

# **LIVING WITH ALBINISM IN SOUTH AFRICA: UNCOVERING THE HEALTH CHALLENGES FROM A LEGAL PERSPECTIVE\***

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## **SUMMARY**

The Cancer Association of South Africa (CANSA) has acknowledged that persons with albinism face the highest risk of developing skin cancer. While information concerning their susceptibility to cancer is very important, CANSA observed that such information is communicated to persons with albinism at a very late stage, especially those living in rural areas of South Africa. The Albinism Society of South Africa has revealed that the national health system has failed to adequately consider and take into account the health care needs of persons living with albinism. Very few persons with albinism have access to sunglasses with a high UV protection screen to relieve light sensitivity, or to preventative services such as dermatological skin checks, eye checks and eye corrections. This article establishes that the specialised health intervention required by persons with albinism is not prioritised in South Africa's health care plan. The author argues that a well-timed intervention into the health needs of persons with albinism will have a penetrative influence on the fate of a small yet significant population. The recognition of the right of access to health care in the South African Constitution affords persons living with albinism the right to challenge the government's failure to provide them with essential health care services and health accessories. This article also discusses the pertinent clinical aspects of albinism, with the aim of contextualising the legal discussion in the rest of the article.

## **1 INTRODUCTION**

Despite the fact that albinism affects several South Africans, it is a condition that remains deeply misunderstood. Albinism is steeped in myth and false notions and is perceived by many as a curse and contamination.<sup>1</sup>

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<sup>1</sup> Mswela and Slabbert "Colour Discrimination Among People With Albinism in South Africa" 2013 6(1) *South African Journal of Bioethics and Law* 25 25–27; Mswela *A Selection of Legal Issues Relating to Persons Living With Albinism* (thesis, University of South Africa) 2016 1–283; Olagunju "Towards a Biblical Response to Myth and Discrimination Against the

Throughout history, persons with albinism (PWA) have been treated with doubt and suspicion. In schools and in the wider community, children with albinism are also subjected to violence and ridicule.<sup>2</sup> In certain areas on the African continent, including South Africa, PWA are killed for the trade in body parts for use as sacramental medicines, or sexually assaulted as a result of the belief that raping them may offer a cure for HIV/AIDS.<sup>3</sup> All of this highlights the extreme vulnerability of PWA, apart from the many violations of their fundamental rights that follow from the manner in which they are treated.<sup>4</sup> The vulnerability of PWA is exacerbated as a result of the unique health concerns associated with their condition. For those living with albinism in Africa, life may be particularly difficult.<sup>5</sup> Poverty and a lack of knowledge about the condition deprives these individuals of protection against skin cancer.<sup>6</sup> Many PWA die prematurely because of skin cancer.<sup>7</sup> The susceptibility of PWA to skin cancer leading to premature death is one result of the lack of insight into their health needs.<sup>8</sup> They are either unaware of this danger or only informed when a cancer has reached an advanced stage.<sup>9</sup> Severe eye problems, which in many cases translate into blindness, are another health issue affecting PWA.<sup>10</sup> The vicious cycle of social ostracism, stigmatisation and discrimination towards PWA means that they are reluctant to seek medical help and even if they do, they may find themselves marginalised.

The primary purpose of this article is to highlight some of the pertinent health challenges faced by South Africans living with albinism. This article establishes that the specialised health intervention required by this small population is not prioritised in South Africa's health care plan. It is argued that a well-timed intervention into the health needs of PWA will have a decisive influence on the fate of a small yet significant population. The article argues that the recognition of the right of access to health care as enshrined in the South African Constitution affords PWA the right to challenge the government's failure to provide them with such essential health care necessities.

Although most legal researchers do not characteristically have training in medicine, the need to research health care, diagnoses, injuries, and of

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Human Right of Albinos in Yorubaland" 2012 1 *Journal of Studies in Social Sciences* 46–58; United Nations General Assembly "Persons With Albinism" Report of the Office of the United Nations High Commissioner for Human Rights (12 September 2013) A/HRC/24/57 5–9.

<sup>2</sup> Mswela *A Selection of Legal Issues Relating to Persons Living with Albinism v.*

<sup>3</sup> *Ibid.*

<sup>4</sup> *Ibid.*

<sup>5</sup> Norman *The Woman Who Lost Her Skin and Other Dermatological Stories* (2004) 39.

<sup>6</sup> *Ibid.*

<sup>7</sup> *Ibid.*

<sup>8</sup> CANSA "Albinism Increases Skin Cancer Risk in South Africa" (24 May 2012) <http://www.cansa.org.za/albinism-increases-skin-cancer-risk-in-south-africa/> (accessed 2017-03-05) 1.

<sup>9</sup> CANSA <http://www.cansa.org.za/albinism-increases-skin-cancer-risk-in-south-africa/1>.

<sup>10</sup> *Ibid.*

course medical terminology arises from time to time.<sup>11</sup> Legal research involving a strong medical component requires the researcher to be aware of the finer points, and to have a fundamental understanding of the most relevant medical details. In what follows, the discussion briefly focuses on the pertinent clinical aspects of albinism in order to gain a greater insight into this condition, with the aim of contextualising the legal discussion in the rest of the article and addressing some of the misconceptions regarding albinism. Fostering an understanding of the genetics behind albinism is as important as in any other awareness campaign concerning a stigmatised condition or disease.

## 2 CLINICAL ASPECTS OF ALBINISM

Albinism, a condition caused by a lack of skin pigmentation in humans,<sup>12</sup> results from a mutation of one of numerous genes.<sup>13</sup> It is a heterogeneous genetic disorder, characterised by a lack of or huge reduction in pigment in the skin, hair and eyes.<sup>14</sup> The genetic information is stored within the deoxyribonucleic acid (DNA) molecule.<sup>15</sup> Specific genes within the DNA molecules encode for proteins involved in the production of melanin in the melanocytes.<sup>16</sup> A mutation in one or several genes may lead to a deficiency of melanin production or a complete stop in the production of melanin.<sup>17</sup>

A person has to inherit two copies of a mutated gene, one from each parent, to have albinism.<sup>18</sup> Clinically, this is known as recessive inheritance.<sup>19</sup> A person who has merely one copy of the mutated gene will

<sup>11</sup> Iyer *Nursing Home Litigation: Investigation and Case Preparation* (2006) 9.

