁸⁰ Office of the United Nations High Commissioner for Human Rights, 'Committee on the Elimination of Racial Discrimination' (OHCHR) <<https://www.ohchr.org/en/treaty-bodies/cerd>> accessed 3 September 2024.

¹⁸¹ Committee on the Elimination of Racial Discrimination, 'Concluding observations on the combined ninth to eleventh periodic reports of South Africa' (27 December 2023) UN Doc CERD/C/ZAF/CO/9-11 <<https://www.ohchr.org/en/documents/concluding-observations/cerdczafco9-11-concluding-observations-combined-ninth-eleventh>> accessed 3 September 2024.

¹⁸² Ibid, para 35.

¹⁸³ Ibid, para 34.

¹⁸⁴ Ibid, para 35.

¹⁸⁵ Ibid.

¹⁸⁶ Ibid.

2.5.3. The International Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)

The CEDAW, a landmark international treaty adopted by the United Nations General Assembly in 1979 aims to eliminate discrimination against women in all forms and promote gender equality.¹⁸⁷ South Africa ratified ICEDAW on 15 December 1995, meaning it is bound to follow its obligations.¹⁸⁸ The ICEDAW includes several provisions addressing the right to health and access to healthcare services.¹⁸⁹ Article 12 requires state parties to take all appropriate measures to eliminate discrimination against women in the field of healthcare to ensure equal access to healthcare services, including those related to family planning.¹⁹⁰ Article 14(2)(b) focuses on rural women, emphasising the need for state parties to ensure they have access to adequate healthcare facilities, including information, counseling, and services in family planning.¹⁹¹ These provisions collectively underscore the importance of ensuring that women have equal access to healthcare services, free from discrimination. For South Africa, as a state party to ICEDAW,¹⁹² these obligations mean that the state must take steps to ensure that women, including those with albinism, have equal access to healthcare services.

State Reporting Obligations under the International Convention on the Elimination of All Forms of Discrimination Against Women

The regulatory body overseeing the implementation of ICEDAW is the Committee on the Elimination of Discrimination Against Women (hereafter referred to as the CEDAW).¹⁹³ This committee is responsible for monitoring the progress of state parties in implementing the treaty's provisions.¹⁹⁴ It reviews periodic reports submitted by member states, dealing with measures taken to eliminate discrimination against women and promote gender equality.¹⁹⁵ The committee also issues general

¹⁸⁷ CEDAW (n 42 above).

¹⁸⁸ University of Minnesota Human Rights Library, 'Convention on the Elimination of All Forms of Discrimination Against Women' (15 December 1995) <<http://hrlibrary.umn.edu/research/ratification-southafrica.html>> accessed 3 September 2024.

¹⁸⁹ CEDAW (n 42 above).

¹⁹⁰ Ibid.

¹⁹¹ Ibid.

¹⁹² Ibid.

¹⁹³ Office of the United Nations High Commissioner for Human Rights, 'Committee on the Elimination of Discrimination Against Women' (OHCHR, 2024) <<https://www.ohchr.org/en/treaty-bodies/cedaw>> accessed 4 November 2024.

¹⁹⁴ Ibid.

¹⁹⁵ Ibid.

recommendations and observations based on these reports to guide countries in their efforts.¹⁹⁶ Member countries of CEDAW, including South Africa, have obligations to submit periodic reports to the committee.¹⁹⁷ These reports must outline the legislative, judicial, administrative, and other measures taken to realise the rights enshrined in the treaty, including the right to access healthcare services.¹⁹⁸

South Africa has submitted periodic reports to the CEDAW Committee, detailing its efforts to implement the provisions of the Convention.¹⁹⁹ In its concluding observations on South Africa's fifth periodic report, issued on 23 November 2023, the Committee made specific recommendations regarding the right to health.²⁰⁰ One key recommendation is that the government should ensure that women with albinism have affordable access to sexual and reproductive health services, free from gender-based violence, discrimination, or harassment.²⁰¹

The CEDAW issues general comments to provide authoritative guidance on the provisions of the ICEDAW.²⁰² One of its general comments is as follows:

General Recommendation No. 24 of the Convention on the Elimination of All Forms of Discrimination Against Women

The CEDAW has made significant strides in promoting women's health rights through its general recommendations. General Recommendation No. 24 is particularly noteworthy as it focuses on women and health, urging state parties to ensure women have access to healthcare services without facing discrimination.²⁰³ One of the important aspects of General Recommendation No. 24 is its emphasis on the health needs of marginalised groups, including women with albinism.²⁰⁴ Women with albinism

¹⁹⁶ Ibid.

¹⁹⁷ United Nations, 'CEDAW Reporting' (UN, 2024) <<https://www.un.org/womenwatch/daw/cedaw/reporting.htm>> accessed 4 November 2024.

¹⁹⁸ Ibid.

¹⁹⁹ UN Committee on the Elimination of Discrimination Against Women (CEDAW), 'Concluding observations on the fifth periodic report of South Africa' (23 November 2023) UN Doc CEDAW/C/ZAF/CO/5 para 54(d) <<https://www.ohchr.org/en/documents/concluding-observations/cedawczafco5-concluding-observations-fifth-periodic-report-south>> accessed 3 September 2024.

²⁰⁰ Ibid.

²⁰¹ Ibid, para 54(d).

²⁰² UN Committee on the Elimination of Discrimination Against Women (CEDAW), 'General Recommendation No. 24: Article 12 of the Convention (Women and Health)' (1999) UN Doc A/54/38/Rev.1, chap. I <<https://www.refworld.org/docid/453882a73.html>> accessed 3 September 2024

²⁰³ Ibid, para 8.

²⁰⁴ Ibid.

often face unique challenges due to their condition, such as increased vulnerability to skin cancer and vision problems as discussed in chapter one of this dissertation. The recommendation calls for state parties to take proactive measures to address these barriers.²⁰⁵ This includes implementing policies and programs that provide specialised healthcare services tailored to the needs of all women, including those with albinism.²⁰⁶ In South Africa, General Recommendation No. 24 of CEDAW shows the need for the government to implement tailored healthcare policies and programs that ensure all women, including those with albinism, have equitable access to essential health services without facing discrimination, thus addressing their unique healthcare challenges.

2.5.4. United Nations Convention on the Rights of the Child (UNCRC)

The UNCRC is a legally binding international agreement that outlines every child's civil, political, economic, social, and cultural rights.²⁰⁷ This instrument has provisions to protect the health rights of vulnerable children, such as those with albinism.²⁰⁸ South Africa ratified the UNCRC on 16 June 1995.²⁰⁹ This means that this instrument is binding for South Africa. Article 24, paragraph 1 of the UNCRC provides that:

States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.²¹⁰

For South Africa as a state party of the UNCRC, Article 24, paragraph 1 of the UNCRC mandates the government to ensure that all children, including those with albinism, have access to the highest attainable standard of health and necessary medical treatments, thereby addressing their unique healthcare needs and safeguarding their right to health.

Article 3, paragraph 1 of the UNCRC mandates that:

²⁰⁵ Ibid, para 17.

²⁰⁶ Ibid.

²⁰⁷ UNCRC (n 43 above).

²⁰⁸ Ibid, Article 24(1).

²⁰⁹ Parliament of South Africa, 'United Nations Convention on the Rights of the Child' (16 June 1995) <https://www.parliament.gov.za/storage/app/media/Pages/2021/november/17-11-2021_parliament_unicef_webinar/presentations/3.Final_Prof_Ann_Skelton_UN_CRC_Parliament.pdf> accessed 3 September 2024.

²¹⁰ UNCRC (n 43 above).

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.²¹¹

For South Africa, Article 3, paragraph 1 of the UNCRC requires that in all decisions and actions taken by any public or private institutions, including those affecting children with albinism, the best interests of the child must be the foremost consideration, ensuring their welfare and protection are prioritised above all else.²¹² Article 24, paragraph 2 (b) emphasises that countries should ensure all children have access to necessary medical assistance and healthcare, focusing on primary healthcare.²¹³ For children with albinism in South Africa as a party to the UNCRC, this arguably means that health services must be readily accessible within their local communities, facilitating regular and immediate care.

State Reporting Obligations under the United Nations Committee on the Rights of the Child

The regulatory body responsible for overseeing the implementation of the UNCRC is the Committee on the Rights of the Child (hereafter referred to as the CRC).²¹⁴ The Committee reviews the reports submitted by member states, provides feedback in the form of concluding observations, and makes recommendations to guide states in improving their compliance with the Convention.²¹⁵ According to Article 44 of the Convention, states must submit an initial report within two years of ratifying the Convention and subsequent periodic reports every five years or as requested by the CRC.²¹⁶ These reports should detail the measures taken to implement the rights recognised in the Convention and the progress made in their enjoyment.²¹⁷ This means that South Africa, as a signatory to the UNCRC,²¹⁸ is obligated to regularly submit detailed reports to the UNCRC, outlining the steps it has taken to protect and promote children's rights, including the right to health and access to healthcare services for children with albinism.

²¹¹ Ibid.

²¹² Ibid.

²¹³ Ibid.

²¹⁴ Office of the United Nations High Commissioner for Human Rights, 'Committee on the Rights of the Child' (OHCHR) <<https://www.ohchr.org/en/treaty-bodies/crc>> accessed 3 September 2024.

²¹⁵ Ibid.

²¹⁶ Ibid.

²¹⁷ Ibid.

²¹⁸ Parliament of South Africa (n 131 above).

In its combined third to sixth periodic reports, considered by the CRC on 11 March 2024, the Committee expressed concerns about limited and inequitable access to universal healthcare for children, reflecting socioeconomic disparities in South Africa.²¹⁹ This can be said to include vulnerable children such as those with albinism although albinism was not directly mentioned. The Committee recommended that South Africa expand the access, coverage, and quality of healthcare equitably across the state, particularly for children from disadvantaged backgrounds.²²⁰ This means that South Africa must provide adequate human, technical, and financial resources and strengthen the capacity of health professionals to ensure equitable access to quality healthcare for all children, including those with albinism.

The CRC issues general comments to provide authoritative guidance on the provisions of the UNCRC.²²¹ One of its general comments is as follows:

General Comment No. 15 of the United Nations Convention on the Rights of the Child

According to General Comment No. 15 of the CRC, the principle of a child's best interests must be upheld in all health-related decisions affecting children, individually or in groups.²²² For children with albinism in South Africa, this provision imposes an obligation on the state to ensure that all legislation and administrative decisions prioritise their best interests. This means that South African laws must provide for the specific health needs of children with albinism, such as skin protection and vision care. Administrative decisions should also prioritise these children's best interests by implementing policies and interventions that address their unique challenges.

2.5.5. Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD is an international human rights treaty adopted by the United Nations in 2006 that covers various aspects of life, including accessibility, personal mobility, health, education, employment, and participation in political and public life. South

²¹⁹ UN Committee on the Rights of the Child (CRC), Concluding Observations on the Combined Third to Sixth Periodic Reports of South Africa (CRC/C/ZAF/CO/3-6), 11 March 2024, para 34(a).

²²⁰ Ibid, para 35(a).

²²¹ UN Committee on the Elimination of Discrimination Against Women (CEDAW), 'General Recommendation No. 24: Article 12 of the Convention (Women and Health)' (1999) UN Doc A/54/38/Rev.1, chap. I <<https://www.refworld.org/docid/453882a73.html>> accessed 3 September 2024

²²² UN Committee on the Rights of the Child (CRC), General Comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health, CRC/C/GC/15, 17 April 2013, para 13.

Africa ratified the CRPD on 30 November 2007, meaning that this treaty is binding to South Africa.²²³ Article 25 of the CRPD provides that state parties recognise that individuals with disabilities have the right to enjoy the highest attainable standard of health without facing discrimination based on their disabilities.²²⁴ To ensure this, state parties must take all necessary measures to provide access to health services that are sensitive to gender and include health-related rehabilitation.²²⁵ State parties are committed to offering persons with disabilities the same range, quality, and standard of free or affordable healthcare and programs as those available to others. This includes services related to sexual and reproductive health and public health programs.²²⁶ They must provide health services specifically needed due to disabilities, such as early identification and intervention, and services designed to minimise and prevent further disabilities, particularly for children and older persons.²²⁷

The CRPD further states that health services should be made available as close as possible to individual communities, including those in rural areas.²²⁸ Health professionals are required to deliver care of the same quality to persons with disabilities as they do to others, based on free and informed consent. This involves raising awareness about the human rights, dignity, autonomy, and needs of persons with disabilities through training and the establishment of ethical standards for both public and private healthcare providers.²²⁹ Furthermore, state parties must prohibit discrimination against persons with disabilities in the provision of health and life insurance, ensuring these are provided fairly and reasonably as permitted by national law.²³⁰ They must also prevent the discriminatory denial of healthcare, health services, or essential food and fluids based on disability.²³¹

Article 25 of the CRPD ensures that persons with disabilities have the right to the highest attainable standard of health without discrimination. It mandates that state parties take appropriate measures to provide access to health services that are gender-sensitive and include health-related rehabilitation. This provision emphasises

²²³ CRPD (n 44 above).

²²⁴ Ibid.

²²⁵ Ibid.

²²⁶ Ibid, (n 43 above), Article 25(a).

²²⁷ Ibid, (n 43 above), Article 25(b).

²²⁸ Ibid, (n 43 above), Article 25(c).

²²⁹ Ibid, (n 43 above), Article 25(d).

²³⁰ Ibid, (n 43 above), Article 25(e).

²³¹ Ibid, (n 43 above), Article 25(f).

the need for equal access to health care, ensuring that persons with disabilities receive the same range, quality, and standard of healthcare as others. It also highlights the importance of providing specific health services required due to disabilities, early identification and intervention, and services aimed at minimising and preventing further disabilities.²³²

For South Africa, as a state party to the CRPD, this means that the state is obligated to ensure that persons with disabilities, including those with albinism, have access to comprehensive healthcare services. South Africa must provide these services without discrimination and ensure they are available as close as possible to people's communities, including rural areas. Health professionals in South Africa must be trained to provide care of the same quality to persons with disabilities as to others, based on free and informed consent. South Africa must prohibit discrimination in the provision of health insurance and prevent the discriminatory denial of healthcare or health services. Considering Article 25 of the CRPD,²³³ South Africa is obligated to provide early intervention services for children with albinism. This includes ensuring access to dermatological care to protect their skin from the harmful effects of the sun and providing regular eye examinations and corrective measures to address vision impairments. Early intervention can significantly reduce the risk of developing severe skin conditions and permanent vision loss.

In *Y v Republic of Tanzania*²³⁴ the author had albinism and at the age of 12, was attacked in the Geita Region by a man with a machete who severed three fingers from his right hand and inflicted severe injuries on his left shoulder, leaving him unable to use his right hand and left arm. Despite escaping the attacker, the author was left wounded and received no medical aid or rehabilitation from the State party.²³⁵ The Committee found that the State party violated the author's rights under Article 16 of the CRPD. Article 16 (4) of the Convention requires States parties to take all appropriate measures to promote the physical, cognitive, and psychological recovery, rehabilitation, and social reintegration of persons with disabilities who become victims of exploitation, violence, or abuse, including providing protection services. The State

²³² Ibid, (n 43 above), Article 25.

²³³ Ibid.

²³⁴ *Y v Republic United of Tanzania Communication 023/2014*.

²³⁵ Ibid, para 2.4.

party's failure to provide any medical care or assistance for the author's rehabilitation constituted a breach of these obligations.²³⁶ This Communication underscores the significance of State parties including South Africa to provide medical assistance persons with disabilities, including those with albinism, who become victims of exploitation, violence, or abuse.

State Reporting Obligations under the CRPD Committee

The Committee on the Rights of Persons with Disabilities (hereafter referred to as the Committee) is the regulatory body responsible for overseeing the implementation of the Convention on the Rights of Persons with Disabilities. This committee is composed of independent experts who review the progress of state parties in fulfilling their obligations under the Convention.²³⁷ Under Article 35 of the CRPD, state parties have obligations to submit regular reports to the Committee on the measures they have taken to implement the CRPD and the progress made in this regard.²³⁸ The Committee reviews these reports and provides feedback in the form of “concluding observations,” which include recommendations for further action.²³⁹ As a member state that ratified the CRPD in 2007,²⁴⁰ South Africa is obligated to submit detailed reports on its progress in implementing the CRPD.

In 2018, South Africa submitted its initial report to the Committee, detailing the measures taken to implement the provisions of the Convention, which included the right to health and access to healthcare services for persons with disabilities.²⁴¹ The committee indicated that there was a need for better access to healthcare services for persons with disabilities.²⁴² The report acknowledged that while there have been efforts to improve healthcare access, significant gaps remain, particularly in rural and underserved areas.²⁴³ The Committee emphasised the importance of making

²³⁶ Ibid, para 8.8.

²³⁷ Office of the United Nations High Commissioner for Human Rights, ‘Committee on the Rights of Persons with Disabilities’ (OHCHR) <<https://www.ohchr.org/en/treaty-bodies/crpd>> accessed 3 September 2024.

²³⁸ CRPD (n 43 above).

²³⁹ Office of the United Nations High Commissioner for Human Rights (n 223 above).

²⁴⁰ ‘Committee on the Rights of Persons with Disabilities examines the report of South Africa’ (OHCHR 2018) <<https://www.ohchr.org/en/press-releases/2018/08/committee-rights-persons-disabilities-examines-report-south-africa>> accessed 13 November 2024.

²⁴¹ Committee on the Rights of Persons with Disabilities, ‘Concluding Observations on the Initial Report of South Africa’ (UN Committee on the Rights of Persons with Disabilities 2018) 1.

²⁴² Ibid, para 42(a) and (b).

²⁴³ Ibid, para 43(a).

healthcare services more accessible and ensuring they are of high quality and responsive to the needs of persons with disabilities.²⁴⁴ This includes training healthcare professionals to provide appropriate care for people with disabilities.²⁴⁵ The Committee's emphasis on improving access to high-quality, responsive healthcare services and training for healthcare professionals highlights South Africa's obligation under the CEDAW to ensure that all women and girls including those with albinism, receive equitable and appropriate healthcare.

General comment No. 3 on Women and Girls with Disabilities of the CRPD Committee

General comment No 3 shows the availability of strong evidence to show that women and girls with disabilities face barriers in most areas of life including access to healthcare services.²⁴⁶ In its wide explanation of people with disabilities, albinism is included. As a result, this General comment calls upon the member states of the CPRD, including South Africa, to take additional measures with regard to health of women and girls with disabilities, which includes those with albinism, and that such measures are necessary.²⁴⁷ This General Comment emphasises that States parties to the Convention are required to respect, protect, and fulfill the rights of women with disabilities. These stated obligations to respect, protect, and to fulfil are similar to those discussed by this dissertation earlier on which were established by the CESCR in General Comment No. 14. According to the CPRD, this obligation extends not only under Article 6 but also across all other substantive provisions of the Convention. The aim is to ensure that women with disabilities including those with albinism can fully enjoy and exercise all their human rights and fundamental freedoms, including their right to access healthcare services.²⁴⁸

2.6. AFRICAN REGIONAL INSTRUMENTS

2.6.1. African Charter on Human and Peoples' Rights (ACHPR)

The ACHPR is a significant human rights instrument adopted by the Organisation of African Unity on 27 June 1981.²⁴⁹ South Africa ratified the African Charter on 9 July

²⁴⁴ Ibid.