<sup>12</sup> Opara and Jiburum "Skin Cancers in Albinos in a Teaching Hospital in Eastern Nigeria: Presentation and Challenges of Care" 2010 8(73) *World Journal of Surgical Oncology* 701 701. Also see Hunter *Lets Review Biology: The Living Environment* (2008) 148; Kings and Summers "Albinism: Ocular and Oculataneous Albinism and Hermansky Pudlak Syndrome" in Suzzane *Management of Genetic Syndromes* (2010) ch 5; Riede and Werner *Color Atlas Pathological Principles* (2011) 96.

<sup>13</sup> Hunter *Lets Review Biology* 148; Kings *et al* in Suzzane *Management of Genetic Syndromes* ch 5; Riede *et al Color Atlas Pathological Principles* 96.

<sup>14</sup> Scott "New Category of Color: Analyzing Albinism Under the Title VII and the Americans With Disabilities Act" 1999 2 *The Journal of Gender, Race and Justice* 493 494; and Jack *Clinical Ophthalmology: A Systematic Approach* (2011) 648. Also see Hunter *Lets Review Biology* 148; Kings *et al* in Suzzane *Management of Genetic Syndromes* ch 5; Riede *et al Color Atlas Pathological Principles* 96. For a discussion on the definition of Genetic Heterogeneity, see Moll, Berry, Weidman, Ellefson, Gordon and Kottke "Detection of Genetic Heterogeneity Among Pedigrees Through Complex Segregation Analysis: An Application to Hypercholesterolemia" 1985 36 *American Journal of Human Genetics* 197 198; and Thomas, Francis and David *Principles of Medical Genetics* (1998) 28.

<sup>15</sup> Naafs and Padovese "Rural Dermatology in the Tropics" 2009 27(3) *Clinics in Dermatology* 252 261 and 269. Also see Pearson "ATP Released via Gap Junction Hemichannels From the Pigment Epithelium Regulates Neural Retinal Progenitor Proliferation" 2005 46(5) *Neuron* 731 731.

<sup>16</sup> Richards and Hawley *The Human Genome: A User's Guide* (2010) 35.

<sup>17</sup> Denniston and Murray *The Oxford Handbook of Ophthalmology* (2009) 518. Also see Horobin (ed) *Diseases and Disorders* (2008) 29.

<sup>18</sup> Richards and Hawley *The Human Genome* 35.

<sup>19</sup> Horobin *Diseases and Disorders* 29. Also see Thomas and Kumar *Clinical Paediatric Dermatology* (2013) 114; and Kutzbach "Evaluation of Vision-Specific Quality-of-Life in

have normal hair, skin or eyes.<sup>20</sup> A gene that comprises several diverse properties is considered pleiotropic.<sup>21</sup> Albinism is believed to be pleiotropic since it has an effect on skin colour or eyes.<sup>22</sup>

In spite of the type of mutated gene that is present in any human being, vision impairment is a common feature in all types of albinism.<sup>23</sup> Such eye impairments are the result of a deranged development of the nerve trail from the eye to the brain, as well as an irregular growth of the retina.<sup>24</sup> The symptoms of albinism in early childhood comprise poor vision, sensitivity to bright light, nystagmus and strabismus.<sup>25</sup> Vision may vary from normal for persons who are moderately affected by albinism, to legal blindness or complete blindness for people with the more severe types of albinism.<sup>26</sup> Typically, persons with albinism who have the least pigmentation have the poorest vision.<sup>27</sup> An ophthalmologist can perform an electroretinogram to test vision problems associated with albinism. Where the test result is uncertain, a "visual evoked potentials test" may be useful.<sup>28</sup>

Where albinism affects the hair and the skin, it leaves a stark white to whitish-yellow colour. Such skin is extremely fair and people with this form of albinism suffer from photo-ageing cancer and an amplified prevalence of all types of skin cancer. An error in the synthesis of tyrosinase means people living with oculocutaneous albinism have little protection against ultraviolet radiation (UVR) damage.<sup>29</sup> As a result, exposure to high levels of UVR enhances the risk of contracting all three main types of skin cancer.<sup>30</sup> Long term exposure to sunburn promotes skin cancers among people living with albinism. The Cancer Association of South Africa (CANSA) believes that PWA in South Africa face the highest risk of developing skin cancer. While this information regarding their susceptibility to cancer is very important, CANSA has acknowledged that such information is often communicated at a very late stage to PWA, especially those living in rural areas of South Africa.

It would be impractical and impossible to discuss all the clinical aspects relating to albinism in this article. The vulnerability of PWA makes them a category in need of specific health protection, ranging from visual aids, eye surgery and regular check-ups for skin cancer, to sunglasses offering high

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Albinism" 2009 13(2) *Journal of American Association for Paediatric Ophthalmology and Strabismus* 191.

<sup>20</sup> Richards and Hawley *The Human Genome*: 35. Also see Horobin *Diseases and Disorders* 29.

<sup>21</sup> Horobin *Diseases and Disorders* 29.

<sup>22</sup> *Ibid.*

<sup>23</sup> *Ibid.*

<sup>24</sup> *Ibid.*

<sup>25</sup> *Ibid.*

<sup>26</sup> *Ibid.*

<sup>27</sup> *Ibid.*

<sup>28</sup> *Ibid.*

<sup>29</sup> Reisler "Interesting Case Series: Albinism and Skin Cancer" <http://www.eplasty.com/images/PDF/eplasty-d-09-00135.pdf> (accessed 2020-03-05).

<sup>30</sup> Reisler <http://www.eplasty.com/images/PDF/eplasty-d-09-00135.pdf>. Also see Lund and Taylor "Lack of Adequate Sun Protection for Children With Oculocutaneous Albinism in South Africa" 2008 8(225) *BMC Public Health* 1 2.