²⁴⁵ Ibid, para 43(c).

²⁴⁶ United Nations Committee on the Rights of Persons with Disabilities, 'General Comment No. 3 (2016) on Women and Girls with Disabilities' (25 November 2016) UN Doc CRPD/C/GC/3.para 2.

²⁴⁷ Ibid, para 21.

²⁴⁸ Ibid, para 24.

²⁴⁹ ACHPR (n 45 above).

1996,²⁵⁰ meaning that this instrument is binding to South Africa. The ACHPR has provisions to protect the health rights of vulnerable groups such as people with albinism.

The ACHPR addresses the right to health in Article 16. It states:

Every individual shall have the right to enjoy the best attainable state of physical and mental health. States parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.²⁵¹

Considering Article 16 of the ACHPR,²⁵² South Africa is obligated to ensure that individuals, including those with albinism, have the right to the highest attainable standard of physical and mental health. This would entail taking necessary measures to protect their health, ensuring they have access to medical attention when sick, and implementing specific policies and programs to address their unique healthcare needs.

In *Egyptian Initiative for Personal Rights and INTERIGHTS v Egypt*,²⁵³ the complainant represented four women who were victims of violence during a protest organized by the Egyptian Movement for Change. During the protest, riot police surrounded the demonstrators and allowed members of the National Democratic Party, sometimes acting on instructions from State Security Intelligence (SSI) officers, to beat, insult, intimidate, and sexually harass the victims. When the victims filed complaints with the domestic authorities, they were further threatened by SSI officers and other unidentified men to withdraw their statements. The complainant argued that these actions violated the African Charter on Human and Peoples' Rights. The African Commission on Human and Peoples' Rights found that the state's actions violated the victims' freedom of expression under Article 9 and their right to health under Article 16(1).

²⁵⁰ Ibid.

²⁵¹ Ibid.

²⁵² Ibid.

²⁵³ *Egyptian Initiative for Personal Rights and INTERIGHTS v Egypt* December 2011, ACHPR, 323/06, 10th Extra-ordinary Session.

Resolution 141 of the African Commission of Human and People's Rights (ACHPR)

The Resolution on Access to Health and Needed Medicines in Africa, adopted by the ACHPR in November 2008, emphasises the significance of ensuring access to health services and essential medicines as a fundamental human right.²⁵⁴ This resolution is particularly pertinent to South Africa's obligations to the health rights of people with albinism. Its preamble sets the foundation by reaffirming that Article 16 of the ACHPR guarantees the right to the best attainable state of physical and mental health.²⁵⁵ It emphasises that states must ensure everyone has access to medical care.²⁵⁶ The preamble highlights alarming statistics about the availability of essential medicines in Africa, underscoring the urgency of addressing this issue.²⁵⁷ Furthermore, it stresses that the right to health extends beyond healthcare services to include all underlying determinants of health, such as access to needed medicines for treatment, prevention, and palliative care.²⁵⁸ The preamble recognises access to medicines as fundamental to the right to health and acknowledges the obligation of states to provide or facilitate access to them.²⁵⁹

The resolution calls on states to guarantee comprehensive access to needed medicines, covering aspects such as their availability in sufficient quantities, accessibility without discrimination, and the acceptability and quality of medicine supplies.²⁶⁰ It outlines the necessity for physical, economic, and informational accessibility to medicines, ensuring they are safe, effective, and culturally appropriate.²⁶¹ The resolution also urges states to refrain from actions that hinder access to medicines, such as discriminatory practices or interference with humanitarian aid, and to protect access through regulatory systems.²⁶² Additionally, it mandates positive measures to promote access, including the creation of national

²⁵⁴ The Resolution on Access to Health and Needed Medicines in Africa (ACHPR/Res.141 (XXXXVIII) 08), adopted by the African Commission on Human and Peoples' Rights in November 2008.

²⁵⁵ Ibid.

²⁵⁶ Ibid.

²⁵⁷ Ibid.

²⁵⁸ Ibid.

²⁵⁹ Ibid.

²⁶⁰ Ibid.

²⁶¹ Ibid.

²⁶² Ibid.

medicine strategies, participation of affected individuals in decision-making, and expedited regulatory processes for needed medicines.²⁶³

For South Africa, this resolution means adopting comprehensive measures to ensure that all people, including those with albinism, have access to necessary healthcare services and medicines. This entails addressing socio-economic barriers that hinder access and ensuring that medicines are available, affordable, and culturally acceptable. The resolution reinforces South Africa's obligations to provide inclusive healthcare services to all, including marginalised groups like people with albinism.

Principles And Guidelines on The Implementation of Economic, Social and Cultural Rights in the African Charter on Human and Peoples' Rights

According to these guidelines, the minimum core obligations of the right to health require ensuring access to health facilities, goods, and services on a non-discriminatory basis, particularly for vulnerable or marginalised groups.²⁶⁴ National plans must prioritise the health care needs of these groups, ensuring they have access to affordable health facilities, infrastructure, goods, and services without any form of discrimination.²⁶⁵ States parties are obligated to distribute health facilities, goods, and services equitably and to implement measures that ensure physical access for all, especially for vulnerable and disadvantaged groups. Additionally, health indicators, such as maternal mortality rates, should be disaggregated by various factors, including rural/urban location, sex, and race, to ensure there is no discrimination in access to and use of the health system.²⁶⁶

For people with albinism in South Africa, these guidelines mean that their specific health needs must be recognised and addressed within the national health system. This includes ensuring they have access to specialised care, such as dermatological services, regular skin cancer screenings, and visual aids. The equitable distribution of health services must also consider the unique challenges faced by persons with albinism, such as their heightened vulnerability to skin cancer and visual impairments.

²⁶³ Ibid.

²⁶⁴ African Commission on Human and Peoples' Rights, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and Peoples' Rights' (24 October 2011) AU Doc CAB/LEG/24.12/18, para 67 (a).

²⁶⁵ Ibid, para 67 (x).

²⁶⁶ Ibid, para 67 (y).

The African Commission Resolution on the Regional Action Plan on Albinism in Africa

In its resolution, the African Commission on Human and Peoples' Rights acknowledged the significant human rights challenges faced by people with albinism. The Commission called on State parties to adopt specific measures to address attacks and discrimination against persons with albinism.²⁶⁷ These measures include prevention, protection, accountability, and ensuring equality and non-discrimination. The resolution also urged States Parties to take all necessary steps to adopt and implement the Regional Action Plan on Albinism in Africa, which aims to ensure the effective protection and promotion of the rights of persons with albinism and their families.²⁶⁸ For people with albinism in South Africa, this resolution means that the government is encouraged to take proactive steps to safeguard their rights. This includes implementing policies and programs that prevent violence and discrimination, providing protection and support services, holding perpetrators accountable, and promoting equality and non-discrimination.

2.6.2. African Charter on the Rights and Welfare of the Child (ACRWC)

The ACRWC is a regional human rights instrument specifically designed to address the unique challenges faced by children in Africa. Adopted by the Organisation of African Unity on 11 July 1990, and coming into force on 29 November 1999, the ACRWC sets out comprehensive rights and principles to ensure the well-being and development of children across the continent. This instrument also contains provisions that protect the right of access to healthcare services for vulnerable children, such as children with albinism. South Africa ratified the ACRWC on 7 January 2000,²⁶⁹ formally agreeing to be bound by the provisions of the Charter and committing to implement its principles and obligations within its national legal framework. South Africa has an obligation to report periodically to the African Committee of Experts on the Rights and Welfare of the Child on the progress and challenges in implementing the Charter including the right of access to healthcare services for children including those with albinism.²⁷⁰

²⁶⁷ Resolution on the Regional Action Plan on Albinism in Africa (2017-2021) ACHPR/Res.373(LX)2017

²⁶⁸ Ibid.

²⁶⁹ ACRWC (n 47 above).

²⁷⁰ African Committee of Experts on the Rights and Welfare of the Child, 'State Party Reporting' (ACERWC) <<https://www.acerwc.africa/en/state-party-reporting>> accessed 3 September 2024.

Article 14(2)(b) of the ACRWC requires state parties to ensure the provision of necessary medical assistance and healthcare to all children, with a particular focus on primary healthcare.²⁷¹ Arguably, this provision imposes an obligation on South Africa as a state party to the ACRWC to make healthcare services accessible to all children, emphasising community-based primary healthcare.

2.6.3. Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol)

The Maputo Protocol is a human rights treaty adopted by the African Union in 2003 to promote and protect the rights of women in Africa, focusing on issues such as health, education, and gender equality.²⁷² Article XIV (1) of the Maputo Protocol mandates that countries must ensure women's health rights, including sexual and reproductive health, are upheld and promoted.²⁷³ Article XIV (2) requires countries to take necessary actions to provide adequate, affordable, and accessible health services, along with information, education, and communication programs, particularly for women in rural areas.²⁷⁴ For women with albinism in South Africa, these provisions mean they should have equal access to comprehensive health services and educational programs that address their unique health needs and challenges, ensuring their right to health is protected and promoted.

²⁷¹ ACRWC (n 47 above).

²⁷² African Union, Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (adopted 11 July 2003, entered into force 25 November 2005) AU Doc CAB/LEG/66.6.

²⁷³ Ibid.

²⁷⁴ Ibid.

2.6.4. Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (Disability Rights Protocol)

The Disability Rights Protocol is a treaty adopted by the African Union to protect and promote the rights of persons with disabilities across Africa.²⁷⁵ Article 1 of the protocol states that every person with a disability has the right to the highest attainable standard of health. Article 2 requires State parties to ensure that persons with disabilities have equal access to health services, including sexual and reproductive health.²⁷⁶ This includes providing the same range, quality, and standard of free or affordable healthcare and programs as those available to others. Additionally, it mandates the provision of health services specifically needed by persons with disabilities, such as those designed to minimise or prevent further disability, and the provision of necessary medicines, including pain-relieving drugs. The article also emphasizes that healthcare services should be provided in accessible formats and that effective communication between healthcare providers and persons with disabilities is essential. Furthermore, it calls for the training of healthcare providers to consider the specific needs and rights of persons with disabilities.²⁷⁷

For people with albinism in South Africa, this dissertation posits that these provisions mean they should have equal access to comprehensive health services tailored to their unique needs, including skin care and protection from the sun, which are critical for their health. It also ensures that healthcare providers are trained to understand and address the specific health challenges faced by people with albinism, promoting their overall well-being and protecting their right to health.

2.7. SOUTHERN AFRICAN DEVELOPMENT COMMUNITY (HEREAFTER REFERRED TO AS THE SADC) INSTRUMENTS

2.7.1. Declaration on the Protection of Persons with Albinism (DPPA)

DPPA adopted and signed by the SADC during the 44th Ordinary Summit of Heads of State and Government held on 17 August 2024, in Harare, Zimbabwe, is a crucial

²⁷⁵ African Union, Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (adopted 29 January 2018, entered into force 10 February 2020) AU Doc CAB/LEG/704.1.

²⁷⁶ Ibid.

²⁷⁷ Ibid.

initiative aimed at improving healthcare access for people with albinism.²⁷⁸ It recognises the unique health challenges faced by persons with albinism, such as the increased risk of skin cancer due to sun exposure and the need for specialised medical care.²⁷⁹ The Declaration underscores the commitment of SADC member states including South Africa, to non-discrimination and emphasises the importance of coordinated efforts to improve healthcare services for people with albinism.²⁸⁰ This includes ensuring the availability of sunscreen and other protective measures and improving access to specialised medical services.²⁸¹ This instrument must be considered in the interpretation of the Bill of Rights because the Constitutional Court in *S v Makwanyane and Another*²⁸² stated that the international law that must be considered in interpreting the Bill of Rights includes both binding and non-binding international laws. The DPPA can serve as valuable guidance for South Africa because it provides a framework and best practices for protecting the rights and well-being of persons with albinism.

Article 2(b) of the DPPA provides for protective measures and the state parties undertakes to:

- (iii) train all health-care workers of all kinds on all issues relevant to the human rights of persons with albinism.
- (iv) put in place social schemes or services that address economic, psychological, education, and healthcare needs of persons with albinism and;
- (v) ensure that sunscreen lotion is on national lists of essential medicines and ensure that it is available to persons with albinism in the remotest regions and areas.²⁸³

This article outlines several key measures that state parties intend to take to improve healthcare access for individuals with albinism. Firstly, state parties undertook to ensure the training of all healthcare workers on issues relevant to the human rights of persons with albinism.²⁸⁴ This would ensure that healthcare providers are

²⁷⁸ Southern African Development Community, 'Declaration on the Protection of Persons with Albinism' (17 August 2024) <<https://www.sadc.int/latest-news/declaration-protection-persons-albinism-17-august-2024>> accessed 3 September 2024.

²⁷⁹ Ibid.

²⁸⁰ Ibid.

²⁸¹ Ibid.

²⁸² *Makwanyane* (n 37 above).

²⁸³ DPPA (n 46 above).

²⁸⁴ Ibid, Article 2(b)(iii).

knowledgeable and sensitive to the unique needs and challenges faced by this group, leading to better and more inclusive healthcare services. Secondly, the state parties under the above article undertook to establish social schemes or services that address the economic, psychological, educational, and healthcare needs of persons with albinism.²⁸⁵ This approach would ensure that individuals with albinism receive good support, including access to necessary medical care. Thirdly, the state parties undertook to make sunscreen lotion available as an essential medicine.²⁸⁶ This commitment would address a critical health need for persons with albinism, who are particularly vulnerable to skin damage and cancer due to sun exposure, by ensuring that sunscreen is included in national lists of essential medicines and is accessible even in the remotest regions.

Adopting the DPPA's above provisions would enable South Africa to comply with its obligations under various international human rights instruments discussed in this dissertation. For instance, CRPD, as already discussed, particularly Article 25, emphasises the right to health for persons with disabilities and mandates states to provide healthcare services without discrimination.²⁸⁷ South Africa would align with CRPD's requirements and ensure non-discriminatory healthcare access by implementing the commitments it made under the DPPA, such as training healthcare workers about the needs of persons with albinism, as this would make these healthcare workers provide equitable healthcare services for people with albinism.²⁸⁸

Furthermore, the ICESCR, as already discussed in this chapter,²⁸⁹ General Comment No. 14 emphasises the right to the highest attainable standard of health, which includes obligations for states to take deliberate steps to ensure equal access to healthcare services.²⁹⁰ The DPPA's focus on making sunscreen and specialised dermatological care available²⁹¹ aligns with the ICESCR's broader obligations to progressively realise the right to health and ensure that everyone has access to essential health services²⁹² including people with albinism. This helps South Africa

²⁸⁵ Ibid, Article 2(b)(iv).

²⁸⁶ Ibid, Article 2(b)(v).

²⁸⁷ CRPD (n 44 above).

²⁸⁸ Ibid, Article 2(b)(iii).

²⁸⁹ ICESCR (n 40 above).

²⁹⁰ General Comment No. 14 (n 87 above), para 12.

²⁹¹ DPPA (n 46 above), Article 2(b)(v).

²⁹² ICESCR (n 40 above), Article 2(1).

fulfill its commitments under this Covenant by addressing the specific healthcare needs of persons with albinism.

The ACHPR as already discussed in this chapter, especially Article 16, asserts the right to health and obligates states to ensure access to medical care.²⁹³ Resolution 141 of the ACHPR underscores the importance of access to essential medicines and healthcare services.²⁹⁴ South Africa would adhere to both regional standards and its broader international human rights obligations by implementing the DPPA's directives to include sunscreen as an essential medicine and ensure its availability even in remote areas.²⁹⁵ This implementation would support the implementation of the Charter's principles by ensuring that persons with albinism have access to necessary health protections and services.

South Africa can enhance the healthcare rights and access for persons with albinism by implementing its commitments outlined in the DPPA.²⁹⁶ This alignment would not only show its commitment to the SADC region's initiatives but also ensure its compliance with established international human rights norms and standards. This comprehensive approach shows the relevance and necessity of incorporating the DPPA²⁹⁷ into national policies to uphold and protect the health rights of this vulnerable population effectively.

2.8. CONCLUSION

This chapter addressed the alluded question of South Africa's obligations under international human rights law to provide access to healthcare services for people with albinism, clarifying such obligations. South Africa has clear obligations to provide access to health healthcare services to people with albinism under the international human rights law. These obligations include respecting their right to access healthcare by not hindering it, protecting this right by enacting and enforcing relevant laws, and fulfilling this right by taking proactive steps such as creating laws, setting up administrative systems, allocating budgets, and promoting health initiatives. The right of access to healthcare services for people with albinism is recognised under various

²⁹³ ACHPR (n 45 above).

²⁹⁴ The Resolution on Access to Health and Needed Medicines in Africa 141 (n 236 above).

²⁹⁵ DPPA (n 46 above), Article 2(b)(v).

²⁹⁶ DPPA (n 46 above).

²⁹⁷ Ibid.

international instruments, which South Africa has ratified and those not ratified as discussed. These instruments mandate that South Africa must ensure access to healthcare for all its citizens, including marginalised groups like people with albinism. The following chapter clarifies South Africa's constitutional obligations regarding their right of access to healthcare services, supported by court judgments to clarify these obligations.

CHAPTER THREE

AN ANALYSIS OF SOUTH AFRICA'S CONSTITUTIONAL OBLIGATIONS TO PROVIDE ACCESS TO HEALTHCARE SERVICES FOR PEOPLE WITH ALBINISM

3.1. INTRODUCTION

The previous chapter clarified South Africa's obligations under international human rights law to provide access to healthcare services for people with albinism. This chapter clarifies South Africa's constitutional obligations regarding their right of access to healthcare services, supported by court judgments to clarify these obligations. Section 2 of the Constitution establishes it as the state's supreme law and provides that any law or conduct inconsistent with it is invalid.²⁹⁸ This section also mandates the fulfilment of the Constitution's obligations.²⁹⁹ This supremacy of the Constitution provided by its section 2³⁰⁰ extends to the right of access to healthcare services, making any law or conduct that is inconsistent with this right invalid.

Section 7(2) of the Constitution further mandates the state to respect, protect, promote, and fulfil the rights enshrined in the Bill of Rights, including the right to access healthcare services.³⁰¹ This right is protected under section 27(1)(a) of the Constitution, which guarantees every person the right to access both general and reproductive healthcare services reflecting the international human rights law standards.³⁰² This chapter provides that the right of access to healthcare services in the Constitution imposes negative and positive obligations on the state.³⁰³ In line with international law, specifically the ICESCR,³⁰⁴ as clarified by the CESCR in its General Comment No.14, the realisation of this right is not immediate or absolute; it is subject to conditions such as the availability of resources and the principle of progressive realisation.³⁰⁵ These conditions are also provided by section 27(2) of the Constitution, which provides that the state must take reasonable legislative and other measures

²⁹⁸ The Constitution of the Republic of South Africa, 1996.

²⁹⁹ Ibid, sec 2.

³⁰⁰ Ibid.

³⁰¹ Ibid.

³⁰² The Constitution of the Republic of South Africa, 1996.

³⁰³ Ibid.

³⁰⁴ ICESCR (n 40 above), Article 2(1).