UV protection. To compound their vulnerability, they are also at increased risk of becoming victims of *muti* killings, stigmatisation and discrimination based on their appearance.

### 3 THE RIGHT TO HEALTHCARE SERVICES

The right to health as such is not explicitly mentioned in the South African Constitution.<sup>31</sup> The Bill of Rights, however, guarantees the right of access to health care services, adequate housing, sufficient food and social security, for the reason that insufficient access to such rights violates the protected interests of various other rights, such as the right to human dignity, equality and life, as well as the right to bodily and physical integrity.<sup>32</sup>

The right to health is basic to the physical and mental well-being of all human beings and is essential for the exercise of other human rights. Section 27(1)(a) of the Constitution states:

“[e]veryone has the right to have access to health care services, including reproductive health care.”

Section 27(2) states that the State must take reasonable legislative and other measures within its available resources to achieve the progressive realisation of the right to health.<sup>33</sup> This means that the government has to ensure that this right is protected, promoted and fulfilled, and that eventually universal access to quality and all-inclusive health care is realised. This incorporates the passing of laws by Parliament<sup>34</sup> and the provincial

<sup>31</sup> S 27(1) of the Constitution of 1996. Also see Rautenbach and Malherbe *Constitutional Law* (2012) 386.

<sup>32</sup> Rautenbach and Malherbe *Constitutional Law* 386.

<sup>33</sup> S 27(2) of the Constitution of 1996 reads as follows: “The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.”

<sup>34</sup> The National Health Act 61 of 2003 was passed by Parliament to give effect to the right to access to health care services. The objectives of the National Health Act are to regulate the national health system, to afford equality in respect of health services by harmonising the inequalities of health services of the past and to institute a national health system that protects, respects, promotes and fulfils the rights of everyone in South Africa – in particular, the progressive realisation of the constitutional right of access to health care services. Section 3 of the National Health Act reads as follows: “The Minister must, within the limits of available resources– (a) endeavour to protect, promote, improve and maintain the health of the population; (b) promote the inclusion of health services in the socio-economic development plan of the Republic; (c) determine the policies and measures necessary to protect, promote, improve and maintain the health and well-being of the population; (d) ensure the provision of such essential health services, which must at least include primary health care services, to the population of the Republic as may be prescribed after consultation with the National Health Council; and (e) equitably prioritise the health services that the State can provide. (2) The national department, every provincial department and every municipality must establish such health services as are required in terms of this Act, and all health establishments and health care providers in the public sector must equitably provide health services within the limits of available resources.” Not every person accessing the health system is able to exercise their health rights easily. Vulnerabilities such as having a disability or being an illegal migrant are further barriers to access to health care services. As a result, one of the objectives of the National Health Act is to protect, respect, promote and fulfil the rights of vulnerable groups such as women, children, older people and people

legislatures but is not limited to such. Section 27 is a powerful provision aimed at ensuring health policy and practice.

The right to health imposes a negative duty on the State and members of society not to impair access to the amenities and services associated with this right.<sup>35</sup> Limitations with respect to the right to health must meet the terms of the limitation clause.<sup>36</sup> The State has a further positive duty to fulfil the right to health.<sup>37</sup> Thus far, the Constitutional Court has addressed the impact and effect of the State's failure to act in terms of the conduct and interests protected by the rights to human dignity, equality, life, and personal freedom and security.<sup>38</sup> In the very first stage of an inquiry into an alleged infringement of the right to health, it must be established whether or not the State's failure to provide health care indeed impairs the right to human dignity and life, and the physical and psychological integrity of the claimants.<sup>39</sup>

In terms of the second stage of inquiry, section 27(2) of the Constitution stipulates that the State must take "reasonable legislative and other steps within its available resources to attain the progressive realisation of health care services".<sup>40</sup> This implies that the State may justify its failure to act or its failure to meet a positive obligation, provided that reasonable legislative and

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with disabilities. The National Health Act prescribes eligibility for free health services in public health institutions. Section 4 of the National Health Act reads as follows: "(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.
- (3) 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."

Also see Berger, Hassim and Heywood *Health & Democracy: A Guide to Human Rights, Health Law and Policy in Post-Apartheid South Africa* (2007) 296–307.

<sup>35</sup> Rautenbach and Malherbe *Constitutional Law* 386.

<sup>36</sup> *Ibid.*

<sup>37</sup> *Ibid.*

<sup>38</sup> Rautenbach and Malherbe *Constitutional Law* 386. Also see the following cases: *Soobramoney v Minister of Health, Kwazulu Natal* 1998 (1) SA 765 (CC) 37 42; *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46 (CC) 23 25, 44 and 83; *Mahlaule v Minister of Social Development* 2004 (6) SA 505 (CC) 82; *Minister of Health v Treatment Action Campaign* 2002 (10) BCLR 1033 (CC) 72–73 and 78.

<sup>39</sup> Rautenbach and Malherbe *Constitutional Law* 386.

<sup>40</sup> *Ibid.*

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other measures were taken within its available resources to accomplish the progressive realisation of the right.<sup>41</sup>

### **3 1 Guidelines formulated by the Constitutional Court to determine whether the State has realised its positive duties**

The qualification “reasonable legislative and other measures” suggests that the State ought to institute rational programmes that assign responsibility to the various levels of government to guarantee appropriate resources are available.<sup>42</sup> Bearing in mind that both legislative and other measures may be taken, reasonableness can be evaluated at the level of a legislative programme as well as the level of its implementation.<sup>43</sup> Courts may require that the State demonstrate which measures were taken to realise socio-economic rights.<sup>44</sup>

Taking into account that socio-economic rights are a constitutional imperative and that the State ought to try to attain certain developmental objectives, the State has a duty to justify the choices it makes in achieving these objectives to the public.<sup>45</sup> Put differently, the reasonableness standard first calls for reasons to be given.<sup>46</sup> It is then the duty of the court to evaluate the reasonableness of these reasons<sup>47</sup> and a reasonable person should be convinced of the coherence of the reasons.<sup>48</sup>

The duty of justification involves the provision of explanations that would satisfy most people regarding the rationality of a policy, even if they are not convinced of the good judgment of choosing such a policy in the first place.<sup>49</sup>

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<sup>41</sup> Rautenbach and Malherbe *Constitutional Law* 386. In *Minister of Health v Treatment Action Campaign supra* 71–73, the court found that the government’s measures to make available health care services for both HIV-positive mothers as well as their newly born babies failed to conform with the State’s duty as stipulated in s 27(2). In this matter, the court considered that the State could afford to buy Nevirapine and that the administration of Nevirapine was a straightforward matter.

<sup>42</sup> *Minister of Health v Treatment Action Campaign supra* 71–73. Also see Rautenbach and Malherbe *Constitutional Law* 386.

<sup>43</sup> *Government of the Republic of South Africa v Grootboom supra* 21 28 35. Legislative measures by themselves are not likely to ensure constitutional compliance. The State is obliged to act to achieve the intended result, and 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. The programme should also be reasonably implemented. An otherwise reasonable programme that is not implemented reasonably will not constitute compliance with the State’s obligations.

<sup>44</sup> *Government of the Republic of South Africa v Grootboom supra* 32; and *Minister of Health v Treatment Action Campaign supra* 34.

<sup>45</sup> Currie and De Waal *Bill of Rights Handbook* (2013) 581–584.

<sup>46</sup> Currie and De Waal *Bill of Rights Handbook* 574.

<sup>47</sup> *Ibid.*

<sup>48</sup> *Ibid.*

<sup>49</sup> *Ibid.*

Notwithstanding the centrality of the reasonableness standard, the Constitutional Court does not refer to any definition of such a standard. Instead, the court stipulates that each case should be determined on its own facts.<sup>50</sup> According to the court in the *Bel Porto* case,<sup>51</sup> the test of reasonableness when dealing with socio-economic rights is considered to be on a higher level than the rationality test in section 9(1).

A feature of the legal standard is that substantial “interpretive discretion” is given to the person in charge of adjudicating the application of the reasonableness standard, and that such application does not specify a result in advance.<sup>52</sup> Standards are applied *ad hoc* and their application varies considerably from one case to another.<sup>53</sup> However, standards gradually become “more rule-bound” as courts build up guidelines and sets of factors with future applications in mind.<sup>54</sup>

In the *Grootboom* case, the court held that reasonableness entails the “design, adoption and implementation” of certain measures to achieve the realisation of socio-economic rights that are inclusive in that they include those who need protection the most.<sup>55</sup> At the initial application of the *Grootboom* case, the court found that reasonableness was absent; hence the State was held to have failed in its duties in terms of section 26(2).<sup>56</sup>

In the *Minister of Health v Treatment Action Campaign* case,<sup>57</sup> the court’s finding in the *Grootboom* case (that reasonableness is inclusive) was the foundation for the court’s decision that the government’s policy on the prevention of mother-to-child transmission (MTCT) of HIV was unreasonable. Government policy only made Nevirapine available to a small number of “pilot sites”, namely two state hospitals in each province.<sup>58</sup> The reasoning behind this decision was that the results of the use of the medication at the selected sites would be used to assess the safety of Nevirapine before making it available to more people. For this reason, Nevirapine would not be available to the public but only at the specific pilot sites.<sup>59</sup>

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<sup>50</sup> *Government of the Republic of South Africa v Grootboom supra* par 92.

<sup>51</sup> *Bel Porto School Governing Body v Premier of the Western Cape Province* 2002 (3) SA 265 (CC) par 46.

<sup>52</sup> Currie and De Waal *Bill of Rights Handbook* 574.

<sup>53</sup> *Ibid.*

<sup>54</sup> *Ibid.*

<sup>55</sup> *Ibid.*

<sup>56</sup> *Government of the Republic of South Africa v Grootboom supra* 99.

<sup>57</sup> *Minister of Health v Treatment Action Campaign supra* par 1–2 and 23.

<sup>58</sup> *Government of the Republic of South Africa v Grootboom supra* par 41.

<sup>59</sup> *Government of the Republic of South Africa v Grootboom supra* par 92.



### 3 1 1 *Progressive realisation*

Progressive realisation means that it is accepted that socio-economic rights, including the right to health care services, cannot be attained instantly.<sup>60</sup> The State is nevertheless required to work towards its goal promptly and efficiently.<sup>61</sup> The meaning of the qualification of progressive realisation was interpreted in the *Soobramoney* case<sup>62</sup> as follows:

“What is apparent from these provisions is that the obligations imposed on the State by sections 26 and 27 in regard to access to housing, health care, food, water and social security are dependent upon the resources available for such purposes, and that the corresponding rights themselves are limited by reason of the lack of resources. Given this lack of resources and the significant demands on them that have already been referred to, an unqualified obligation to meet these needs would not presently be capable of being fulfilled. This is the context within which section 27(3) must be construed.”<sup>63</sup>

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<sup>60</sup> These guidelines are listed in the *Government of the Republic of South Africa v Grootboom supra* par 36–46. Also see Rautenbach and Malherbe *Constitutional Law* 386; *Government of the Republic of South Africa v Grootboom supra* par 35 and 71–73.

<sup>61</sup> *Government of the Republic of South Africa v Grootboom supra* par 36–46. Also see Rautenbach and Malherbe *Constitutional Law* 386.