³⁰⁵ General Comment No. 14 (n 87 above), para 30.

within its available resources to ensure the progressive realisation of the right of access to healthcare services.³⁰⁶ The negative and positive obligations of the state on the right of access to healthcare services for people with albinism are clarified in this chapter. The chapter concludes with a summary of the key analyses and insights discussed within it.

3.2. OBLIGATIONS TO RESPECT, PROTECT, PROMOTE, AND FULFIL

Section 7(2) of the Constitution provides that the state must respect, protect, promote, and fulfil the rights in the Bill of Rights.³⁰⁷ In the case of *Glenister v President of the Republic of South Africa and Others*,³⁰⁸ former Chief Justice Ngcobo elucidated these four obligations under section 7(2) of the Constitution. He articulated that section 7(2) mandates the state to "respect, protect, promote, and fulfil" the rights enshrined in the Bill of Rights.³⁰⁹ He further stated that this duty extends beyond merely refraining from actions that would infringe or limit these rights.³¹⁰ According to him, the duty imposes positive duties on the state to actively take deliberate and reasonable measures to ensure that all fundamental rights contained in the Bill of Rights are realised and upheld.³¹¹

Considering the former Chief Justice Ngcobo's articulation of the obligations under section 7(2) of the Constitution,³¹² this dissertation asserts that these obligations impose negative duties on South Africa to refrain from actions that would infringe upon the right of access to healthcare services. Furthermore, this dissertation posits that these obligations also impose positive duties on South Africa to take deliberate and reasonable measures to ensure that the right of access to healthcare services is realised and upheld, including for individuals with specific vulnerabilities, such as people with albinism. This includes ensuring that all necessary steps are taken to provide adequate healthcare services to people with albinism and address their unique medical needs.

³⁰⁶ The Constitution of the Republic of South Africa, 1996.

³⁰⁷ Ibid.

³⁰⁸ *Glenister v President of the Republic of South Africa and Others* (CCT 48/10) [2011] ZACC 6; 2011 (3) SA 347 (CC); 2011 (7) BCLR 651 (CC)

³⁰⁹ Ibid, para 105.

³¹⁰ Ibid.

³¹¹ Ibid.

³¹² Ibid.

In the case of *Sonke Gender Justice NPC v President of the Republic of South Africa and Others*,³¹³ Justice Theron articulated the meaning of obligations to respect, protect, promote, and fulfil human rights in the Constitution.³¹⁴ She stated that the duty to "respect" requires the state to refrain from any actions that would violate these rights.³¹⁵ The duty to "protect" involves the state taking positive steps to safeguard individuals' rights from being infringed by others.³¹⁶ The duty to "fulfil" mandates the state to implement measures that enable individuals and communities to fully realise their rights.³¹⁷ Additionally, the duty to "promote" includes raising awareness and educating the public about these rights, ensuring that everyone is informed and able to exercise them effectively.³¹⁸

Justice Theron further showed that the obligations under section 7(2) of the Constitution can be interpreted in light of international law.³¹⁹ General Comment No.14 of the CESCR which is international law, as discussed in chapter two of this dissertation, clarifies the meaning of the obligations to respect, protect, and fulfil human rights.³²⁰ According to this General Comment, the obligation to respect requires states to avoid actions that directly or indirectly harm individuals' health rights.³²¹ This includes refraining from policies or practices that would negatively impact the health of individuals or groups, thereby ensuring that the state does not violate the right to health.³²² The obligation to protect includes adopting legislation or taking measures to ensure equal access to healthcare services provided by third parties.³²³ Lastly, the obligation to fulfil requires states to take specific actions to realise the rights. This entails recognising the right to health within national legal and political systems, preferably through legislative measures.³²⁴

³¹³ *Sonke Gender Justice NPC v President of the Republic of South Africa and Others* (CCT307/19) [2020] ZACC 26; 2021 (3) BCLR 269 (CC).

³¹⁴ *Ibid*, para 41.

³¹⁵ *Ibid*.

³¹⁶ *Ibid*.

³¹⁷ *Ibid*.

³¹⁸ *Ibid*.

³¹⁹ *Ibid*, para 11.

³²⁰ General Comment No. 14 (n 87 above), para 34.

³²¹ *Ibid*.

³²² *Ibid*.

³²³ *Ibid*.

³²⁴ *Ibid*.

In light of the explanation by the CESC in its General Comment No.14 of the obligations to respect, promote, and fulfil human rights³²⁵ and Justice Theron's articulation of the meaning of the obligations to respect, protect, promote, and fulfil human rights in the Constitution, this dissertation asserts that the obligations under section 7(2) of the Constitution³²⁶ in South Africa regarding the right of access to healthcare services for people with albinism entails that South Africa must refrain from actions that would infringe on their health rights and must take deliberate, reasonable measures to ensure that these individuals have equal access to healthcare services. This would include adopting specific legislative measures, ensuring that healthcare services are not compromised by privatisation, and addressing the unique health needs of people with albinism through comprehensive health policies and regulations. This would also include educating them about their health rights. This approach would not only align with international standards discussed in the previous chapter of this dissertation but also ensure that the health rights of vulnerable populations, such as people with albinism, are adequately protected and fulfilled within South Africa's constitutional framework.

3.3. INTRODUCTION TO SECTION 27 OBLIGATIONS IN THE SOUTH AFRICAN CONSTITUTION

Section 27 of the Constitution provides that:

- (1) Everyone has the right to have access to—
 - (a) health care services, including reproductive health care;
 - (b) sufficient food and water; and
 - (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
- (2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.
- (3) No one may be refused emergency medical treatment.³²⁷

³²⁵ Ibid.

³²⁶ The Constitution of the Republic of South Africa, 1996.

³²⁷ Ibid.

This chapter focuses on section 27(1)(a) of the Constitution concerning the right to access healthcare services and its qualifier, section 27(2), which must be read together.³²⁸ The focus on these provisions is crucial to understanding South Africa's obligations under the Constitution to ensure access to healthcare services for people with albinism. Authors such as Currie and De Waal,³²⁹ along with courts in cases discussed in the following sections of this dissertation, have categorised the interpretation of rights in the Bill of Rights of the Constitution, including the right of access to healthcare services in section 27,³³⁰ as imposing both negative and positive obligations on the state to ensure the realisation of these rights. This dissertation categorises these obligations into negative and positive obligations. The basis for these obligations is found in section 7(2) of the Constitution, which mandates the state to "respect, protect, promote, and fulfil" the rights in the Bill of Rights.³³¹ Justice Theron professed in the *Sonke Gender Justice NPC* case that section 7(2) imposes both negative and positive obligations on the state.³³² Thus, this dissertation posits that the distinction between negative and positive obligations originates in section 7(2) of the Constitution,³³³ and is further emphasised by section 27, particularly when addressing the right of access to healthcare services, sufficient food and water, and social security.³³⁴

Currie and De Waal have elucidated that negative obligations regarding human rights entail the state refraining from actions that would infringe upon these rights.³³⁵ These scholars further elucidated that positive obligations regarding human rights entail that the state should take positive measures to ensure the realisation of human rights.³³⁶ Applying this to the context of the right of access to healthcare services for people with albinism, this dissertation asserts that the negative obligations entail that the state should refrain from any actions that would impede their access to necessary healthcare services. Furthermore, this dissertation argues that positive obligations, as

³²⁸ Ibid.

³²⁹ Iain Currie and Johan de Waal, *The Bill of Rights Handbook* (Juta 2013) 569.

³³⁰ The Constitution of the Republic of South Africa, 1996.

³³¹ Ibid.

³³² *Sonke Gender Justice NPC* (n 286 above), para 40.

³³³ The Constitution of the Republic of South Africa, 1996.

³³⁴ Ibid.

³³⁵ Currie and de Waal (n 302 above).

³³⁶ Ibid.

elucidated by Currie and De Waal,³³⁷ involve the state taking active steps to fulfil these rights.

In the context of healthcare services for people with albinism, section 27(2) of the Constitution clarifies these positive obligations by providing qualifiers such as the availability of resources and the requirement to implement reasonable legislative and other measures.³³⁸ These qualifiers guide how the state should fulfil its positive obligations, ensuring that it progressively realises the right of access to healthcare services within its available resources. Both negative and positive obligations are analysed before an analysis of the interpretation qualifiers such as “within the state’s available resources,” “progressive realisation” and “legislative and other measures” under section 27(2) of the Constitution³³⁹ in this chapter of this dissertation.

3.4. NEGATIVE OBLIGATIONS

In the *Ex parte Chairperson of the Constitutional Assembly: In re Certification of the Constitution of the Republic of South Africa*³⁴⁰ decision, the Constitutional Court emphasised that socio-economic rights could be negatively protected.³⁴¹ This means that there is a negative obligation not to interfere with someone exercising their constitutional rights. When it comes to socio-economic rights, negative protection allows courts to prevent the state from acting in ways that directly infringe on these rights. This includes rights to housing, healthcare, sufficient food and water, social security, and basic education. Courts can stop the state from implementing “deliberately retrogressive measures,” which are actions that deny individuals their existing access to these rights or prevent them from using their resources to meet their needs.³⁴²

Negative obligations are not subject to progressive realisation and the state’s available resources.³⁴³ Currie and De Waal assert that there is a positive aspect to negative enforcement: the state is prohibited from interfering in people’s attempts to exercise

³³⁷ Ibid.

³³⁸ The Constitution of the Republic of South Africa, 1996, sec 27(2).

³³⁹ The Constitution of the Republic of South Africa, 1996.

³⁴⁰ *Ex parte Chairperson of the Constitutional Assembly: In re Certification of the Constitution of the Republic of South Africa*, 1996 (4) SA 744 (CC).

³⁴¹ Ibid, para 78.

³⁴² Office of the High Commissioner for Human Rights (OHCHR), Economic, social and cultural rights (OHCHR, 2024) <<https://www.ohchr.org/en/human-rights/economic-social-cultural-rights>> accessed 3 September 2024.

³⁴³ *Jafftha v Schoeman* 2005 (2) SA 140 (CC) paras 31 and 33.

their socio-economic rights. It must protect against interference by private individuals.³⁴⁴ Any measure that deprives a person of existing access to a socio-economic right is a limitation that must be justified under section 36 of the Constitution.³⁴⁵ This entails a two-stage approach. First, the scope of the right is analysed to determine whether the challenged law, conduct, or omission amounts to a breach of the right.³⁴⁶ Secondly, if a breach has been established, the court assesses whether it is a reasonable and justifiable limitation in terms of section 36. In the first stage, the burden falls on the applicant to persuade the court that a breach has occurred; in the second, the state bears a special type of onus. Although not a conventional onus of proof as understood in civil and criminal trials, the state bears the burden to justify the limitation.³⁴⁷

In the *Government of the Republic of South Africa v Grootboom*,³⁴⁸ the Constitutional Court considered the legality of the conduct of a local authority that evicted a group of squatters who had moved onto private land earmarked for low-cost housing.³⁴⁹ A magistrate's court had ordered the squatters to vacate the land by a particular date or face eviction.³⁵⁰ However, the eviction, under the control of the municipality, took place a day early, and the squatters' homes were bulldozed, with their building materials and many possessions deliberately destroyed.³⁵¹ Former Justice Yacoob indicated that this was a violation of the negative obligation in section 26(1).³⁵²

In the *Governing Body of the Juma Musjid Primary School & Others v Essay NO and Others*³⁵³ case, the Constitutional Court considered an application to evict a public school operating on private property.³⁵⁴ The property owner sought to evict the school after the MEC for Education failed to conclude a statutorily required agreement setting out the tenancy terms and conditions.³⁵⁵ The Constitutional Court found that the MEC

³⁴⁴ Currie and de Waal (n 302 above).

³⁴⁵ *Jafftha* (n 316 above) para 34.

³⁴⁶ *Ibid.*

³⁴⁷ *Minister of Home Affairs v National Institute for Crime Prevention and the Re-Integration of Offenders (NICRO) and Others* (CCT 03/04) [2004] ZACC 10; 2005 (3) SA 280 (CC) paras 34 and 36.

³⁴⁸ *Government of the Republic of South Africa v Grootboom* [2000] ZACC 19, 2001 (1) SA 46 (CC).

³⁴⁹ *Ibid.*, para 3.

³⁵⁰ *Ibid.*, para 9.

³⁵¹ *Ibid.*, para 10.

³⁵² *Ibid.*, para 88.

³⁵³ *Governing Body of the Juma Musjid Primary School & Others v Essay N.O. and Others* (CCT 29/10) [2011] ZACC 13; 2011 (8) BCLR 761 (CC).

³⁵⁴ *Ibid.*, para 25.

³⁵⁵ *Ibid.*, para 11.

had failed to fulfil her constitutional mandate to respect, protect, promote, and fulfil the right to basic education.³⁵⁶ It also found that while the property owner did not bear a primary positive obligation to provide basic education, section 8(2) of the Constitution requires private parties not to interfere with or diminish the enjoyment of a right.³⁵⁷ The property owner was subject to a negative duty not to interfere with or diminish the enjoyment of the learners' right to basic education.³⁵⁸

3.4.1. Negative obligations and the right to access healthcare services for people with albinism

Drawing parallels from the *Juma*³⁵⁹ case which indicated that section 8(2) of the Constitution imposes negative obligations on private parties, requiring them to refrain from actions that infringe upon the rights protected by the Bill of Rights.³⁶⁰ It is the view of this dissertation that the principle of the negative obligations imposed on third parties by section 8(2) of the Constitution³⁶¹ as applied in the *Juma*³⁶² case to the right to basic education can similarly be applied to other rights, including the right of access to healthcare services for all, including people with albinism.

Currie and De Waal indicate that the Constitutional Court made it clear in the *First Certification* decision that negative enforcement is the minimum level of justiciability and is not the only way socio-economic rights are justiciable.³⁶³ This dissertation opines that the concept of negative obligations, as discussed in the *First Certification*³⁶⁴ decision, applies significantly to the right of access to healthcare services for people with albinism in South Africa and that the state has a clear negative obligation not to interfere with the ability of individuals with albinism to access necessary healthcare services.

Any laws or policies that directly or indirectly prevent these individuals from obtaining essential healthcare would be unconstitutional thereby, undermining the principle of negative obligations. For instance, a law that restricts access to sunscreen which is

³⁵⁶ Ibid, para 51.

³⁵⁷ Ibid, paras 57 and 58.

³⁵⁸ Ibid, para 58.

³⁵⁹ *Governing Body of the Juma Masjid Primary School* (n 326 above).

³⁶⁰ Ibid, paras 57 and 58.

³⁶¹ Ibid.

³⁶² *Governing Body of the Juma Masjid Primary School* (n 326 above).

³⁶³ Currie and de Waal (n 302 above).

³⁶⁴ *Ex parte Chairperson of the Constitutional Assembly: In re Certification of the Constitution of the Republic of South Africa* (n 312 above).

crucial for preventing skin cancer in people with albinism, would be a direct infringement on their right of access to healthcare services. The state must avoid implementing any measures that reduce the existing access to healthcare services for people with albinism. This includes ensuring that healthcare facilities remain accessible and that there are no cuts to programs specifically designed to support individuals with albinism. For example, discontinuing a program that provides free skin cancer screenings to people with albinism would be considered a deliberately retrogressive measure, which the state is obligated to prevent.

As indicated in *Jaftha*³⁶⁵ negative obligations are immediate and unconditional; they cannot be subject to progressive realisation.³⁶⁶ This dissertation posits that this can be interpreted to mean that the state must act without delay to prevent any interference with the right to access healthcare services of people with albinism. The availability of state resources is not a valid excuse for failing to meet the negative obligations as stated in the *Jaftha*³⁶⁷ case and this principle applies even in the context of the right of access to healthcare services.

Drawing parallels from the case of *National Institute for Crime Prevention and the Re-Integration of Offenders*³⁶⁸ as already discussed in this section of this dissertation, any measure that limits the access of people with albinism to healthcare services must be justified under section 36 of the Constitution. This involves a two-stage process. First, the scope of the right is analysed to determine whether the challenged law, conduct, or omission amounts to a breach of the right of access to healthcare services. If a breach is established, the court then assesses whether the limitation is reasonable and justifiable. The burden of proof initially falls on the applicant to show that a breach has occurred. If a breach is proven, the state must then justify the limitation.³⁶⁹ Drawing parallels from the *Grootboom* case,³⁷⁰ this dissertation posits that if a local authority were to deny access to healthcare services for people with albinism or destroy facilities that provide such services, it would be a violation of the negative obligation to respect their right of access to healthcare services.

³⁶⁵ *Jaftha* (n 316 above).

³⁶⁶ *Ibid*, paras 31 and 33.

³⁶⁷ *Ibid*.

³⁶⁸ *National Institute for Crime Prevention and the Re-Integration of Offenders* (n 320 above).

³⁶⁹ *Ibid*, paras 34 and 36.

³⁷⁰ *Grootboom* (n 321 above).

3.5. POSITIVE OBLIGATIONS

The Constitutional Court's handling of positive duties arising from socio-economic rights differs from its approach to negative duties.³⁷¹ According to Currie and De Waal, as already discussed in this dissertation, positive obligations regarding human rights mean that the state should take positive measures to ensure the realisation of human rights.³⁷² Due to the qualifications attached to positive duties under sections 26(2) and 27(2), the court has essentially merged the typical two-stage process for assessing justifiability when evaluating the justification of alleged breaches of these positive obligations.³⁷³ For these duties, the entire justification argument is conducted within the framework of the reasonableness test.³⁷⁴

To comply with the positive duties, the state's efforts must be reasonable considering the qualifiers. This entails (a) reasonable legislative and other measures; (b) aimed at progressively realising the right; and (c) within available resources. The review for reasonableness, as applied to the positive duties from sections 26 and 27, does not clearly distinguish between determining the scope of the right, whether it has been breached, and justifications for potential infringements.³⁷⁵ Such limitations do not need to be in terms of a law of general application, as required by section 36.³⁷⁶

In the *Grootboom*³⁷⁷ case, the Constitutional Court analysed the positive duties imposed on the state by section 26(2) of the Constitution. This section, similarly phrased in sections 27(2) and 25(5), qualifies the right to access adequate housing by mandating the state to take reasonable legislative and other measures within its available resources to achieve the progressive realisation of this right. The court clarified that the right to access socio-economic services in sections 26(1) and 27(1) is not an automatic entitlement to these services. Instead, it is about access to the services the state provides under its obligations in sections 26(2) and 27(2). The court outlined that the state's positive obligations are limited by three criteria: (a) The need to take reasonable legislative and other measures; (b) The goal of achieving the

³⁷¹ *Minister of Health and Others v Treatment Action Campaign and Others* (No 1) [2002] ZACC 16, 2002 (5) SA 721 (CC) paras 23 and 39.

³⁷² Currie and de Waal (n 302 above) 573.

³⁷³ Ibid.

³⁷⁴ Sandra Liebenberg, *Socio-Economic Rights: Adjudication under a Transformative Constitution* (Juta 2010) 96.

³⁷⁵ Ibid, 175.

³⁷⁶ Currie and de Waal (n 302 above) 574.

³⁷⁷ *Grootboom* (n 321 above).

progressive realisation of the right; (c) The constraint of available resources.³⁷⁸ Each of these qualifications is examined in this section of this dissertation.