<sup>62</sup> *Soobramoney v Minister of Health, Kwazulu Natal supra* par 11. The *Soobramoney* case brought the issue of socio-economic rights to the Constitutional Court. The case involved the issue of access to renal dialysis in a government hospital; when provided, this is supplied at the cost of the State. Only those who meet stringent medical criteria qualify for renal dialysis. However, not all of those who require the dialysis qualify. One requirement for admission to the dialysis programme is medical eligibility for a kidney transplant. Mr Soobramoney did not satisfy the medical criteria and was therefore denied access. After an unsuccessful application to the Durban High Court, he appealed directly to the Constitutional Court, challenging the denial of access on the basis of two constitutional rights, namely the right to life in s 11 and the guarantee in s 27(3) that no person may be refused emergency medical treatment. The Constitutional Court, however, decided that his claim had to be considered under s 27(2), which sets out the State's positive duties in terms of the provision of health care services. In the court's view, the State had indeed complied with its s 27(2) constitutional duties, because the guidelines according to which access to renal dialysis is limited, are reasonable, and in the case at hand, had been applied “fairly and rationally”. Mr Soobramoney's claim was therefore dismissed. A week later, he died from renal complications. The decision elucidates why the claim had to be considered under s 27(2) and not under s 27(1) or (3), the right to life or emergency medical treatment. Access to health care services is specifically dealt with in s 27, so it is not essential to see the right to health as part and parcel of the right to life as some courts (such as the Indian Supreme Court) have done. The focus should remain on s 27. The question arises as to why the courts opt to apply s 27(2) and not s 27(3). The court concluded that emergency medical treatment does not consist of chronic treatment for “an on-going state of affairs resulting from a deterioration of the applicant's renal function, which is incurable”. Despite the fact that renal dialysis may be urgently needed, it is not seen as an emergency treatment. Such an analysis by the court is useful in construing why such reasoning is in fact sound. If s 27(3) had been construed in line with Mr Soobramoney's claim, the State's duty to guarantee access to health care services for everyone would have been severely compromised. Instead of the State taking realistic measures to guarantee the progressive realisation of the right to health, as described in s 27(2), the State would continually be required to supply instant access to health care services wherever and whenever such was required.

<sup>63</sup> *Soobramoney v Minister of Health, Kwazulu Natal supra* par 11.

The above denotes that the positive dimension of socio-economic rights is realised over a period of time.<sup>64</sup> However, the fact that the realisation of socio-economic rights occurs progressively does not prevent the State from taking those steps that are within its powers at any point in time.<sup>65</sup> The burden of proof lies with the State to prove its progress towards the realisation of the right in question.<sup>66</sup>

### 3 1 2 *Within available resources*

The qualification “within available resources” suggests that both the pace at which the goal is realised and the reasonableness of the measures employed are administered through and affected by available resources.<sup>67</sup> In the absence of available resources, it is clear that the State’s failure to provide any particular service will not amount to a violation of the right to health.<sup>68</sup> However, where resources are available, it would be difficult for the State to justify its failure to allocate resources to the advancement of the right to health care services.<sup>69</sup> In circumstances where adequate resources are available, the State is expected to do more to realise the right to health care services and any other socio-economic right.<sup>70</sup> This implies that a significant aspect of the “positive dimension” of socio-economic rights is that the State should satisfactorily substantiate its use of public resources to its citizens.<sup>71</sup> The Constitutional Court in the *Soobramoney* case confirmed this through its action in terms of the policy justification advanced by the Department of Health’s provincial health authorities.<sup>72</sup>

<sup>64</sup> Currie and De Waal *Bill of Rights Handbook* 572.

<sup>65</sup> *Ibid.*

<sup>66</sup> Currie and De Waal *Bill of Rights Handbook* 572. Also see *Government of the Republic of South Africa v Grootboom supra* par 45 and 88, where the court states: “Nevertheless, the fact that realization over time, or in other words progressively, is foreseen under the Covenant should not be misinterpreted as depriving the obligation of all meaningful content. It is on the one hand a necessary flexibility device, reflecting the realities of the real world and the difficulties involved for any country in ensuring full realization of economic, social and cultural rights. On the other hand, the phrase must be read in the light of the overall objective, indeed the *raison d’être*, of the Covenant which is to establish clear obligations for State parties in respect of the full realization of the rights in question. It thus imposes an obligation to move as expeditiously and effectively as possible towards that goal. Moreover, any deliberately retrogressive measures in that regard would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the Covenant and in the context of the full use of the maximum available resources.” (The Covenant referred to is UNGA International Covenant on Economic, Social and Cultural Rights 999 UNTS 3 (1966). Adopted 16/12/1966; EIF 03/01/1976.)

<sup>67</sup> *Government of the Republic of South Africa v Grootboom supra* 71–73. Also see Rautenbach and Malherbe *Constitutional Law* 386; and Currie and De Waal *Bill of Rights Handbook* 390.

<sup>68</sup> Gabru “Some Comments on Water Rights in South Africa” 2005 8(1) *Potchefstroom Electronic Law Journal* 1 9.

<sup>69</sup> Gabru 2005 *PELJ* 10.

<sup>70</sup> *Ibid.*

<sup>71</sup> Currie and De Waal *Bill of Rights Handbook* 572.

<sup>72</sup> *Soobramoney v Minister of Health, Kwazulu Natal supra* 24–25 29, 24 reads: “At present the Department of Health in KwaZulu-Natal does not have sufficient funds to cover the cost of the services which are being provided to the public. In 1996–1997 it overspent its budget

The “available resources” qualification is also employed in the International Covenant on Economic, Social and Cultural Rights, and it refers to the discretion that an instrument of the State has in its selection of means for the realisation of socio-economic rights.<sup>73</sup> In particular, a shortage of resources does not reduce the State’s duty to realise its “core minimum obligations”.<sup>74</sup> Even when resources are scarce, the obligation still resides with the State to ensure fulfilment of the relevant socio-economic rights.<sup>75</sup>

In the *Grootboom* case,<sup>76</sup> the Constitutional Court rejected the call to set a minimum obligation guideline specifically in respect of the right to housing, finding instead that the real question in terms of our Constitution is whether the measures taken by the State to realise the right afforded by section 26 are reasonable.

The court stated that there may be circumstances in which it is possible to consider a core minimum obligation in determining the reasonableness of measures taken by the State.<sup>77</sup> This however cannot be done in the absence of adequate information to determine the minimum core duty in a given situation.<sup>78</sup>

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by R152 million, and in the current year it is anticipated that the overspending will be R700 million rand unless a serious cutback is made in the services which it provides. The renal unit at the Addington Hospital has to serve the whole of KwaZulu-Natal and also takes patients from parts of the Eastern Cape. There are many more patients suffering from chronic renal failure than there are dialysis machines to treat such patients. This is a nationwide problem and resources are stretched in all renal clinics throughout the land. Guidelines have therefore been established to assist the persons working in these clinics to make the agonising choices which have to be made in deciding who should receive treatment, and who not. These guidelines were applied in the present case.” Par 25, in addition, reads: “By using the available dialysis machines in accordance with the guidelines more patients are benefited than would be the case if they were used to keep alive persons with chronic renal failure, and the outcome of the treatment is also likely to be more beneficial because it is directed to curing patients, and not simply to maintaining them in a chronically ill condition. It has not been suggested that these guidelines are unreasonable or that they were not applied fairly and rationally when the decision was taken by the Addington Hospital that the appellant did not qualify for dialysis.” Par 29, furthermore, states: “The provincial administration which is responsible for health services in KwaZulu-Natal has to make decisions about the funding that should be made available for health care and how such funds should be spent. These choices involve difficult decisions to be taken at the political level in fixing the health budget, and at the functional level in deciding upon the priorities to be met. A court will be slow to interfere with rational decisions taken in good faith by the political organs and medical authorities whose responsibility it is to deal with such matters.”

<sup>73</sup> Article 2 of the International Covenant on Economic, Social and Cultural Rights reads as follows: “1. Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.”

<sup>74</sup> Par 10 of CESCR General Comment No 3 on the Nature of State Parties’ Obligations (Art 2 Par 1 of the Covenant) E/1991/23 (1990). Adopted: 14/12/ 1990.

<sup>75</sup> Gabru 2005 *Potchefstroom Electronic Law Journal* 11.

<sup>76</sup> *Government of the Republic of South Africa v Grootboom supra* 14.

<sup>77</sup> *Government of the Republic of South Africa v Grootboom supra* 33.

<sup>78</sup> *Ibid.*

In the case of the *Minister of Health v Treatment Action Campaign*,<sup>79</sup> the court was again advised to establish a core minimum content for the right to health care services. The court rejected the argument that it only had the power to issue a declaratory order and further argued that where an infringement of any right has occurred, including a violation of a socio-economic right, a court is under an obligation to make sure that efficient relief is established.<sup>80</sup> In implementing section 27, the State is obliged to take reasonable measures progressively, and it is the court's duty to ensure that this occurs.<sup>81</sup>

### 3 2 How the principle of freedom from discrimination relates to health

Within the public at large, vulnerable and marginalised people are often burdened with a range of health problems.<sup>82</sup> Unfair discrimination not only violates basic human rights in general, but is often found to have a direct impact on a person's health status.<sup>83</sup> The proscription of discrimination does not mean that differentiation should not be recognised, only that the failure to treat equal cases equally ought to be based on an objective and rational standard aimed at correcting disparities within society.<sup>84</sup>

<sup>79</sup> *Minister of Health v Treatment Action Campaign supra* 26.

<sup>80</sup> *Ibid*

<sup>81</sup> *Ibid*.

<sup>82</sup> Durojaye "Realising Equality in Access to HIV Treatment for Vulnerable and Marginalised Groups in Africa" 2012 15(1) *Potchefstroom Electronic Law Journal* 214 218.

<sup>83</sup> Durojaye 2012 *PELJ* 214. The Preamble and art 1 of the Convention on the Rights of Persons With Disabilities (UNGA (2007) A/RES/61/106. Adopted: 24/01/2007) affirms the social construction of disability by stating that the definition of disability ought to be advanced from the social perspectives that generate attitudinal and physical barriers preventing persons with disabilities from effectively contributing to society, and not from the viewpoint of the supposed medical condition of such individuals. The Convention looks beyond the question of "access to the physical environment" and tackles concerns of equality and the elimination of legal, social and attitudinal obstructions to the involvement of people with disabilities. In other words, the social approach to disability shifts the focus from individuals and their physical or mental deficits to the manner in which society embraces or rejects them. Instead of disability being seen as unavoidable, it is viewed as a product of social arrangements that can be reduced or perhaps even eliminated. The Convention accepts that impairment and the environment interact to produce the experience of disability when people with impairments cannot participate in society on an equal basis. This more inclusive understanding of disability offers a more realistic framework for addressing the common loss suffered by persons living with albinism. Because persons living with albinism have a lifelong physical impairment, they are continuously required to navigate circumstances arising from their distinctiveness. The social model advances disability rights by removing obstructions in society. Signatories to the Convention on the Rights of Persons with Disabilities are mandated to observe the provisions of the Convention by using them to drive domestic law and policy reforms. Among other things, the Convention requires that states undertake to adopt immediate, effective and appropriate measures: to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life.

<sup>84</sup> Macklem *Indigenous Indifference and the Constitution of Canada* (2001) 1 212; Van Reenen "Equality, Discrimination and Affirmative Action: An Analysis of Section 9 of the Constitution of the Republic of South Africa" 1997 12 *SA Public Law* 151 153.

With respect to health and health care, the foundation for non-discrimination has been developed and can be summarised as prohibiting

“any discrimination in access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental stability, health status (including HIV/AIDS), sexual orientation, civil, political, social or other status, which has the purpose of nullifying the equal satisfaction or exercise of the right to health.”<sup>85</sup>

The question of whether persons with albinism are adequately protected in the present South African legal framework is explored next.

### 3 3 The right to health care services in the context of albinism

Owing to an absence of melanin in their skin, persons living with albinism are prone to a number of lifelong physical health problems – in particular, skin damage caused by sensitivity to the ultraviolet rays of the sun, and visual impairment. As seen from the previous discussion, skin cancer is common among persons living with albinism. Regular visits to a dermatologist for skin check-ups are imperative. It is equally important to have skilled eye assessments and examinations from a very young age.