3.5.1. The obligation to take reasonable legislative and other measures

The Constitutional Court emphasises that the justiciability of socio-economic rights in the Constitution hinges on the standard of reasonableness. While the state is granted a significant degree of discretion in determining how to fulfil these rights, the reasonableness of the measures it adopts can still be scrutinised by the court.³⁷⁹ The *Grootboom*³⁸⁰ case in explaining reasonable measures stated that,

The precise contours and content of the measures to be adopted are primarily a matter for the legislature and the executive. They must, however, ensure that the measures they adopt are reasonable. In any challenge based on section 26 in which it is argued that the state has failed to meet the positive obligations imposed upon it by section 26(2), the question will be whether the legislative and other measures taken by the state are reasonable. A court considering reasonableness will not enquire whether other more desirable or favourable measures could have been adopted, or whether public money could have been better spent. The question would be whether the measures that have been adopted are reasonable. It is necessary to recognise that a wide range of possible measures could be adopted by the state to meet its obligations. Many of these would meet the requirement of reasonableness. Once it is shown that the measures do so, this requirement is met.³⁸¹

It is essential to note that both legislative and other measures must be undertaken. The reasonableness of these measures can be assessed at both the legislative programme level and during implementation.³⁸² As the court in *Grootboom*³⁸³ stated,

Legislative measures by themselves are not likely to constitute compliance. Mere legislation is not enough. The state is obliged to act to achieve the intended result, and the legislative measures will invariably have to be supported by appropriate, well-directed policies and programmes implemented by the executive. These policies and programmes must be reasonable both in their conception and their implementation. The formulation of a programme is only the first stage in meeting the state's obligations.

³⁷⁸ Ibid, para 38.

³⁷⁹ Ibid, para 41.

³⁸⁰ *Grootboom* (n 321 above).

³⁸¹ Ibid, para 41.

³⁸² Currie and de Waal (n 302 above) 575.

³⁸³ *Grootboom* (n 321 above).

The programme must also be reasonably implemented. An otherwise reasonable programme that is not implemented reasonably will not constitute compliance with the state's obligations.³⁸⁴

Currie and De Waal stated that the importance of this holding is that it allows courts to demand that the state explain the measures it has chosen to fulfil socio-economic rights and report on these measures' progress.³⁸⁵ Socio-economic rights are a constitutional commitment requiring the state to pursue specific developmental goals. Although there may be differing opinions on how best to achieve these goals, the state must justify its chosen methods to the public.³⁸⁶ The standard of reasonableness necessitates providing reasons. However, the courts' role extends beyond merely requiring an explanation; they must also assess the reasonableness of the explanation, ensuring it is coherent and convincing.³⁸⁷ The obligation to justify means offering reasons that most people would find reasonable, even if they disagree with the policy itself. This enables courts, as demonstrated in the *Grootboom*³⁸⁸ case, to determine that the state has violated an individual's socio-economic rights if the state's program is not reasonable.³⁸⁹

The Constitutional Court emphasises that reasonableness must be assessed on a case-by-case basis, sensitive to context.³⁹⁰ In the *Grootboom*³⁹¹ case, the Court applied this reasonableness standard. The applicants lived in dire conditions, moved out, and illegally occupied land, leading to eviction and homelessness. Their plight stemmed from intolerable living conditions while waiting for low-cost housing allocation.³⁹² The state had implemented legislative and policy measures aimed at alleviating housing shortages over time by providing access to permanent, durable residential structures with secure tenure rights. However, there was a lack of provision for temporary shelter for those experiencing homelessness. There was no explicit provision to facilitate access to temporary relief for people without land or a roof over their heads, those living in intolerable conditions, or those in crisis due to natural

³⁸⁴ *Grootboom* (n 321 above), para 42.

³⁸⁵ Currie and de Waal (n 302 above) 575.

³⁸⁶ *Ibid.*

³⁸⁷ *Ibid.*

³⁸⁸ *Grootboom* (n 321 above).

³⁸⁹ Currie and de Waal (n 302 above) 575.

³⁹⁰ *Grootboom* (n 321 above), para 92.

³⁹¹ *Grootboom* (n 321 above).

³⁹² *Ibid.*, para 4.

disasters or threats of demolition. These individuals were in desperate need. The legislative and policy measures had overlooked those most in need, which was deemed unreasonable, particularly because it conflicted with other constitutional obligations to respect human dignity and the right to equality.³⁹³ The court, in explaining the reasonableness test stated:

Reasonableness must also be understood in the context of the Bill of Rights as a whole. The right of access to adequate housing is entrenched because we value human beings and want to ensure that they are afforded their basic human needs. A society must seek to ensure that the basic necessities of life are provided to all if it is to be a society based on human dignity, freedom and equality. To be reasonable, measures cannot leave out of account the degree and extent of the denial of the right they endeavour to realise. Those whose needs are the most urgent and whose ability to enjoy all rights therefore is most in peril, must not be ignored by the measures aimed at achieving realisation of the right. It may not be sufficient to meet the test of reasonableness to show that the measures are capable of achieving a statistical advance in the realisation of the right. Furthermore, the Constitution requires that everyone must be treated with care and concern. If the measures, though statistically successful, fail to respond to the needs of those most desperate, they may not pass the test.³⁹⁴

In the *Grootboom*³⁹⁵ case, the Constitutional Court held that reasonableness requires measures to realise socio-economic rights to be comprehensive, ensuring they do not exclude those most in need. At the time of the *Grootboom* application, such measures were not in place, leading to a violation of the state's obligations under section 26(2).³⁹⁶ This principle was also applied in the *Treatment Action Campaign*³⁹⁷ case, where the Court found the government's policy on preventing mother-to-child transmission of HIV unreasonable. The policy limited the provision of nevirapine, an anti-retroviral drug, to a few pilot sites, delaying its availability across the public health system. This meant many mothers and their babies, unable to access private healthcare or pilot sites, were left without necessary treatment.³⁹⁸

³⁹³ Ibid, para 52.

³⁹⁴ Ibid, para 44.

³⁹⁵ *Grootboom* (n 321 above).

³⁹⁶ Ibid, para 99.

³⁹⁷ *Treatment Action Campaign* (n 344 above).

³⁹⁸ Ibid.

The government justified this by citing concerns about the drug's efficacy, potential resistance, safety, and the public health system's capacity. However, the Court dismissed these justifications, noting that scientific evidence supported the drug's effectiveness and that the benefits outweighed the minor risks. The lack of capacity in some areas was deemed irrelevant where facilities for testing and counseling existed. The Court emphasised that a reasonable programme for socio-economic rights must be balanced, flexible, and address immediate, short-term, and long-term needs. Excluding a significant segment of society from such programmes is unreasonable.³⁹⁹

In the *Grootboom* and *Treatment Action Campaign* cases, the court established criteria for evaluating the reasonableness of government programmes aimed at realising socio-economic rights.⁴⁰⁰ Liebenberg outlines the features of a reasonable government programme as follows:

It must be capable of facilitating the realisation of the right.⁴⁰¹

It must be comprehensive, coherent and co-ordinated.⁴⁰²

Appropriate financial and human resources must be made available for the programme.⁴⁰³

It must be balanced and flexible.⁴⁰⁴

It must make appropriate provision for short-, medium- and long-term needs.⁴⁰⁵

It must be reasonably conceived and implemented.⁴⁰⁶

It must be transparent, and its contents must be made known effectively to the public.⁴⁰⁷

It must make short-term provision for those whose needs are most urgent and who are living in intolerable conditions.⁴⁰⁸

³⁹⁹ Ibid, para 43.

⁴⁰⁰ Currie and de Waal (n 302 above) 578.

⁴⁰¹ *Grootboom* (n 321 above), para 41.

⁴⁰² Ibid, paras 39 and 40.

⁴⁰³ Ibid, para 39.

⁴⁰⁴ Ibid, paras 68,78 and 95.

⁴⁰⁵ Ibid, para 43.

⁴⁰⁶ Ibid, paras 40-43.

⁴⁰⁷ *Treatment Action Campaign* (n 344 above), para 123.

⁴⁰⁸ Liebenberg (n 347 above) 152-153.

In the case of *Khosa v Minister of Social Development*,⁴⁰⁹ the Constitutional Court emphasised the interconnectedness of the rights in the Bill of Rights. It held that the reasonableness of a measure must consider its impact on other rights. The Court found that limiting social security benefits to citizens only was unreasonable as it violated the equality rights of permanent residents. Permanent residents, who contribute to the welfare system through taxes, were unfairly excluded from its benefits, suggesting they were inferior to citizens and less deserving of social assistance.⁴¹⁰

In *Mazibuko and Others v City of Johannesburg and Others*,⁴¹¹ the Constitutional Court addressed the right of access to sufficient water. The applicants, residents of one of Johannesburg's poorest suburbs, were required to choose between a prepayment meter and a yard tap with restricted water flow as part of a programme to curb water loss and non-payment. The prepayment meters provided six kilolitres of free water per month per household, cutting off the supply once the free allocation was used unless more credit was purchased. Unlike other suburbs, these residents could not buy water on credit but paid less for water than those with credit meters. The applicants argued that the City's free basic water policy was insufficient and violated their rights to water and equality. They also challenged the legality of the prepayment meters. The Court held that the right to water did not require the state to provide sufficient water on demand to every person. It found the City's policy to be a reasonable measure for progressively realising the right to water and declined to define a specific amount of water that must be provided.⁴¹²

In this case, the court stated the following reasonableness test:

The positive obligations imposed upon government by the social and economic rights in our Constitution will be enforced by courts in at least the following ways. If government takes no steps to realise the rights, the courts will require government to take steps. If government's adopted measures are unreasonable, the courts will similarly require that they be reviewed so as to meet the constitutional standard of reasonableness. From *Grootboom* it is clear that a measure will be unreasonable if it

⁴⁰⁹ *Khosa and Others v Minister of Social Development and Others; Mahlaule and Another v Minister of Social Development and Others* [2004] ZACC 11, 2004 (6) SA 505 (CC).

⁴¹⁰ *Ibid*, para 44.

⁴¹¹ *Mazibuko and Others v City of Johannesburg and Others* [2009] ZACC 28, 2010 (4) SA 1 (CC).

⁴¹² *Ibid*.

makes no provision for those most desperately in need. If government adopts a policy with unreasonable limitations or exclusions as described in *Treatment Action Campaign (No 2)*, the court may order that those be removed. Finally, the obligation of progressive realisation imposes a duty upon government continually to review its policies to ensure that the achievement of the right is progressively realised.⁴¹³

This reasonableness test is crucial for this dissertation as it provides a judicial framework to assess whether the state's measures to ensure healthcare access for people with albinism are adequate, thus ensuring compliance with constitutional obligations.

The obligation to take reasonable legislative and other measures in the context of the right of access to healthcare services for people with albinism

As outlined by the Constitutional Court in the *Grootboom*⁴¹⁴ case, the state's obligation under section 26(2) of the Constitution to take reasonable legislative and other measures to achieve the progressive realisation of socio-economic rights, such as adequate housing, is paralleled in section 27(2) concerning the right to access healthcare services. This dissertation posits that the principles established in *Grootboom* are equally applicable to section 27(2) of the Constitution⁴¹⁵ due to the similar textual formulation of these rights.

The Constitutional Court emphasises that the justiciability of socio-economic rights hinges on the standard of reasonableness. While the state has significant discretion in determining how to fulfil these rights, the reasonableness of the measures can still be scrutinised by the court.⁴¹⁶ As the *Grootboom*⁴¹⁷ judgment indicates, it is essential that both legislative and other measures adopted by the state be reasonable in their conception and implementation.⁴¹⁸ This requirement is applicable to the right of access to healthcare services, meaning that any legislative or policy measures must be reasonable in addressing the healthcare needs of individuals with albinism.

⁴¹³ Ibid, para 67.

⁴¹⁴ *Grootboom* (n 321 above).

⁴¹⁵ The Constitution of the Republic of South Africa, 1996.

⁴¹⁶ *Grootboom* (n 321 above), para 41.

⁴¹⁷ *Grootboom* (n 321 above).

⁴¹⁸ Ibid, para 42.

It is the view of this dissertation that, as stated in *Grootboom*,⁴¹⁹ the obligation to take reasonable measures must include comprehensive, coherent, and coordinated policies and programs. This should be specifically designed to address the unique healthcare challenges faced by people with albinism, such as their increased risk of skin cancer and visual impairments. The state must allocate appropriate financial and human resources to ensure the effective implementation of these programs, as emphasised in Liebenberg's features of a reasonable government program. Drawing wisdom from the *Treatment Action Campaign*⁴²⁰ case, this dissertation posits that a reasonable healthcare program for people with albinism must be balanced and flexible, addressing their immediate, short-term, and long-term healthcare needs. The state's failure to provide such a program could be deemed unreasonable, particularly if it excludes those in dire need of healthcare services.

The *Khosa*⁴²¹ case further underscores the interconnectedness of rights and the necessity for measures to be reasonable in their impact on other rights.⁴²² This principle applies to healthcare services for people with albinism, where the exclusion or inadequate provision of necessary healthcare services would violate their right to equality and dignity. Applying the reasoning from the *Mazibuko*⁴²³ case to the healthcare needs of people with albinism, the state must adopt reasonable legislative and other measures to ensure their access to essential healthcare services. This means that the state's policies must be comprehensive, well-coordinated, and adequately resourced to address the immediate, short-term, and long-term healthcare needs of individuals with albinism. These measures must be transparent and publicly known, prioritising those with the most urgent needs. Any exclusion or inadequate provision of necessary healthcare services would be unreasonable and unconstitutional, requiring the state to ensure that its healthcare programs are reasonably conceived and implemented effectively. This aligns with the reasonableness standard established in *Mazibuko*,⁴²⁴ which mandates that state

⁴¹⁹ *Grootboom* (n 184 above).

⁴²⁰ *Treatment Action Campaign* (n 344 above).

⁴²¹ *Khosa* (n 379 above).

⁴²² *Ibid.*

⁴²³ *Mazibuko* (n 384 above).

⁴²⁴ *Ibid.*

actions must be practical, effective, and inclusive, ensuring that the healthcare needs of people with albinism are fully met.⁴²⁵

3.4.2. Progressive realisation

The positive aspect of socio-economic rights is further defined by the phrases in sections 26(2) and 27(2), which require the state to take steps “within its available resources” to realise these rights progressively. The Constitutional Court, in the *Soobramoney*⁴²⁶ case, interpreted this to mean that the state’s obligations regarding access to housing, healthcare, food, water, and social security are contingent on available resources.⁴²⁷ According to Currie and de Waal, resource constraints limit these rights.⁴²⁸ Given these constraints and the significant demands on resources, an unqualified obligation to meet these needs is currently unfeasible.⁴²⁹ This indicates that the positive aspect of socio-economic rights is achieved through state action over time.⁴³⁰ Although the full realisation of these rights can only be achieved progressively, the state must take immediate steps within its power and continue making progress. The state must demonstrate that it is moving towards the full realisation of these rights.⁴³¹

In the *Grootboom*⁴³² case, the Constitutional Court stated that “progressive realisation” implies that the right cannot be immediately fulfilled. Progressive realisation requires the state to take steps to achieve this goal, meaning that accessibility should be progressively facilitated. Legal, administrative, operational, and financial barriers should be examined and, where possible, reduced over time.⁴³³ The Constitutional Court also approved a passage from the CESCR’s General Comment 3, as discussed in chapter two of this dissertation, which emphasises that progressive realisation should not be misunderstood as stripping the obligation of meaningful content. It is a necessary flexibility mechanism, reflecting real-world challenges and the difficulties countries face in ensuring the full realisation of economic, social, and cultural rights. However, it also imposes an obligation to move as quickly and effectively as possible

⁴²⁵ Ibid, para 67.

⁴²⁶ *Soobramoney* (n 229 above).

⁴²⁷ Ibid.

⁴²⁸ Currie and de Waal (n 181 above) 580.

⁴²⁹ Ibid.

⁴³⁰ Ibid.

⁴³¹ Ibid.

⁴³² *Grootboom* (n 321 above).

⁴³³ Ibid, para 45.

toward full realisation. Any deliberately retrogressive measures must be carefully considered and fully justified, considering the totality of the rights provided in the Covenant and the full use of available resources.⁴³⁴

Progressive realisation in the context of the right of access to healthcare services for people with albinism

The concept of progressive realisation, as articulated in sections 26(2) and 27(2) of the Constitution, requires the state to take action "within its available resources" to achieve socio-economic rights over time.⁴³⁵ In the *Soobramoney*⁴³⁶ case, the Constitutional Court's interpretation suggests that the state's obligations concerning access to essential services, such as healthcare, are contingent upon the resources at its disposal.⁴³⁷ As noted by Currie and de Waal, resource limitations can restrict these rights, making it impractical to impose an unconditional obligation to meet all needs immediately.⁴³⁸ Nonetheless, this dissertation argues that the positive aspect of socio-economic rights, including the right to access healthcare services for individuals with albinism, must be actively pursued through ongoing state action. Thus, the state is required to take immediate steps within its capacity and demonstrate consistent progress toward the full realisation of these rights.

In the *Grootboom*⁴³⁹ case, the Constitutional Court clarified that "progressive realisation" means that the state must take deliberate steps to make rights accessible over time.⁴⁴⁰ As endorsed by the Constitutional Court, the CESCR's General Comment 3 states that progressive realisation should not diminish the obligation's significance but rather serve as a flexible approach to addressing practical challenges. The state must move as swiftly and effectively as possible towards the full realisation of these rights and avoid any deliberately retrogressive measures unless they are fully justified.⁴⁴¹ Applying these principles, this dissertation asserts that the state must actively work to ensure that people with albinism have increasing access to healthcare services, such as dermatological care and skin cancer prevention. Immediate actions

⁴³⁴ Ibid.

⁴³⁵ The Constitution of the Republic of South Africa, 1996.

⁴³⁶ *Soobramoney* (n 229 above).

⁴³⁷ Ibid.

⁴³⁸ Currie and de Waal (n 181 above) 580.

⁴³⁹ *Grootboom* (n 321 above).

⁴⁴⁰ Ibid, para 45.

⁴⁴¹ Ibid.

could include providing education on skin protection, ensuring access to sunscreen, and establishing specialised healthcare programs. Over time, the state should work towards eliminating all barriers that prevent people with albinism from accessing comprehensive healthcare, demonstrating a clear trajectory towards fulfilling their rights.

3.4.3. Within the state's available resources

The socio-economic rights in South Africa are inherently limited by the availability of state resources. This limitation is explicitly stated in sections 26(2) and 27(2) of the Constitution, which require that the state's obligations to provide these rights are contingent upon the resources it has.⁴⁴² The Constitutional Court has clarified that sections 26(1) and 27(1), which outline the rights to housing and healthcare, must be interpreted in conjunction with sections 26(2) and 27(2) to fully understand the state's obligations.⁴⁴³ In the *Soobramoney*⁴⁴⁴ case, the court highlighted these limitations, noting that the state's obligations under sections 26 and 27 are dependent on the resources available. It was pointed out that the rights themselves are constrained by the lack of resources. Given the significant demands on these limited resources, it is not feasible for the state to meet all needs unconditionally at present.⁴⁴⁵

The court in *Grootboom*⁴⁴⁶ indicated that for a program to be considered reasonable, it must have the necessary resources allocated to it.⁴⁴⁷ If a program does not allocate adequate resources, it is deemed unreasonable.⁴⁴⁸ However, once a government body shows that it has appropriately allocated resources given the circumstances, it has largely fulfilled its obligation. The Constitutional Court in *Grootboom*⁴⁴⁹ explained the meaning of within the state's available resources and stated that:

The third defining aspect of the obligation to take the requisite measures is that the obligation does not require the State to do more than its available resources permit.