Several governments have failed to guarantee “access and affordability” of essential items and services.<sup>86</sup> In South Africa, interviews with and campaigns led by the Chairperson of the Albinism Society of South Africa<sup>87</sup>

<sup>85</sup> Art 12(18) of the CESCR General Comment No 14 on the Right to the Highest Attainable Standard of Health (Art 12) E/C.12/2000/4 (11 August 2000).

<sup>86</sup> Thuku “Myths, Discrimination, and the Call for Special Rights for Persons Living with Albinism in Sub-Saharan Africa” 2011 *Amnesty International Editorial Review on Special Programme on Africa* 1 11. Thuku writes within the sub-Saharan context. Despite mentioning that several governments have failed to guarantee “access and affordability” in terms of essential items, the author does not list examples of such countries. The current study presents South Africa as an example. An investigation into other countries cites Zimbabwe as an example, where the implementation of effective health interventions to meet the health needs of people with albinism remains a challenge due to the current economic and political situation. See Taylor and Lund “Experiences of a Feasibility Study of Children with Albinism in Zimbabwe: A Discussion Paper” 2008 45(8) *International Journal of Nursing Studies* 1247. Somalia is yet another example where prolonged conflict and the challenges stemming from the lack of a strong central government affect its population and generate barriers to socio-economic progress. This has major implications for the most vulnerable members of society, including people with albinism. No organisation or government has tried to support people with albinism in Somalia and they do not have access to health care – see Mohamud “What Do You Know about Persons with Albinism in Somalia” (2014) <http://aphad.org/maxaad-kala-socotaa-xaalka-dadka-albinoga-ah-ee-soomaaliyeed/> (accessed 2020-06-13) 1. In a report on albinism compiled by the United Nations Office of the High Commissioner for Human Rights, it is evident that people with albinism in Burundi require government-sponsored specialised medical care – see United Nations Office of the High Commissioner for Human Rights “Situation of People Living with Albinism in Burundi” (2016) [www.ohchr.org/.../albinism/situation\\_of\\_people\\_living\\_with\\_albinism\\_in\\_burundi-inputs\\_from\\_binuca.docx](http://www.ohchr.org/.../albinism/situation_of_people_living_with_albinism_in_burundi-inputs_from_binuca.docx) (accessed 2020-06-13) 4.

<sup>87</sup> Fazel “Albinos’ Lonely Call for Recognition” (2012) <http://mg.co.za/article/2012-05-17-albinos-lonely-call-for-recognition> (accessed 2020-06-13) 1.

have revealed that the national health system has failed adequately to consider and take into account the health needs of PWA. The failure of the government to take into account the health concerns of this vulnerable group is perhaps due to the fact that albinism is not viewed as an actual health concern in South Africa because the condition is surrounded by so many myths, stereotypes and false notions.

The connection between albinism, sunlight and skin cancer, and the extreme importance of a prevention programme in this regard, has been explained above. Currently, the government does not provide PWA with protective sunscreen lotion. Very few PWA have access to sunglasses with a high UV protection screen to relieve light sensitivity, or to preventative services such as dermatological skin checks, eye checks and eye corrections. As mentioned earlier on, the vulnerability of PWA means that they need specific types of health protection, including visual aids, eye surgery, regular skin cancer check-ups and sunglasses offering high UV protection. Government has failed to take into account the health concerns of PWA, despite the submission of several petitions in this regard.<sup>88</sup>

The recognition of the right of access to health care services in the South African Constitution<sup>89</sup> affords PWA the right to challenge the government's failure to provide skin protection for the prevention of skin cancer, or sunglasses and low vision aids. Under the South African Constitution, the right of access to health care services is a fundamental human right and this right applies equally to all persons, including those living with albinism. Where resources are available, PWA ought to be provided with sunscreen at no cost and in cases where the government does not have the resources to do so, it should subsidise the provision of sunscreen, sunglasses and low vision aids for PWA.

Drawing from the clinical discussion above, if not assisted, PWA face a shortened life span. It is therefore submitted that the State has a specific duty towards this very unique and vulnerable group in society. Resources should be progressively made available to address the needs of PWA.

As acknowledged by the Cancer Association of South Africa (CANSA), many PWA face the highest risk of developing skin cancer but are unaware of the health hazards associated with their condition, especially those living

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<sup>88</sup> Mazibuko, the founder of the Albinism Society of South Africa, has been an advocate for the needs of persons living with albinism and has pushed the South African government and medical aid firms to subsidise sunscreen lotions and eye care for people with albinism since the Albinism Society of South Africa was founded in 1991. See IRIN News "Southern Africa: Too White to be Black: The Challenge of Albinism" (2016) <http://www.irinnews.org/Report/58169/southern-africa-too-white-to-be-black-the-challenge-of-albinism> (accessed 2020-01-05) 1, where Mazibuko talks about her concerns regarding the accessibility as well as affordability of sunscreen lotion and the government's failure to provide this to persons living with albinism. Also see Mecaomere "Public-To-Learn-About-Albinism" (2011) <http://www.sowetanlive.co.za/news/2011/09/02/public-to-learn-about-albinism> (accessed 2020-01-05) 1.

<sup>89</sup> S 27(1) of the Constitution of 1996 provides as follows: "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."

in rural areas of South Africa. It is therefore imperative that the government also introduce health education programmes aimed at educating PWA about the health risks associated with their condition. An awareness of the causes of albinism and the measures that can be taken to prevent skin cancer, for example, will certainly enhance the health of PWA and reduce the risk of complications associated with the condition. Not only are basic health awareness education programmes for PWA crucial, but programmes to educate people on clinical aspects of albinism will undeniably influence the way in which society perceives persons affected by this condition. These programmes could begin by targeting schools and hospitals.

Depending on the availability of resources, public health programmes, such as open days to educate the public on albinism, are another possibility. The Albinism Society of South Africa has been active in this regard.<sup>90</sup> The month of September has been dedicated to albinism awareness.<sup>91</sup>

Such programmes may assist in dispelling myths such as that sex with a young woman with albinism may cure HIV/AIDS. This is a myth that perpetuates gender-based violence towards vulnerable young women. Lack of knowledge about albinism affects the position of young women with albinism who live in fear of being raped and of the danger of becoming infected with HIV.