This means that both the content of the obligation in relation to the rate at which it is

⁴⁴² The Constitution of the Republic of South Africa, 1996.

⁴⁴³ *Treatment Action Campaign* (n 344 above), paras 29-32; *Soobramoney v Minister of Health (KwaZulu-Natal)* [1997] ZACC 17, 1998 (1) SA 765 (CC) para 22; *Grootboom* (n 184 above) para 74; *Khosa* (217 above) para 43.

⁴⁴⁴ *Soobramoney* (n 229 above).

⁴⁴⁵ *Ibid*, para 11.

⁴⁴⁶ *Grootboom* (n 321 above).

⁴⁴⁷ *Ibid*, para 46.

⁴⁴⁸ *Ibid*.

⁴⁴⁹ *Ibid*.

achieved as well as the reasonableness of the measures employed to achieve the result are governed by the availability of resources. Section 26 does not expect more of the State than is achievable within its available resources.⁴⁵⁰

According to Currie and De Waal when resources become available, it becomes challenging for the state to justify not using them to fulfil socio-economic rights. As more resources are accessible, the state is expected to do more to realise these rights. This underscores the idea that a key aspect of socio-economic rights is the state's obligation to justify its use of public resources to its citizens.⁴⁵¹ Although the Constitutional Court has not yet ruled that a specific budget allocation is an unreasonable attempt to realise a right, this does not mean that budgetary decisions are beyond judicial review. For instance, in the *City of Johannesburg Metropolitan Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Another*⁴⁵² case, the municipality cited its insufficient budget as a reason for not providing temporary accommodation to evictees. The Constitutional Court dismissed this argument. It stated:

The city provided information relating specifically to its housing budget but did not provide information relating to its budget in general. We do not know exactly what the City's overall financial position is. This Court's determination of the reasonableness of measures within available resources cannot be restricted by budgetary and other decisions that may well have resulted from a mistaken understanding of constitutional or statutory obligations. In other words, it is not good enough for the City to state that it has not budgeted for something if it should indeed have planned and budgeted for it in the fulfilment of its obligations.⁴⁵³

This ruling is significant as it opens the door for courts to examine the reasonableness of budgeting processes and decisions.

Within the state's available resources in the context of the right of access to healthcare services for people with albinism

The socio-economic rights in South Africa, including the right to access healthcare services, are inherently tied to the availability of state resources, as explicitly stated in

⁴⁵⁰ *Grootboom* (n 321 above), para 46.

⁴⁵¹ Currie and de Waal (n 181 above) 582.

⁴⁵² *City of Johannesburg Metropolitan Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Another* [2011] ZACC 33, 2012 (2) SA 104 (CC).

⁴⁵³ *Ibid*, para 74.

sections 26(2) and 27(2) of the Constitution.⁴⁵⁴ These sections mandate that the state's obligations are contingent upon the resources at its disposal.⁴⁵⁵ This principle has been consistently emphasised by the Constitutional Court, notably in the *Soobramoney*⁴⁵⁶ case, where former Chief Justice Chaskalson highlighted that resource constraints inherently limit the state's duties under sections 26 and 27.⁴⁵⁷

As already discussed in chapter two of this dissertation, Article 2, paragraph 1 of the ICESCR mandates that each State Party commits to taking necessary actions, using the maximum available resources, to progressively achieve the full realisation of the rights outlined in the Covenant.⁴⁵⁸ This international legal framework reinforces the notion that resource availability is a fundamental consideration in fulfilling socio-economic rights. Compliance with section 27(2) of the Constitution's⁴⁵⁹ obligations also ensure that South Africa meets its commitments under international law.

This dissertation posits that, drawing from the *Grootboom*⁴⁶⁰ case, the state must ensure that adequate resources are allocated to healthcare programs tailored to meet the unique needs of individuals with albinism. The court in *Grootboom*⁴⁶¹ clarified that for a program to be deemed reasonable, it must appropriately allocate the necessary resources.⁴⁶² This standard applies equally to the right of access to healthcare services for people with albinism because, although the *Grootboom*⁴⁶³ case dealt with the right to have access to adequate housing, this right has the same textual formulation as the right of access to healthcare services. As noted by Currie and De Waal, when resources become available, the state is expected to intensify its efforts to fulfil socio-economic rights.⁴⁶⁴ This dissertation opines that as more resources become accessible, the state must do more to realise these rights, including those of healthcare services for people with albinism.

⁴⁵⁴ The Constitution of the Republic of South Africa, 1996.

⁴⁵⁵ Ibid.

⁴⁵⁶ *Soobramoney* (n 321 above).

⁴⁵⁷ Ibid, para 11.

⁴⁵⁸ ICESCR (n 40 above).

⁴⁵⁹ The Constitution of the Republic of South Africa, 1996.

⁴⁶⁰ *Grootboom* (n 321 above).

⁴⁶¹ Ibid.

⁴⁶² Ibid, para 46.

⁴⁶³ *Grootboom* (n 321 above).

⁴⁶⁴ Currie and de Waal (n 181 above) 582.

The Constitutional Court's ruling in *City of Johannesburg Metropolitan Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Another*⁴⁶⁵ further supports this view. The Court dismissed the municipality's argument of the insufficient budget as a reason for not providing temporary accommodation to evictees, emphasising that reasonableness cannot be constrained by budgetary decisions stemming from misunderstandings of constitutional obligations.⁴⁶⁶ This dissertation asserts that the state must actively plan and budget for healthcare services that address the needs of people with albinism. This includes ensuring that specialised programs are well-resourced and that any budgetary decisions are transparent and justifiable.

3.5. CONCLUSION

This chapter answered the alluded question of South Africa's constitutional obligations to ensure access to healthcare services for people with albinism by clarifying such obligations. Under section 7(2) of the Constitution, the state must respect, protect, promote, and fulfill the right of access to healthcare services for these people. It has positive and negative obligations on their right of access to healthcare. Negative obligations require it to avoid interfering with access to healthcare, which must be immediate and unconditional, without excuses related to resource availability. Any limitations must be justified under section 36 of the Constitution through a two-stage process: determining if there is a breach and if the limitation is reasonable and justifiable. Negative obligations are immediate and are not subject to qualifiers under section 27(2) of the Constitution. South Africa's positive obligations differ from its negative obligations, as they are justified within the framework of the reasonableness test and subject to qualifiers under section 27(2) of the Constitution. Positive obligations require the state to take reasonable legislative and other measures to progressively realise the right of access to healthcare services within its available resources. The following chapter assesses South Africa's legislative and other efforts to provide access to healthcare services for people with albinism and identifies areas needing improvement to meet international and constitutional obligations.

⁴⁶⁵ *City of Johannesburg Metropolitan Municipality* (n 425 above).

⁴⁶⁶ *Ibid*, para 74.

CHAPTER FOUR

ASSESSING SOUTH AFRICA'S COMPLIANCE WITH CONSTITUTIONAL AND INTERNATIONAL OBLIGATIONS CONCERNING THE PROVISION OF ACCESS TO HEALTH FOR PEOPLE WITH ALBINISM

4.1. INTRODUCTION

Chapter two clarified South Africa's obligations under international human rights law to provide access to healthcare services for people with albinism. Chapter three clarified South Africa's constitutional obligations to ensure access to healthcare services for people with albinism. It was noted in the previous chapters that both international law and the Constitution mandate South Africa to take legislative and other measures to comply with access to health rights for people with albinism. This chapter notes that South Africa has taken legislative and other measures to ensure access to healthcare services for people with albinism. Legislative measures include the National Health Act,⁴⁶⁷ Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000⁴⁶⁸ (hereafter referred to as the Promotion of Equality and Prevention of Unfair Discrimination), and the National Health Insurance Act 20 of 2023⁴⁶⁹ (hereafter referred to as the National Health Insurance Act). Other measures include the Ekurhuleni Declaration on the Rights of Persons with Albinism,⁴⁷⁰ the provision of sunscreens and dermatological checkups, and the provision of sunglasses and eye checkups. Drawing from the last two chapters, this chapter assesses the adequacy of the legislative and other measures adopted by South Africa to provide access to healthcare services for people with albinism. The adequacy of such measures is measured against the aspirations of international law discussed in chapter two of this dissertation. The chapter ends with a conclusion which summarises the whole discussion.

⁴⁶⁷ Act 61 of 2003.

⁴⁶⁸ Act 4 of 2000.

⁴⁶⁹ Act 20 of 2023.

⁴⁷⁰ South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (n 59 above).

4.2. AN ASSESSMENT OF LEGISLATIVE MEASURES ENACTED BY SOUTH AFRICA

4.2.1. Introduction

As established above, the South African government has an obligation under international law to make legislative measures to ensure access to healthcare services for people with albinism. This obligation is rooted in international instruments such as the CRPD⁴⁷¹ and the ICESCR.⁴⁷² It is also reflected in the state's Constitution, specifically in section 27, which guarantees the right to access healthcare services.⁴⁷³ However, this obligation is not immediate under international law⁴⁷⁴ and the Constitution,⁴⁷⁵ meaning it must be fulfilled progressively within the state's available resources. These legislative measures must be reasonable, as established in the case of *Grootboom*,⁴⁷⁶ where the Constitutional Court emphasised that the state must take reasonable legislative and other measures to achieve the progressive realisation of socio-economic rights.⁴⁷⁷

To date, the South African government has enacted several pieces of legislation to fulfil this obligation, including the National Health Act,⁴⁷⁸ the Promotion of Equality and Prevention of Unfair Discrimination Act,⁴⁷⁹ and the National Health Insurance Act.⁴⁸⁰ The obligation to fulfil is in the international instruments⁴⁸¹ and is reflected by the South African Constitution.⁴⁸² This section will discuss these legislations below. While Daklo's study praises South Africa for its legislative measures protecting the health rights of people with albinism,⁴⁸³ this dissertation respectfully disagrees. It posits that significant gaps and areas requiring improvement still exist within South Africa's legislative framework. The ensuing discussion in this section critically examines these

⁴⁷¹ CRPD (n 44 above), Article 25.

⁴⁷² ICESCR (n 40 above), Article 2(1).

⁴⁷³ The Constitution of the Republic of South Africa, 1996.

⁴⁷⁴ ICESCR (n 40 above), Article 2(1).

⁴⁷⁵ The Constitution of the Republic of South Africa, 1996, sec 27(2).

⁴⁷⁶ *Grootboom* (n 321 above).

⁴⁷⁷ *Ibid*, para 41.

⁴⁷⁸ Act 61 of 2003.

⁴⁷⁹ Act 4 of 2000.

⁴⁸⁰ Act 20 of 2023.

⁴⁸¹ Office of the High Commissioner for Human Rights (n 75 above).

⁴⁸² The Constitution of the Republic of South Africa, 1996, sec 7(2).

⁴⁸³ Daklo (n 72 above).

shortcomings, underscoring the necessity for further legislative improvements to better safeguard and advance the health rights of individuals with albinism in South Africa.

4.2.2. National Health Act 61 of 2003

One of the legislative measures enacted by the South African government to establish a structured and uniform health system across the state is the National Health Act.⁴⁸⁴ This Act is grounded in the principles of the Constitution,⁴⁸⁵ aiming to address the past's socio-economic injustices and health service imbalances. It seeks to ensure that all citizens have access to quality healthcare services,⁴⁸⁶ to fulfil the state's obligations under both national⁴⁸⁷ and international law, as discussed in the previous chapters of this dissertation.⁴⁸⁸

The National Health Act⁴⁸⁹ addresses the healthcare challenges faced by people with albinism through several provisions to ensure equitable access to healthcare services. Section 4 of the Act provides that the Minister of Health must prescribe conditions under which free health services must be provided to certain categories of persons.⁴⁹⁰ It reads as follows:

4(1) The Minister, after consultation with the Minister of Finance, may prescribe conditions subject to which categories of persons are eligible for such free health services at public health establishments as may be prescribed. (2) In prescribing any condition contemplated in subsection (1), the Minister must have regard to- (a) the range of free health services currently available; (b) the categories of persons already receiving free health services; (c) the impact of any such condition on access to health services; and (d) the needs of vulnerable groups such as women, children, older persons and persons with disabilities.⁴⁹¹

According to Daklo, section 4(2)(d) identifies individuals with disabilities, including those with albinism, as a vulnerable group entitled to free healthcare services under the Act.⁴⁹² This dissertation argues, contrary to Daklo's view, that the structure and

⁴⁸⁴ Act 61 of 2003.

⁴⁸⁵ The Constitution of the Republic of South Africa, 1996, sec 27.

⁴⁸⁶ Act 61 of 2003.

⁴⁸⁷ The Constitution of the Republic of South Africa, 1996, sec 7(2).

⁴⁸⁸ Office of the High Commissioner for Human Rights (n 75 above).

⁴⁸⁹ Act 61 of 2003.

⁴⁹⁰ Ibid.

⁴⁹¹ Ibid.

⁴⁹² Daklo (n 72 above).

provisions of section 4 do not sufficiently guarantee free access to healthcare services for people with albinism. Firstly, the Act's language is discretionary, allowing the Minister to prescribe conditions for free healthcare services after consultation with the Minister of Finance.⁴⁹³ This implies that the provision of free healthcare is not a guarantee but rather contingent upon the Minister's determination and the state of available resources.

Secondly, the criteria listed in section 4(2) are broad and non-specific.⁴⁹⁴ While subsection (d) acknowledges the needs of vulnerable groups, including those with disabilities, it does not explicitly mandate free healthcare services for people with albinism.⁴⁹⁵ Instead, it places the responsibility on the Minister to consider various factors, which can result in inconsistent application and potential gaps in service provision. Moreover, this dissertation contends that the discretionary nature of these provisions may lead to insufficient allocation of resources, failing to address the specific and ongoing healthcare needs of individuals with albinism. This lack of explicit guarantees leaves room for subjective interpretation and potentially inadequate healthcare support for this vulnerable group.

Section 4(3) of the National Health Act stipulates that:

Subject to any condition prescribed by the Minister, the State and clinics and community health centres funded by the State must provide- (a) pregnant and lactating women and children below the age of six years, who are not members or beneficiaries of medical aid schemes, with free health services; (b) all persons, except members of medical aid schemes and their dependants and persons receiving compensation for compensable occupational diseases, with free primary health care services; and (c) women, subject to the Choice on Termination of Pregnancy Act, 1996 (Act 92 of 1996), free termination of pregnancy services.⁴⁹⁶

Section 4(3) requires state-funded clinics and community health centers to offer free health services to specific groups following any conditions set by the Minister.⁴⁹⁷ These groups include pregnant and lactating women and children under six years old,

⁴⁹³ Act 61 of 2003.

⁴⁹⁴ Ibid.

⁴⁹⁵ Ibid.

⁴⁹⁶ Ibid.

⁴⁹⁷ Ibid.

provided they are not members or beneficiaries of medical aid schemes.⁴⁹⁸ Additionally, it mandates that all individuals, excluding members of medical aid schemes, their dependents, and those receiving compensation for occupational diseases, are entitled to free primary healthcare services.⁴⁹⁹ While children with albinism below the age of six are entitled to free access to healthcare services under section 4(3),⁵⁰⁰ those people with albinism who are six years old and above are only entitled to free primary healthcare services, despite their healthcare needs being the same as those below the age of six.

Drawing from South African Constitutional Court jurisprudence discussed in chapter three of this dissertation, the reasonableness test is the standard used to determine whether state measures to realise constitutional rights meet the constitutional obligations⁵⁰¹ which are also provided for in the international human rights instruments which are discussed in the second chapter of this dissertation. This test, as established in landmark cases such as *Grootboom*⁵⁰² and *Mazibuko*,⁵⁰³ mandates that state measures must not exclude those whose other rights would be most in peril or whose ability to enjoy other rights will be at risk. The *Grootboom*⁵⁰⁴ case emphasises that the reasonableness of a measure must take into account the degree and extent of the denial of the right it aims to realise. Measures that fail to address the needs of those most in peril, no matter how statistically successful, do not pass the reasonableness test.⁵⁰⁵

People with albinism face unique and severe healthcare challenges, including heightened risks of skin cancer, visual impairments, and other health issues.⁵⁰⁶ The Act's failure to explicitly include people with albinism who are 6 years old or above as a vulnerable group amongst those who must receive free health services⁵⁰⁷ raises significant concerns about its comprehensiveness and inclusivity. This dissertation opines that such omission is a failure to consider this group's specific and urgent

⁴⁹⁸ Ibid, sec 4(3)(a).

⁴⁹⁹ Act 61 of 2003, sec 4(3)(b).

⁵⁰⁰ Act 61 of 2003.

⁵⁰¹ *Mazibuko* (n 384 above), para 67, *Grootboom* (n 321 above), para 44.

⁵⁰² *Grootboom* (n 321 above), para 44.

⁵⁰³ *Mazibuko* (n 384 above), para 67.

⁵⁰⁴ *Grootboom* (n 321 above), para 44.

⁵⁰⁵ Ibid.

⁵⁰⁶ Anthonie Kruger and Radloff (n 222 above).

⁵⁰⁷ Act 61 of 2003, sec 4(3).

needs, which conflicts with the Constitutional Court's reasonableness requirement that measures must be inclusive and comprehensive, addressing the most desperate needs.⁵⁰⁸ Without explicit access to free healthcare services, people with albinism are left without a solid basis to advocate for their health rights as free entitlements.

The right to dignity, enshrined in the South African Constitution, is fundamentally about acknowledging the inherent worth of every individual.⁵⁰⁹ Denying children with albinism aged six and above or even adults access to the same level of free healthcare services as those below six, regardless of sharing the same health problems, sends a clear message that their health and well-being are less important. Such an exclusion diminishes their sense of self-worth and respect, directly impacting their dignity. This exclusion also puts their right to life⁵¹⁰ at stake.

As discussed in this dissertation, research shows that most people with albinism die at the ages of 30 and 40 because of skin cancer.⁵¹¹ This shows how people with albinism face a significantly higher risk of life-threatening conditions such as skin cancer. The provision of free healthcare services for only those under six neglects the urgent and continuous healthcare needs of older children with albinism and adults, potentially leading to preventable medical conditions and even fatalities and this affects their right to life.⁵¹² This shows that without access to healthcare services people with albinism's ability to enjoy other rights like dignity⁵¹³ and life⁵¹⁴ are at risk.

Resource allocation and practical implementation are vital in assessing the reasonableness of the Act. Section 4 mandates consultations with the Minister of Finance, but this does not guarantee that sufficient resources are directed towards the healthcare needs of people with albinism.⁵¹⁵ As highlighted in the *Grootboom*⁵¹⁶ case, mere legislative enactment is insufficient; appropriate financial and human resources must support these measures.⁵¹⁷ Without specific allocations, the intended benefits

⁵⁰⁸ *Grootboom* (n 321 above), para 44.

⁵⁰⁹ The Constitution of the Republic of South Africa, 1996, sec 10.

⁵¹⁰ The Constitution of the Republic of South Africa, 1996, sec 11.

⁵¹¹ *Ero* (n 19 above).

⁵¹² The Constitution of the Republic of South Africa, 1996, sec 11.

⁵¹³ The Constitution of the Republic of South Africa, 1996, sec 10.

⁵¹⁴ The Constitution of the Republic of South Africa, 1996, sec 11.

⁵¹⁵ Act 61 of 2003.

⁵¹⁶ *Grootboom* (n 321 above).

⁵¹⁷ *Ibid*, para 39.

for vulnerable populations such as people with albinism may remain theoretical rather than translating into real-world improvements.

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

Another legislative measure taken by the South African government is the enactment of the PEPUDA, which is important in ensuring access to healthcare services for all individuals, including people with albinism.⁵¹⁸ Its primary objective is to give effect to section 9 of the Constitution, which guarantees the right to equality and prohibits unfair discrimination.⁵¹⁹ It reflects South Africa's commitment to its international obligations, as discussed in Chapter two of this dissertation. Its Preamble acknowledges South Africa's binding international obligations under various treaties in the field of human rights, particularly those promoting equality and prohibiting unfair discrimination.⁵²⁰ It specifically references the CEDAW and the CERD.⁵²¹ Section 8(g) of the PEPUDA addresses unfair discrimination based on gender, specifically mentioning health services.⁵²² It provides that limiting women's access to social services or benefits, such as health, education, and social security, constitutes unfair discrimination.⁵²³ It is the view of this dissertation that while this provision is commendable in its intent to protect women's access to health services, it does not equally emphasise the protection against discrimination for men, including men with albinism.

The CERD, in its periodic report, as discussed in chapter two of this dissertation, highlighted the need for persons with albinism to have equal access to education, healthcare, and employment.⁵²⁴ The Committee's recommendations do not distinguish between men and women, implying that both genders should be afforded equal access to necessary healthcare services without discrimination.⁵²⁵ However, this dissertation argues that section 8(g) of PEPUDA,⁵²⁶ by specifically focusing on women's access to

⁵¹⁸ Act 4 of 2000.

⁵¹⁹ The Constitution of the Republic of South Africa, 1996.

⁵²⁰ Act 4 of 2000.

⁵²¹ Ibid.

⁵²² Ibid.

⁵²³ Ibid.

⁵²⁴ Committee on the Elimination of Racial Discrimination, 'Concluding observations on the combined ninth to eleventh periodic reports of South Africa' (n 172 above).

⁵²⁵ Ibid.

⁵²⁶ Act 4 of 2000.

health services, fails to provide an equivalent level of protection and guarantee for men, including men with albinism.

Notably, the only place where the Act includes men when it comes to health is in its schedule 3(b), which states: "Unfairly denying or refusing any person access to health care facilities or failing to make health care facilities accessible to any person."⁵²⁷ This dissertation posits that the language used in section 8(g) is different from that in schedule 3(b).⁵²⁸ The phrase "access to healthcare facilities provided to any person, including men"⁵²⁹ could mean that individuals can physically access the facilities, but it does not guarantee that they will receive the necessary health services once inside. In contrast, section 8(g) mentions health services afforded to women,⁵³⁰ ensuring that women not only access the facilities but also the comprehensive range of health services provided within them.

4.2.4. National Health Insurance Act 20 of 2023 (NHI Act)

To comply with its international and constitutional obligations of making legislative and other measures to realise health rights, as discussed in the previous chapters of this dissertation, South Africa has recently enacted the NHI Act.⁵³¹ This Act represents a significant legislative step toward the realisation of universal health care for all citizens including those with albinism.⁵³² The preamble of this Act acknowledges South Africa's dedication to fulfilling its international obligations⁵³³ as articulated in human rights instruments discussed in chapter two of this dissertation. Its Preamble references Article 12 of the ICESCR, which enshrines the right of every individual to attain the highest possible standard of physical and mental health.⁵³⁴

Furthermore, the Preamble highlights Article 16 of the ACHPR, which emphasises the duty of state parties to enact measures that safeguard the health of their populace and ensure access to medical care when necessary.⁵³⁵ These international mandates resonate deeply within the South African constitutional framework discussed,

⁵²⁷ Ibid.

⁵²⁸ Ibid.

⁵²⁹ Ibid.

⁵³⁰ Ibid.

⁵³¹ Act 20 of 2023.

⁵³² Ibid.

⁵³³ Ibid.

⁵³⁴ Ibid.

⁵³⁵ Ibid.

particularly in relation to section 27(1)(a) as discussed in chapter three of this dissertation, which guarantees that every individual possesses the right to access health care services.⁵³⁶ In its essence, the NHI Act serves to give effect to section 27(2)(a) of the South African Constitution, which compels the state to take "reasonable legislative and other measures" to progressively realise the right to health care.⁵³⁷ In light of the above, it is the view of this dissertation that the Preamble of the NHI Act,⁵³⁸ encompasses the health rights of vulnerable groups such as people with albinism.

Prinsen acknowledges the noble intentions of the NHI Act in striving for universal healthcare access.⁵³⁹ She praises the Act for its alignment with constitutional mandates and its potential to bridge the gap in healthcare disparities in South Africa.⁵⁴⁰ However, Prinsen criticises the Act for its vague implementation guidelines and lack of a clear funding mechanism.⁵⁴¹ She also raises concerns about potential corruption and inconsistencies in coverage scope, which could hinder effective implementation and impact existing healthcare structures.⁵⁴² This dissertation agrees with Prinsen's criticisms, particularly regarding the vagueness in implementation and the lack of a clear funding strategy. Ensuring access to healthcare for people with albinism requires a well-defined and funded plan. The uncertainties in the NHI Act⁵⁴³ could lead to inefficiencies and inadequate healthcare infrastructure, affecting the quality and accessibility of services for people with albinism.

Gwarube has labelled the NHI Act a political ploy, warning of potential corruption and questioning its financial feasibility.⁵⁴⁴ This dissertation acknowledges these concerns, particularly in the context of ensuring access to healthcare services for people with albinism. The potential for corruption and financial mismanagement could undermine

⁵³⁶ The Constitution of the Republic of South Africa, 1996.

⁵³⁷ Ibid.

⁵³⁸ Act 20 of 2023.

⁵³⁹ Larisse Prinsen, 'OPINION | The pros and cons of the National Health Insurance Bill: Recap of what experts have raised about the NHI' (TimesLIVE, 14 May 2024) <<https://www.timeslive.co.za>> accessed 20 November 2024.

⁵⁴⁰ Ibid.

⁵⁴¹ Ibid.

⁵⁴² Ibid.

⁵⁴³ Act 20 of 2023.

⁵⁴⁴ Navigating the Future of Healthcare Redress in South Africa, Regent Business School Blog (21 November 2024) <<https://regent.ac.za/blog/navigating-future-healthcare-redress-south-africa>> accessed 22 November 2024.

the effectiveness of the NHI Act,⁵⁴⁵ leading to inadequate healthcare infrastructure and services for vulnerable groups, including people with albinism.

The case of *City of Johannesburg Metropolitan Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Another*⁵⁴⁶ was discussed in chapter three of this dissertation, where the Constitutional Court emphasised that insufficient budgeting cannot excuse the failure to fulfill constitutional obligations to realise human rights, which includes the rights of health for people with albinism.⁵⁴⁷ Similarly, in *Grootboom*,⁵⁴⁸ the Court highlighted that government programs must have adequate resources allocated to them to be considered reasonable.⁵⁴⁹ In light of what was stated in these cases, this dissertation posits that without clear and sufficient funding, the NHI Act⁵⁵⁰ risks being deemed unreasonable under these standards. The lack of a detailed implementation plan further worsens this issue, making it difficult to ensure that healthcare services for people, including those with albinism are adequately provided.

4.3. AN ASSESSMENT OF OTHER MEASURES TAKEN BY THE GOVERNMENT TO PROVIDE ACCESS TO HEALTHCARE SERVICES FOR PEOPLE WITH ALBINISM

4.3.1. Introduction

The Constitution,⁵⁵¹ along with international instruments such as the ICESCR⁵⁵² and ACHPR,⁵⁵³ discussed in the previous chapters of this dissertation mandates the state to take comprehensive measures beyond legislative actions to ensure the realisation of socio-economic rights. This includes rights like access to healthcare services for people with albinism in South Africa.

In the *Grootboom*⁵⁵⁴ case, the court emphasised that legislative measures alone are insufficient. The state must also implement well-directed policies and programs to achieve the intended outcomes. These policies and programmes must be reasonable

⁵⁴⁵ Act 20 of 2023.

⁵⁴⁶ *City of Johannesburg Metropolitan Municipality* (n 425 above).

⁵⁴⁷ *Ibid*, para 74.

⁵⁴⁸ *Grootboom* (n 321 above).

⁵⁴⁹ *Ibid*, para 42.

⁵⁵⁰ Act 20 of 2023.

⁵⁵¹ The Constitution of the Republic of South Africa, 1996, sec 27(2).

⁵⁵² ICESCR (n 40 above), Article 2(1).

⁵⁵³ ACHPR (n 45 above), Article 16.

⁵⁵⁴ *Grootboom* (n 321 above).

in both their design and execution. Simply formulating a program is not enough; it must be effectively implemented. A program that is reasonable in theory but poorly executed will not fulfil the state's obligations. Therefore, the state must ensure that legislative measures are complemented by well-designed and effectively implemented policies and programs.⁵⁵⁵ The other measures taken by the state to fulfil its obligation to ensure access to healthcare services for people with albinism are as follows:

4.3.2. The Ekurhuleni Declaration on the Rights of Persons with Albinism, 2013

The most significant step by the South African government towards ensuring access to healthcare services for people with albinism was the adoption of the Ekurhuleni Declaration on the Rights of Persons with Albinism.⁵⁵⁶ It was adopted during the National Albinism Conference in 2013 and outlines various measures to improve the rights and access to healthcare services for persons with albinism.⁵⁵⁷ The measures outlined in the Ekurhuleni Declaration on the Rights of Persons with Albinism⁵⁵⁸ align with international standards and commitments, such as the ICESCR⁵⁵⁹ and the ACHPR,⁵⁶⁰ as previously discussed in chapter two of this dissertation. These international laws emphasise the right to the highest attainable standard of health without discrimination and urge the state to take measures to ensure equitable access to healthcare services for all people, including those with albinism.⁵⁶¹

The South African Constitution mandates the state to take reasonable legislative and other measures to achieve the progressive realisation of the right to healthcare, as detailed in section 27.⁵⁶² Furthermore, the Ekurhuleni Declaration reflects the best practices outlined in the SADC DPPA.⁵⁶³ This includes a commitment to protecting the rights of people with albinism and improving their quality of life across the region. The declaration is not binding. It is a set of recommendations and commitments made by

⁵⁵⁵ *Grootboom* (n 321 above), para 42.

⁵⁵⁶ South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (n 59 above).

⁵⁵⁷ *Ibid.*

⁵⁵⁸ *Ibid.*

⁵⁵⁹ ICESCR (n 40 above).

⁵⁶⁰ ACHPR (n 45 above).

⁵⁶¹ ICESCR (n 40 above), Article 2(1), ACHPR (n 45 above), Article 16.

⁵⁶² The Constitution of the Republic of South Africa, 1996, sec 27(2)(a).

⁵⁶³ DPPA (n 46 above).

the South African government and various stakeholders to improve the rights and access to services for persons with albinism.⁵⁶⁴

This dissertation posits that without the binding authority, the declaration's principles rely on the goodwill and commitment of various government departments and stakeholders. This can lead to inconsistent implementation and enforcement across different regions and sectors. It can also be challenging to hold the state accountable for failing to adhere to the principles of the declaration. Despite all that, this declaration outlines best practices and guides for the South African government to improve access to healthcare services for people with albinism.⁵⁶⁵

Article 25 of the declaration emphasises the importance of providing free sunscreen to individuals with albinism.⁵⁶⁶ This is important because people with albinism are highly susceptible to skin damage from the sun due to their lack of melanin. The Department of Health and provincial health departments can help protect their skin and reduce the risk of skin cancer, by ensuring free access to adequate sunscreen. Article 26 focuses on the need for free eye tests and the provision of spectacles across all provinces.⁵⁶⁷ People with albinism often have vision problems, so this article highlights the importance of making eye care accessible to them. Accelerating the roll-out of these services ensures that individuals with albinism can receive the necessary eye care to improve their quality of life.

Article 27 calls for the Department of Health to work with the Albinism Society of South Africa and the Council of Medical Aid Schemes. The goal is to include sunscreen and other essential assistive devices as prescribed minimum benefits.⁵⁶⁸ This means that these items would be covered by medical aid schemes, making them more accessible and affordable for people with albinism. Article 28 addresses the need for training medical and non-medical personnel to eliminate discrimination against people with albinism. It also aims to educate them about the different types of albinism and the specific interventions required.⁵⁶⁹ This training is essential to ensure healthcare

⁵⁶⁴ South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (n 59 above).

⁵⁶⁵ Ibid.

⁵⁶⁶ Ibid.

⁵⁶⁷ Ibid.

⁵⁶⁸ Ibid.

⁵⁶⁹ Ibid.

providers can offer appropriate and respectful care to individuals with albinism. Article 29 highlights the importance of improving access to discrimination-free health services in rural areas. This includes rolling out infrastructure to ensure that people with albinism in these areas can receive the same level of care as those in urban areas.⁵⁷⁰

During her visit to South Africa in 2019, Ero, the UN Independent Expert on the enjoyment of human rights by persons with albinism, urged the Government and civil society to collaborate on developing a national action plan.⁵⁷¹ This plan should incorporate measures from the Ekurhuleni Declaration of 2013 and the Regional Action Plan on albinism.⁵⁷² She emphasised the importance of ensuring that people with albinism, who are among the most marginalised, are included in both national and international development agendas.⁵⁷³ This dissertation supports Ero's call, arguing that such a national action plan would significantly enhance the rights and access to healthcare services for people with albinism, aligning with South Africa's international and constitutional obligations discussed in previous chapters.

4.3.3. The current provision of sunscreens and dermatological checkups in public hospitals

Before discussing the current provision of sunscreens by South Africa, it is essential to provide the background that South Africa, located at the southernmost tip of the African continent, spans from latitudes 22.34° S to 34.28° S.⁵⁷⁴ The state's geography includes a narrow coastal plain that rises to a vast plateau known as the Highveld, which is approximately 1200 meters above sea level. This region is characterised by high atmospheric pressure and clear skies, leading to significant levels of ambient solar ultraviolet radiation (hereafter referred to as the UVR).⁵⁷⁵ These environmental conditions pose a particular risk to individuals with albinism. Without melanin, which provides some protection against UVR, people with albinism are much more

⁵⁷⁰ Ibid.

⁵⁷¹ UN Human Rights Office of the High Commissioner, 'South Africa must step up action to end racial discrimination against people with albinism – UN expert' (OHCHR, 17 September 2019) <<https://www.ohchr.org/en/press-releases/2019/09/south-africa-must-step-action-end-racial-discrimination-against-people>> accessed [Date].

⁵⁷² Ibid.

⁵⁷³ Ibid.

⁵⁷⁴ Geodatos, 'South Africa Geographic Coordinates' (2024) <<https://www.geodatos.net/en/coordinates/south-africa>> accessed 6 October 2024.

⁵⁷⁵ Geography of South Africa, 'Highveld' (2024) <<https://en.wikipedia.org/wiki/Highveld>> accessed 6 October 2024.

susceptible to skin damage from UV exposure.⁵⁷⁶ The high levels of UVR in the Highveld, due to its clear skies and altitude, significantly increase the risk of skin cancer for those with albinism.⁵⁷⁷ Their skin lacks the natural defence mechanisms that melanin provides, making them vulnerable to the carcinogenic effects of prolonged UV exposure.⁵⁷⁸ Therefore, the geographical and climatic conditions of South Africa, particularly in the Highveld,⁵⁷⁹ necessitate heightened protective measures for individuals with albinism to mitigate their increased risk of skin cancer such as the provision of sunscreen.

In South Africa currently, the government provides a generic Sun Protection Factor (hereafter referred to as the SPF) 15 sunscreens free of charge through regional hospitals.⁵⁸⁰ However, this SPF level is generally considered insufficient for the high UV exposure that people with albinism face in South Africa due to its geographical location.⁵⁸¹ Ideally, sunscreens with higher SPF, such as SPF 30 or 50, are recommended for better protection and must be applied every hour or two.⁵⁸² This means that people with albinism who want sunscreens with higher SPF might need to buy them for themselves. Currently at South African shops sunscreens with SPF 30 to 50 costs from R150 to R600.⁵⁸³ This can be challenging for those who cannot afford to buy.

South Africa has approximately four hundred public hospitals and over 200 private hospitals.⁵⁸⁴ While some hospitals and clinics provide sunscreen for individuals with albinism, the availability can differ. In rural and remote areas, access to hospitals and

⁵⁷⁶ Mayo Clinic, 'Albinism - Symptoms and Causes' (2024) <<https://www.mayoclinic.org/diseases-conditions/albinism/symptoms-causes/syc-20369184>> accessed 6 October 2024.

⁵⁷⁷ Caradee Yael Wright and Mary Norval, 'Solar Ultraviolet Radiation, Skin Cancer and Photoprotective Strategies in South Africa' (2022) Photochemistry and Photobiology <<https://doi.org/10.1111/php.13676>> accessed 6 October 2024.

⁵⁷⁸ Mayo Clinic (n 301 above).

⁵⁷⁹ Geography of South Africa, 'Highveld' (n 301 above).

⁵⁸⁰ Patricia Margaret Lund and Julie Susan Taylor, 'Lack of adequate sun protection for children with oculocutaneous albinism in South Africa' (2008) BMC Public Health <<https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>> accessed 6 October 2024.

⁵⁸¹ Ibid.

⁵⁸² American Academy of Dermatology, 'How to Apply Sunscreen' (2024) <<https://www.aad.org/public/everyday-care/sun-protection/sunscreen-patients/how-to-apply-sunscreen>> accessed 6 October 2024.

⁵⁸³ Dis-Chem, 'Shop for Sunscreen Online' (2024) <<https://www.dischem.co.za/shop-by-department/beauty-and-skincare/dermocosmetics/sun>> accessed 6 October 2024.

⁵⁸⁴ Wikipedia, 'Healthcare in South Africa' (2024) <https://en.wikipedia.org/wiki/Healthcare_in_South_Africa> accessed 6 October 2024.

clinics that provide sunscreen can be challenging.⁵⁸⁵ For example, regions like the Eastern Cape and parts of Limpopo often have limited healthcare infrastructure, making it difficult for residents, such as those with albinism, to access necessary medical supplies, including sunscreen.⁵⁸⁶ In their research on the lack of adequate sun protection for children with albinism in South Africa, Lund, and Taylor found that government-sponsored sunscreen was only available if actively pursued and that this process required time-consuming trips to regional hospitals, where the supply was often inadequate and insufficient to meet the needs of these children.⁵⁸⁷ In a study conducted by Zungu and Mashige, focusing on individuals with albinism in KwaZulu-Natal, South Africa, participants expressed concerns about the shortage of sunscreens available at hospitals.⁵⁸⁸ This shortage often forces them to purchase sunscreens, which can be a significant financial burden. This shows that there is a need for improvement, depending on the availability of resources, to ensure the availability of adequate sunscreen at South African hospitals.

Regular dermatological checkups are crucial for the early detection and prevention of skin cancer in people with albinism, as this allows dermatologists to closely monitor skin health, identify precancerous lesions early, and provide timely treatment, which is essential for improving outcomes and survival rates.⁵⁸⁹ However, in South Africa, dermatological checkups for people with albinism are not universally available for free, and access to these essential services remains a significant challenge.⁵⁹⁰ The public healthcare system does provide some dermatological services, but the availability and quality of these services can vary greatly depending on the region.⁵⁹¹ People with albinism often face barriers in accessing regular dermatological care. These barriers

⁵⁸⁵ Caradee Yael Wright, 'Solar Ultraviolet Radiation Exposure and Human Health in South Africa: Finding a Balance' (2018) South African Medical Journal <<https://www.samj.org.za/index.php/samj/article/view/12345>> accessed 6 October 2024.

⁵⁸⁶ Michael Mncedisi Willie and Mudasir Maqbool, 'Access to Public Health Services in South Africa's Rural Eastern Cape Province' (2024) Journal of Medicine and Public Health 1402.

⁵⁸⁷ Lund and Taylor (n 260 above).

⁵⁸⁸ Zuzile Zungu and Khathutshelo Percy Mashige, 'Utilisation of eye and skin care, and social services among persons with albinism in Ulundi, KwaZulu-Natal, South Africa' (2019) 78(1) African Vision and Eye Health 484.

⁵⁸⁹ Caradee Yael Wright, Mary Norval, and Beverley Summers, 'Solar Ultraviolet Radiation Exposure and Human Health in South Africa: Finding a Balance' (2012) 102(8) South African Medical Journal 665-666.

⁵⁹⁰ Mswela (n 22 above).

⁵⁹¹ Willie and Maqbool (n 312 above).

include long waiting times, limited availability of specialists, and the costs associated with private healthcare, which many cannot afford.⁵⁹²

Research by Mswela has highlighted the lack of access to preventative services by people with albinism, such as regular dermatological checkups, which are crucial for early detection and treatment of skin cancer.⁵⁹³ Affordability is another critical issue. While some non-governmental organisations (hereafter referred to as NGOs) and initiatives, such as Beyond Suncare, provide free or subsidised dermatological services and sun protection products, these efforts are not widespread enough to meet the needs of all individuals with albinism in South Africa.⁵⁹⁴ The high cost of private dermatological care makes it inaccessible for many, particularly those from low-income backgrounds.⁵⁹⁵ This shows that, while there are some efforts to provide dermatological care for people with albinism in South Africa, much more needs to be done to ensure that these services are accessible, affordable, and effective in preventing and treating skin cancer.

4.3.4. The provision of sunglasses and eye checkups

The provision of free sunglasses and regular checkups for people with albinism is not a standard practice in South Africa,⁵⁹⁶ yet people with albinism in South Africa face significant eye challenges due to the lack of melanin, which affects their vision and makes them highly sensitive to light. This condition results in several visual impairments, including photophobia (sensitivity to light), nystagmus (involuntary eye movements), and reduced visual acuity (sharpness of vision).⁵⁹⁷ According to a study published in BMC International Health and Human Rights, 85% of children with albinism in South Africa were found to have less than 30% vision, even with the best optical correction.⁵⁹⁸ This highlights the severe impact of albinism on visual acuity. The study also noted that individuals with albinism experience a range of visual

⁵⁹² Mswela (n 22 above).

⁵⁹³ Ibid.

⁵⁹⁴ Beyond Suncare, 'Health and dignity for people with albinism' (2024) <<https://beyondsuncare.org/en/>> accessed 6 October 2024.

⁵⁹⁵ Zungu and Mashige (n 268 above).

⁵⁹⁶ Mswela (n 22 above).

⁵⁹⁷ Aldridge Munyoro, 'Understanding the critical health issues experienced by young people with albinism in Southern Africa' (2022) South African Youth Organisation <<https://sayof.org/wp-content/uploads/2022/09/SAYOF-ARTICLE-updated-1.pdf>> accessed 6 October 2024.

⁵⁹⁸ Anita Franklin, Patricia Lund, Caroline Bradbury-Jones, and Julie Taylor, 'Children with albinism in African regions: their rights to 'being' and 'doing'' (2018) 18 BMC International Health and Human Rights 2.

impairments, including photophobia, nystagmus, poor depth perception, strabismus, and refractive error.⁵⁹⁹ These visual impairments necessitate the provision of specialised healthcare services for people with albinism. Access to regular eye examinations, prescription glasses, and sunglasses with high UV protection is crucial to manage light sensitivity and improve visual acuity.⁶⁰⁰

Despite the critical need for specialised eye care and protective measures, the national health system has not adequately addressed these needs.⁶⁰¹ According to the Albinism Society of South Africa, very few individuals with albinism have access to sunglasses with high UV protection, which are crucial for managing light sensitivity.⁶⁰² Preventative services such as regular eye checks and corrections are not readily available. This lack of access is particularly pronounced in rural areas, where healthcare facilities are often under-resourced and far from reach.⁶⁰³

While some non-profit organisations and international partnerships, such as those with Altruist Sunscreen, have made efforts to provide these essential items, the coverage is far from sufficient.⁶⁰⁴ The cost of high-quality sunglasses with UV protection in private healthcare settings can range from R500 to R5000, depending on the brand and specifications.⁶⁰⁵ For many individuals with albinism, especially those from low-income backgrounds, these costs are prohibitive and place a significant financial burden on them and their families. This shows that there is a need for the South African government, depending on the availability of resources, to ensure that sunglasses and regular eye examinations are accessible and affordable.

⁵⁹⁹ Ibid.

⁶⁰⁰ Graham Greenleaf, 'The Global Development of Free Access to Legal Information' (2010) 1(1) EJLT 17.

⁶⁰¹ Mswela (n 22 above).

⁶⁰² Ibid.

⁶⁰³ Department of Health, 'Albinism Awareness Month' (2024) <<https://www.health.fs.gov.za/?p=4453>> accessed 6 October 2024.

⁶⁰⁴ Altruist Sunscreen, 'Albinism Support in Africa: Altruist's Partnership' (2024) <<https://altruistsun.com/stichting-albinisme-in-afrika-and-altruist-sunscreen/>> accessed 6 October 2024.

⁶⁰⁵ Everyday Health, 'Peep the 6 Best Sunglasses We Reviewed and Tested in 2024' (7 August 2024) <<https://www.everydayhealth.com/vision/best-sunglasses/>> accessed 6 October 2024.

4.3.4. Would the recognition of the right of access to healthcare services as a minimum core obligation be an essential measure to ensure the realisation of access to healthcare for people with albinism?

The CESCR has emphasised that states have a fundamental obligation to ensure the fulfilment of minimum essential levels of each right under the ICESCR.⁶⁰⁶ This instrument, as discussed in chapter two of this dissertation, contains the right to health, which encompasses the right to access healthcare services for people with albinism⁶⁰⁷ meaning that South Africa, as a party to this instrument, has this obligation to ensure the fulfilment of minimum essential levels of the right of access to healthcare services. Although these essential levels are dependent on resources, they should be prioritised by the state in its efforts to realise the rights under the ICESCR. This means that the fulfilment of these essential levels depends on South Africa's available resources.

The CESCR interprets State Parties' minimum core obligations under the ICESCR based on extensive experience gained from examining state parties' reports over more than a decade. The Committee asserts that it is incumbent on every State party to ensure at least the minimum essential levels of each right are satisfied. Therefore, a state party where a significant number of individuals lack essential food, healthcare, basic shelter, housing, or basic education is, *prima facie*, failing to fulfil its obligations under the Covenant. If the Covenant did not establish this minimum core obligation, it would lose its purpose. However, any assessment of whether a State has met its minimum core obligation must consider the resource constraints within that state.⁶⁰⁸ Article 2(2) requires each state party to take necessary steps using the maximum available resources.⁶⁰⁹ To justify a failure to meet these obligations due to a lack of resources, a state must demonstrate that it has made every effort to utilise all available resources to satisfy these minimum obligations as a priority.⁶¹⁰

The South African Constitutional Court has historically rejected the doctrine of minimum core obligations in several landmark cases,⁶¹¹ despite its critical importance

⁶⁰⁶ General Comment No. 3 (n 137 above).

⁶⁰⁷ ICESCR (n 40 above), Article 12.

⁶⁰⁸ General Comment No. 3 (n 137 above).

⁶⁰⁹ ICESCR (n 40 above), Article 12.

⁶¹⁰ General Comment No. 3 (n 137 above).

⁶¹¹ *Grootboom* (n 321 above), para 33; *Treatment Action Campaign* (n 344 above), para 34; *Mazibuko* (n 384 above).

in ensuring the fulfilment of socio-economic rights. In the *Grootboom*⁶¹² case, the Court was hesitant to fully endorse the concept of a minimum core obligation in relation to section 26 of the Constitution. This reluctance stemmed from the complexities involved in defining a universal minimum standard for socio-economic rights, given the diverse and varying circumstances and needs of individuals.⁶¹³ Although the Court acknowledged the potential value of minimum core obligations as a tool for assessing the reasonableness of state actions in specific cases, it emphasised the need for detailed information to determine what the minimum core should be in each unique situation.⁶¹⁴

Similarly, in the *Treatment Action Campaign*⁶¹⁵ case, the amici curiae attempted to persuade the Constitutional Court to recognise a 'minimum core' of socio-economic rights.⁶¹⁶ However, the Court reaffirmed its stance from the *Grootboom* case, indicating that while the concept of minimum core obligations could be used to assess the state's actions, it did not establish an independent right under Section 26(1).⁶¹⁷ The Court emphasised that its interpretation was aligned with the role and capacity of courts within a constitutional democracy,⁶¹⁸ highlighting that courts lack the broad capabilities required to determine minimum core standards and are not well-suited to make decisions with extensive social and economic impacts on the community.⁶¹⁹

In *Mazibuko and Others v City of Johannesburg*,⁶²⁰ the issue centered on the right to access sufficient quantities of water for a life of dignity.⁶²¹ The claimants argued that section 27(1)(b) guaranteed a right to 50 litres of water per person daily.⁶²² Despite this, Justice O'Regan dismissed the argument, noting similar reasons to those in the *Grootboom* and *Treatment Action Campaign* cases.⁶²³ Her interpretation of section 27(1) and (2) suggested there is no immediate legal entitlement to a minimum core of a right and, by extension, no immediate claim to the full scope of the right's related

⁶¹² *Grootboom* (n 321 above).

⁶¹³ *Ibid*, para 33.

⁶¹⁴ *Ibid*.

⁶¹⁵ *Treatment Action Campaign* (n 344 above).

⁶¹⁶ *Ibid*, paras 29, 31.

⁶¹⁷ *Ibid*, para 34.

⁶¹⁸ *Treatment Action Campaign* (n 344 above), para 37.

⁶¹⁹ *Ibid*, para 38.

⁶²⁰ *Mazibuko* (n 384 above).

⁶²¹ *Ibid*.

⁶²² *Ibid*.

⁶²³ *Ibid*.

duties. Justice O'Regan elaborated that it was neither anticipated nor feasible for the state to instantly provide all fundamental life necessities to citizens. Social and economic rights enable citizens to require the state to act sensibly and progressively to guarantee the basic necessities of life for everyone. These rights also allow citizens to hold the government accountable for how it endeavours to fulfil social and economic rights. This perspective dismisses the concept of minimum core obligations, even as a means to interpret what constitutes reasonable actions under the principle of progressive realisation.⁶²⁴

Chenwi argues that the concept of minimum core should be viewed as an integral aspect of progressive realisation of human rights.⁶²⁵ She contends that achieving the minimum essential levels of a right is an initial step towards progressive realisation, thus making it an inherent part of the overall concept of progressive realisation.⁶²⁶ This perspective is crucial when considering the Court's decisions in *Grootboom*,⁶²⁷ *Treatment Action Campaign*,⁶²⁸ and *Mazibuko*.⁶²⁹ These cases have significant implications for people with albinism and their right to access healthcare services, even though these cases focused on different rights. By rejecting the minimum core obligation, the Court fails to provide a safety net for the most vulnerable, such as people with albinism who require specialised healthcare.

The minimum core obligation could serve as a benchmark for the state to fulfil its duties, ensuring that basic essential services are not denied. This dissertation opines that the Court's reluctance to adopt this concept may leave people with albinism at risk of not receiving the necessary care, as there is no clear minimum standard that the state is required to meet. The above perspective of this dissertation is endorsed by Liebenberg, who asserts that without fulfilling the minimum essential needs necessary for survival, the state's duty to progressively realise rights becomes ineffective and hollow.⁶³⁰

⁶²⁴ Ibid, para 59.

⁶²⁵ Chenwi (n 32 above) 747.

⁶²⁶ Ibid.

⁶²⁷ *Grootboom* (n 321 above), para 33.

⁶²⁸ *Treatment Action Campaign* (n 344 above), para 34.

⁶²⁹ *Mazibuko* (n 384 above), para 59.

⁶³⁰ Liebenberg (n 347 above) 164.

Since the *Grootboom*,⁶³¹ *Treatment Action Campaign*,⁶³² and *Mazibuko*⁶³³ decisions, South Africa has ratified the ICESCR, which provides for minimum core obligations.⁶³⁴ This dissertation opines that the ratification suggests that the state recognises the importance of setting a baseline for socio-economic rights, which could include access to healthcare services for people with albinism. The ratification raises the possibility that South African courts may now give more weight to the minimum core obligations as defined by international law. This could lead to a shift in the judicial approach to socio-economic rights, potentially resulting in a greater emphasis on ensuring that the basic needs of individuals are met as a matter of legal obligation. The Court's decision predates this ratification, and one could argue that it should now be revisited to align with South Africa's international commitments and to better protect the rights of vulnerable groups. Adopting this doctrine of minimum core obligations could serve as a significant measure that would restore hope and ensure that socio-economic rights are better fulfilled, including the right of access to healthcare services for people with albinism.

Should the courts reconsider their stance in light of the ratification of ICESCR, they would likely acknowledge the right to access essential healthcare services for people with albinism as a fundamental core obligation that the state must satisfy. This would imply that, even in the face of financial difficulties, the state must demonstrate that it has made every effort to utilise available resources to meet the basic healthcare needs of people with albinism. Liebenberg reinforces this perspective by arguing that courts should uphold the government's prioritisation inherent in the minimum core concept.⁶³⁵ Liebenberg further indicated that courts should require the state to provide reasons for any failure to meet survival-related needs as a top priority.⁶³⁶ However, it remains uncertain whether the courts will adopt the concept of minimum core obligations in the future, despite the ratification of the ICESCR.

⁶³¹ *Grootboom* (n 321 above).

⁶³² *Treatment Action Campaign* (n 344 above).

⁶³³ *Mazibuko* (n 384 above).

⁶³⁴ The Government of South Africa ratifies the ICESCR' (ESCR-Net, 20 January 2015) <<https://www.escr-net.org/news/2015/government-south-africa-ratifies-icescr/>> accessed 22 June 2024.

⁶³⁵ Liebenberg (n 347 above) 164.

⁶³⁶ *Ibid.*

4.4. CONCLUSION

This chapter addressed the question of South Africa's legislative and other efforts to ensure access to healthcare services for people with albinism, identifying areas needing improvement. The measures assessed include legislative actions such as the National Health Act, the Promotion of Equality and Prevention of Unfair Discrimination Act, and the National Health Insurance Act. Other measures include the Ekurhuleni Declaration on the Rights of Persons with Albinism, the provision of sunscreens and dermatological checkups, and the provision of sunglasses and eye checkups. While these legislative and other measures represent significant steps towards ensuring healthcare access for people with albinism, there is a clear need for improvement.

The current measures are not sufficiently comprehensive to meet South Africa's international and Constitutional obligations. For instance, the availability of accessible or affordable sunglasses and regular eye checkups remains limited, and many individuals with albinism still struggle to access essential dermatological care and sunscreens. Therefore, the South African government must improve these measures progressively and within its available resources, ensuring that all individuals with albinism have full access to healthcare services.

The concept of minimum core obligations was also analysed in this chapter in the context of the right of access to healthcare services for people with albinism and an argument was made that South Africa's rejection of this important doctrine was before South Africa ratified the ICESCR which provides for its adoption by member states, the courts must reconsider their stance as its adoption would align with South Africa's international obligations under the ICESCR and ensure protection for the rights of vulnerable groups such as people with albinism. The following chapter concludes the research and offers recommendations to improve the legislative and other measures taken by the South African government. The following chapter concludes the research and offers recommendations to improve the legislative and other measures taken by the South African government.

CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

5.1. INTRODUCTION

Chapter one provided an introduction to the study. It covered the background of the research topic, presented the problem statement, outlined the research questions, detailed the research methodology, and included a literature review. It also provided an outline of the study's chapters. Chapter two clarified South Africa's international obligations to provide healthcare access for people with albinism and discussed relevant general comments and recommendations by treaty bodies for clarification of such obligations. Chapter three clarified South Africa's constitutional obligations to ensure access to healthcare services for people with albinism. Chapter four assessed South Africa's legislative and other efforts to provide access to healthcare services for people with albinism. It identified areas needing improvement for South Africa to meet its international and constitutional obligations. This chapter concludes the research and offers recommendations to improve the legislative and other measures taken by the South African government. These recommendations aim to improve access for people with albinism, ensuring that South Africa fulfils its international and constitutional obligations.

5.2. RECOMMENDATIONS

As discussed in this dissertation, the international human rights law and the South African Constitution do not mandate the realisation of the right of access to healthcare services for people with albinism as an absolute obligation. Instead, this right is subject to the availability of state resources and must be realised progressively. Therefore, the implementation of the recommendations provided here depends on the availability of state resources and must be achieved progressively, except for those that can be implemented immediately and require minimal or no resources.

5.2.1. Strengthening of legislative measures adopted by the South African government such as the National Health Act, the Promotion of Equality and Prevention of Unfair Discrimination Act and the National Health Insurance Act

The South African government has taken significant legislative measures to ensure access to healthcare services for people with albinism. However, there are critical

areas where these legislative measures fall short. The National Health Act,⁶³⁷ while aimed at addressing socio-economic injustices and ensuring quality healthcare for all citizens, does not sufficiently guarantee free healthcare for people with albinism. The Act's discretionary language allows the Minister of Health to prescribe conditions for free healthcare services, which can lead to potential inconsistencies and insufficient resource allocation. To address this, it is recommended that section 4 of the National Health Act⁶³⁸ be amended to explicitly recognise all people, including those with albinism, as a vulnerable group entitled to free healthcare services, regardless of age. This aligns with the *Grootboom*⁶³⁹ case, which mandates that state measures must be inclusive and address the needs of those most in peril to be deemed reasonable.

The PEPUDA⁶⁴⁰ is another legislative measure to ensure access to healthcare services for all individuals, including people with albinism. However, Section 8(g) of PEPUDA focuses primarily on women's access to health services and does not equally emphasise protection against discrimination for men, including those with albinism.⁶⁴¹ To address this, it is recommended that section 8(g)⁶⁴² be revised to ensure equal protection against healthcare discrimination for all individuals, regardless of gender. This aligns with the CERD's recommendations for equal access to healthcare services without discrimination.⁶⁴³

The recently enacted NHI Act⁶⁴⁴ represents a significant step towards universal healthcare. However, its vague implementation guidelines and lack of clear funding mechanisms pose challenges to its effective implementation. To ensure the NHI Act effectively provides healthcare services to people with albinism, it is recommended that the Act⁶⁴⁵ include specific provisions and detailed implementation plans for vulnerable groups, including people with albinism. This includes ensuring sufficient budget allocations and mechanisms to prevent corruption and financial mismanagement, as emphasised in the *City of Johannesburg Metropolitan*

⁶³⁷ Act 61 of 2003.

⁶³⁸ Ibid.

⁶³⁹ *Grootboom* (n 321 above).

⁶⁴⁰ Act 4 of 2000.

⁶⁴¹ Ibid.

⁶⁴² Ibid.

⁶⁴³ Committee on the Elimination of Racial Discrimination, 'Concluding observations on the combined ninth to eleventh periodic reports of South Africa' (n 172 above).

⁶⁴⁴ Act 20 of 2023.

⁶⁴⁵ Ibid.

*Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Another*⁶⁴⁶ and *Grootboom*⁶⁴⁷ cases.

5.2.2. Improvement of other measures adopted by the South African government such as the Ekurhuleni Declaration on the Rights of Persons with Albinism, the provision of sunscreens and dermatological checkups, and the provision of sunglasses and eye checkups

The Constitution,⁶⁴⁸ along with international instruments such as the ICESCR⁶⁴⁹ and ACHPR,⁶⁵⁰ mandates the state to take comprehensive measures beyond legislative actions to ensure the realisation of socio-economic rights, including healthcare services for people with albinism. The *Grootboom*⁶⁵¹ case emphasised that legislative measures alone are insufficient and must be complemented by well-designed and effectively implemented policies and programs. The Ekurhuleni Declaration, although a significant step, lacks binding authority, leading to inconsistent implementation across regions and sectors.⁶⁵² To address these issues, it is recommended that the South African government integrates the principles of the Ekurhuleni Declaration into binding legislation. This would ensure consistent application and accountability, aligning with South Africa's constitutional and international obligations to provide equitable healthcare services.

Currently, the government provides SPF 15 sunscreen free of charge through regional hospitals. However, this SPF level is inadequate for the high UV exposure that people with albinism face. Sunscreens with higher SPF, such as SPF 30 or 50, are recommended and should be provided free of charge to better protect against skin damage and reduce the risk of skin cancer. This measure aligns with Article 25 of the Ekurhuleni Declaration, which emphasises the importance of providing free sunscreen to individuals with albinism.⁶⁵³ Similarly, Article 26 focuses on the need for free eye tests and the provision of spectacles.⁶⁵⁴ Regular dermatological checkups, crucial for

⁶⁴⁶ *City of Johannesburg Metropolitan Municipality* (n 425 above).

⁶⁴⁷ *Grootboom* (n 321 above).

⁶⁴⁸ The Constitution of the Republic of South Africa, 1996.

⁶⁴⁹ ICESCR (n 40 above).

⁶⁵⁰ ACHPR (n 45 above).

⁶⁵¹ *Grootboom* (n 321 above).

⁶⁵² South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (n 59 above).

⁶⁵³ Ibid.

⁶⁵⁴ Ibid.

early detection and prevention of skin cancer, should also be universally available for free.

Access to regular eye examinations, prescription glasses, and sunglasses with high UV protection is crucial for managing visual impairments in people with albinism. The national health system should ensure these services are accessible and affordable, especially in under-resourced rural areas. This aligns with Article 29 of the Ekurhuleni Declaration, which calls for improved access to health services in rural areas.⁶⁵⁵ Developing a national action plan, incorporating measures from the Ekurhuleni Declaration and the Regional Action Plan on Albinism, as urged by UN Independent Expert Ero,⁶⁵⁶ would further enhance access to healthcare services for people with albinism. Such a plan would ensure comprehensive healthcare coverage, fulfilling South Africa's obligations under the ICESCR⁶⁵⁷ and ACHPR,⁶⁵⁸ and addressing the unique healthcare challenges faced by individuals with albinism.

5.2.3. The recognition of the right of access to healthcare services as a minimum core obligation

The CESCR has established that states have minimum core obligations for each right under the ICESCR, including the right to healthcare.⁶⁵⁹ Despite this, South African courts have historically been reluctant to adopt the concept of minimum core obligations, as evidenced in landmark cases such as *Grootboom*,⁶⁶⁰ *Treatment Action Campaign*,⁶⁶¹ and *Mazibuko*.⁶⁶² However, since South Africa's ratification of the ICESCR, the state is now bound by these international commitments. This ratification suggests that South Africa recognises the importance of setting a baseline for socio-economic rights, which includes access to healthcare services for people with albinism. Given this development, the South African Constitutional Court should reconsider its stance on minimum core obligations to align with international law and better protect the rights of vulnerable groups.

⁶⁵⁵ Ibid.

⁶⁵⁶ UN Human Rights Office of the High Commissioner (n 545 above).

⁶⁵⁷ ICESCR (n 40 above).

⁶⁵⁸ ACHPR (n 45 above).

⁶⁵⁹ General Comment No. 3 (n 137 above).

⁶⁶⁰ *Grootboom* (n 321 above).

⁶⁶¹ *Treatment Action Campaign* (n 344 above).

⁶⁶² *Mazibuko* (n 384 above).

To ensure the realisation of access to healthcare for people with albinism, it is recommended that the courts recognise the right to essential healthcare services as a minimum core obligation. This recognition would imply that, even in the face of financial constraints, the state must demonstrate that it has made every effort to utilise available resources to meet the basic healthcare needs of all, including people with albinism. This approach aligns with the CESCR's requirement that states must prioritise the fulfilment of these essential levels of rights.⁶⁶³

5.2.4. The implementation of recommendations made by treaty monitoring bodies

South Africa, under international instruments such as the ICESCR,⁶⁶⁴ CEDAW,⁶⁶⁵ CRPD,⁶⁶⁶ and CRC,⁶⁶⁷ has obligations to provide reports on the implementation of the right to health, which encompasses access to healthcare services for people with albinism. Based on the responses and recommendations from treaty monitoring bodies, several key recommendations should be adopted to meet the requirements of these treaties.

The CRC highlighted the need for South Africa to improve healthcare access for children with albinism, addressing their increased vulnerability to skin cancer and vision problems.⁶⁶⁸ South Africa should implement targeted healthcare programs that focus on the specific needs of children with albinism, including regular dermatological check-ups and access to high-quality visual aids.

The CRPD Committee pointed out significant gaps in healthcare access for persons with disabilities, particularly in rural and underserved areas.⁶⁶⁹ To address this, South Africa should improve healthcare infrastructure in these regions, ensuring that specialised services for all people with disabilities, including those with albinism, are readily available.

⁶⁶³ General Comment No. 3 (n 137 above).

⁶⁶⁴ ICESCR (n 40 above).

⁶⁶⁵ CEDAW (n 42 above).

⁶⁶⁶ CRPD (n 44 above).

⁶⁶⁷ UNCRC (n 43 above).

⁶⁶⁸ UN Committee on the Rights of the Child (n 141 above).

⁶⁶⁹ UN Committee on the Rights of Persons with Disabilities (n 154 above).

The CERD emphasised the necessity of providing equal access to healthcare services for persons with albinism without discrimination.⁶⁷⁰ South Africa should ensure that the National Albinism Task Force is fully supported and that the National Action Plan on Albinism includes specific measures to guarantee equal access to healthcare services. This should involve monitoring and evaluating the implementation of these measures to ensure their effectiveness and making necessary adjustments based on feedback from the albinism community.

5.3. CONCLUSIONS

5.3.1. South Africa's international obligations to provide access to healthcare services for people with albinism

This dissertation has clarified South Africa's obligations under the international, regional, and sub-regional human rights instruments to provide people with albinism with access to healthcare services. General comments and recommendations are also discussed to clarify these obligations. At the international level, South Africa has clear obligations to provide access to health healthcare services to people with albinism under the international human rights law. These obligations include respecting their right to access healthcare by not hindering it, protecting this right by enacting and enforcing relevant laws, and fulfilling this right by taking proactive steps such as creating laws, setting up administrative systems, allocating budgets, and promoting health initiatives.⁶⁷¹ These obligations are rooted in foundational documents such as the UDHR,⁶⁷² ICCPR,⁶⁷³ and ICESCR.⁶⁷⁴

The right of access to healthcare services for people with albinism is recognised under various international and regional, which South Africa has ratified, and those that do not require ratification such as the UDHR,⁶⁷⁵ the ICESCR,⁶⁷⁶ the ICERD,⁶⁷⁷ the CEDAW,⁶⁷⁸ the CRC,⁶⁷⁹ the CRPD,⁶⁸⁰ and African regional instruments such as the

⁶⁷⁰ Committee on the Elimination of Racial Discrimination (n 122 above).

⁶⁷¹ Office of the United Nations High Commissioner for Human Rights (n 74 above).

⁶⁷² UDHR (n 39 above).

⁶⁷³ ICCPR (n 76 above).

⁶⁷⁴ ICESCR (n 40 above).

⁶⁷⁵ UDHR (n 39 above).

⁶⁷⁶ ICESCR (n 40 above).

⁶⁷⁷ ICERD (n 41 above).

⁶⁷⁸ CEDAW (n 42 above).

⁶⁷⁹ UNCRC (n 43 above).

⁶⁸⁰ CRPD (n 44 above).

ACHPR,⁶⁸¹ and the ACRWC.⁶⁸² These instruments mandate that South Africa must ensure access to healthcare for all its citizens, including marginalised groups like people with albinism. The SADC DPPA on the other side contains the best practices to ensure access to healthcare services for people with albinism.⁶⁸³ The ICESCR also imposes the minimum obligations on state parties of every right under it which includes the right to health which encompasses the right of access to healthcare services for people with albinism in South Africa.⁶⁸⁴

5.3.2. South Africa's constitutional obligations to provide access to healthcare services for people with albinism

This dissertation has also clarified South Africa's constitutional obligations to ensure access to healthcare services for people with albinism. The South African Constitution reflects the obligations imposed by the international and regional human rights instruments regarding the socio-economic rights which include the right of access to healthcare services for people with albinism.⁶⁸⁵ Under section 7(2) of the Constitution, the state must respect, protect, promote, and fulfil the right of access to healthcare services for these people.⁶⁸⁶ The Constitution also creates positive⁶⁸⁷ and negative obligations on their right of access to healthcare.⁶⁸⁸

Negative obligations require South Africa to avoid interfering with access to healthcare, which must be immediate and unconditional, without excuses related to resource availability. Any limitations must be justified under section 36 of the Constitution through a two-stage process: determining if there is a breach and if the limitation is reasonable and justifiable.⁶⁸⁹ Negative obligations are immediate and are not subject to qualifiers under section 27(2) of the Constitution. South Africa's positive obligations differ from its negative obligations, as they are justified within the framework of the reasonableness test and subject to qualifiers under section 27(2) of the Constitution. Positive obligations require the state to take reasonable legislative and other

⁶⁸¹ ACHPR (n 45 above).

⁶⁸² ACRWC (n 47 above).

⁶⁸³ DPPA (n 46 above).

⁶⁸⁴ ICERD (n 41 above).

⁶⁸⁵ The Constitution of the Republic of South Africa, 1996, sec 27(1).

⁶⁸⁶ The Constitution of the Republic of South Africa, 1996.

⁶⁸⁷ *Treatment Action Campaign* (n 344 above).

⁶⁸⁸ *Ex parte Chairperson of the Constitutional Assembly* (n 178 above).

⁶⁸⁹ The Constitution of the Republic of South Africa, 1996.

measures to progressively realise the right of access to healthcare services within its available resources.⁶⁹⁰

The South African Constitutional Court has employed the reasonableness test in several landmark decisions to determine whether the state has made sufficient efforts to its constitutional obligations regarding socio-economic rights, including the right to access healthcare services for people with albinism. Notable cases include *Grootboom*,⁶⁹¹ *Treatment Action Campaign*,⁶⁹² and *Mazibuko and Others v City of Johannesburg*.⁶⁹³ The reasonableness test, as defined by the Constitutional Court, involves evaluating whether the state's measures to fulfill socio-economic rights are reasonable in the context of the available resources and the specific circumstances of the case. The Court considers factors such as the nature and extent of the rights, the state's capacity to fulfil these rights, and the impact of the measures on the affected individuals. The test requires the state to demonstrate that it has made every effort to use its available resources to meet its obligations and that its actions are justifiable in a constitutional democracy.

5.3.3. Legislative and other measures made by the South African government to ensure access to healthcare services for people with albinism and areas that need improvement to meet its international and constitutional obligations

The South African government is obligated under international law, reflected in instruments such as the CRPD⁶⁹⁴ and ICESCR,⁶⁹⁵ to make legislative measures to ensure access to healthcare services for people with albinism. This obligation is also enshrined in the South African Constitution, particularly in Section 27, which guarantees the right to access to healthcare services.⁶⁹⁶ However, this obligation must be fulfilled progressively within the state's available resources.⁶⁹⁷ The Constitutional Court, notably in the *Grootboom* case, has emphasised the need for reasonable legislative and other measures to achieve the progressive realisation of socio-economic rights.⁶⁹⁸ To meet these obligations, South Africa has enacted several laws,

⁶⁹⁰ The Constitution of the Republic of South Africa, 1996.

⁶⁹¹ *Grootboom* (n 321 above).

⁶⁹² *Treatment Action Campaign* (n 344 above).

⁶⁹³ *Mazibuko* (n 384 above), para 67.

⁶⁹⁴ CRPD (n 44 above).

⁶⁹⁵ ICESCR (n 40 above).

⁶⁹⁶ The Constitution of the Republic of South Africa, 1996.

⁶⁹⁷ The Constitution of the Republic of South Africa, 1996, sec 27(2).

⁶⁹⁸ *Grootboom* (n 321 above).

including the National Health Act,⁶⁹⁹ the Promotion of Equality and Prevention of Unfair Discrimination Act,⁷⁰⁰ and the National Health Insurance Act.⁷⁰¹ While these legislative measures reflect the state's commitment to fulfilling its international and constitutional obligations to ensure healthcare access for all, including marginalised groups like people with albinism, there is a clear need for improvement.

The National Health Act,⁷⁰² despite its intent to establish a structured and uniform health system, fails to sufficiently guarantee free healthcare for people with albinism due to its discretionary language and broad criteria. This lack of explicit recognition and mandated free services for individuals with albinism, especially those above six years old, does not align with the Constitutional Court's reasonableness test. The failure to adequately address their specific and ongoing healthcare needs undermines their right to dignity and life, as these individuals face heightened risks of severe health conditions like skin cancer.

The PEPUA⁷⁰³ focuses primarily on women's access to health services, neglecting equivalent protection against healthcare discrimination for men with albinism. This limitation in PEPUA⁷⁰⁴ highlights the need for a more inclusive approach that ensures equal access to necessary healthcare services for all individuals, irrespective of gender. The NHI Act,⁷⁰⁵ while a significant step toward universal healthcare, suffers from vague implementation guidelines and a lack of clear funding mechanisms. These issues raise concerns about potential inefficiencies and inadequate healthcare infrastructure, which could adversely affect the quality and accessibility of services for people with albinism.

In addition to legislative measures, the South African government, as mandated by the Constitution⁷⁰⁶ and international instruments such as the ICESCR⁷⁰⁷ and ACHPR,⁷⁰⁸ must also implement well-designed and effectively executed policies and programs to ensure the realisation of socio-economic rights, including access to healthcare

⁶⁹⁹ Act 61 of 2003.

⁷⁰⁰ Act 4 of 2000.

⁷⁰¹ Act 20 of 2023.

⁷⁰² Act 61 of 2003.

⁷⁰³ Act 4 of 2000.

⁷⁰⁴ Act 4 of 2000.

⁷⁰⁵ Act 20 of 2023.

⁷⁰⁶ The Constitution of the Republic of South Africa, 1996.

⁷⁰⁷ ICESCR (n 40 above).

⁷⁰⁸ ACHPR (n 45 above).

services for people with albinism, as emphasised in the *Grootboom* case.⁷⁰⁹ To fulfil this obligation, South Africa has taken other measures, including the Ekurhuleni Declaration on the Rights of Persons with Albinism, the provision of sunscreens and dermatological checkups, and the provision of sunglasses and eye checkups.⁷¹⁰ However, the South African Constitutional Court has refused to adopt the minimum core obligation measure.⁷¹¹

The Ekurhuleni Declaration on the Rights of Persons with Albinism outlines best practices and recommendations for improving healthcare access and services for people with albinism, emphasising the provision of free sunscreen, eye care, the inclusion of essential assistive devices in medical aid schemes, training for medical personnel, and improving healthcare access in rural areas.⁷¹² However, its non-binding nature can lead to inconsistent implementation. While some efforts are made to provide sunscreen and dermatological checkups for people with albinism, these services are often insufficient and inconsistent, particularly in rural areas, leading to significant challenges in accessing and affording the necessary care to prevent skin cancer and other related health issues. People with albinism in South Africa also face significant visual impairments and lack access to essential eye care services and UV-protective sunglasses, highlighting the need for the government to ensure these services are accessible and affordable while improving and sustaining healthcare initiatives within available resources.

The South African Constitutional Court has historically rejected the doctrine of minimum core obligations imposed by the ICESCR in several landmark cases,⁷¹³ impacting the fulfilment of socio-economic rights, including access to healthcare services for people with albinism. However, since South Africa's ratification of the ICESCR, which provides for minimum core obligations, there is a potential for the courts to reconsider their stance and better protect the rights of vulnerable groups, ensuring that the basic healthcare needs of people with albinism are met as a

⁷⁰⁹ *Grootboom* (n 383 above).

⁷¹⁰ South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (n 59 above).

⁷¹¹ *Grootboom* (n 181 above), para 33; *Treatment Action Campaign* (n 344 above), para 34; *Mazibuko* (n 384 above).

⁷¹² South African Government, 'Ekurhuleni Declaration on the Rights of Persons with Albinism' (n 59 above).

⁷¹³ *Grootboom* (n 181 above), para 33; *Treatment Action Campaign* (n 344 above), para 34; *Mazibuko* (n 384 above).

fundamental obligation of the state. This dissertation has also argued that the minimum core obligation should be adopted as this would align with South Africa's international obligations under the ICESCR⁷¹⁴ and ensure protection for the rights of vulnerable groups such as people with albinism.

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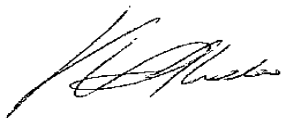
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Kind regards



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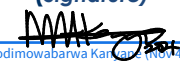
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