Public health programmes need to take into account the diverse challenges facing PWA. At present, there are some programmes ready to deal with the health concerns of PWA in certain parts of Africa.<sup>92</sup> For example, the Regional Dermatological Training Centre (RDTC) in Moshi, Tanzania, runs a mobile skin care clinic where a doctor and nurse frequently visit villages to ensure that the skin of people living with albinism is protected against radiation and to educate them on the relevant measures to protect themselves from the sun.<sup>93</sup> South Africa does not have such a facility specifically catering for people with albinism, but the Cancer Association of South Africa (CANSAs) has a few Mobile Health Clinics for the general public, which travel to all provinces in South Africa in a bid to reach those without access to cancer screening.<sup>94</sup>

Counselling and trauma centres for this specific segment of society should be established in order to assist PWA who have escaped murder or fallen victim to assault, discrimination, rape, amputation of limbs and cancer, to mention but a few of the challenges they face.<sup>95</sup>

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<sup>90</sup> The Albinism Society of South Africa "Albinism" (2015) <http://www.albinism.org.za/> (accessed 2020-06-13) 1.

<sup>91</sup> Albinism Society of South Africa (2014) <http://www.gov.za/albinism-awareness-month-2014> (accessed 2020-06-13) 1.

<sup>92</sup> Hong "Albinism in Africa as a Public Health Issue" 2006 6(212) BMC Public Health 1 6.

<sup>93</sup> *Ibid.*

<sup>94</sup> Cancer Association of South Africa "Advocacy Knowledge into Action" (2014) <http://www.cansa.org.za/files/2014/10/CANSAs-Annual-Report-2013-to-2014-Part-2.pdf> (accessed 2020-06-13) 1.

<sup>95</sup> Thuku 2011 *Amnesty International Editorial Review on Special Programme on Africa* 17.

Discrimination against PWA impedes their right of access to health care services, and the government should adopt a comprehensive approach to ensuring that health care services specifically cater for the unique needs of this group of people. In the *Grootboom* case, the court held that reasonableness entails the “design, adoption and implementation” of certain measures to achieve the realisation of socio-economic rights that are inclusive. These measures should specifically include those in dire need of protection.<sup>96</sup>

South Africa signed the International Covenant on Economic, Social and Cultural Rights in 1994, and ratified this important international covenant in January 2015.<sup>97</sup> The eventual ratification of this Covenant was a timely tribute to former President Nelson Mandela, who originally signed the International Covenant on Economic, Social and Cultural Rights on his first visit to the United Nations in New York in 1994; ratification was a courageous step, demonstrating South Africa’s intention to join the rest of the world in upholding socio-economic rights.<sup>98</sup> The resolution to ratify the International Covenant on Economic, Social and Cultural Rights is commendable as it ensures that South Africa is finally able to honour its international duties and to consolidate its commitment to alleviate poverty and guarantee social justice for everyone.<sup>99</sup>

The International Covenant on Economic, Social and Cultural Rights affords the most comprehensive provisions in terms of the right to the enjoyment of the highest attainable standard of health.<sup>100</sup> Advocacy for the highest possible attainable standard of health of vulnerable members of society entails recognising the obstacles that stand in the way of good health care for vulnerable and disadvantaged persons.<sup>101</sup>

The Covenant recognises the health needs of the vulnerable and defenceless members of society and recommends steps that signatory states have to take in order to achieve health care goals.<sup>102</sup> This naturally

<sup>96</sup> *Government of the Republic of South Africa v Grootboom supra* 54.

<sup>97</sup> South African Human Rights Commission “SAHRC Welcomes Government’s Decision to Ratify the International Covenant on Economic, Social and Cultural Rights (ICESCR)” <http://www.sahrc.org.za/home/index.php?ipkArticleID=318> (accessed 2020-06-13) 1.

<sup>98</sup> South African Human Rights Commission <http://www.sahrc.org.za/home/index.php?ipkArticleID=318> 1.

<sup>99</sup> South African Human Rights Commission <http://www.sahrc.org.za/home/index.php?ipkArticleID=318> 1.

<sup>100</sup> Art 12(1) of the International Covenant on Economic, Social and Cultural Rights reads as follows:

“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.”

<sup>101</sup> Chatrejee and Sheoran *Vulnerable Groups in India, Centre for Enquiry into Health and Allied Themes* (2007) 25.

<sup>102</sup> Art 12(2) of the International Covenant on Economic, Social and Cultural Rights reads as follows:

“2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the still birth-rate and of infant mortality and for the healthy development of the child;



has implications for the health of the general population, as well as that of particular vulnerable groups, including PWA.<sup>103</sup>

In 1990, the African Charter on the Rights and Welfare of the Child (ACRWC) was adopted by the Organisation of the African Union (OAU).<sup>104</sup> Just like the United Nations Convention on the Rights of the Child, the ACRWC is a comprehensive document stating the human rights, global principles and standards applicable to the status of children.<sup>105</sup> The ACRWC was initiated for the reason that the member states of the OAU, now known as the African Union (AU), alleged that the Convention on the Rights of the Child overlooked vital socio-cultural and economic issues specific to Africa.<sup>106</sup>

According to the ACRWC, a child is a human being below the age of 18 years.<sup>107</sup> The Charter acknowledges the child's distinctive and honoured position in African society and that children require protection against abuse and must be granted special care.<sup>108</sup>

African children are notoriously exposed to various forms of maltreatment and deprivation such as economic and sexual abuse, gender discrimination within the educational system, the health care system and involvement in armed conflict.<sup>109</sup> Additional issues affecting African children include child

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- (b) The improvement of all aspects of environmental and industrial hygiene;
  - (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
  - (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness."

<sup>103</sup> Chatrejee and Sheoran *Vulnerable Groups in India, Centre for Enquiry into Health and Allied Themes* 25.

<sup>104</sup> OAU African Charter on the Rights and Welfare of the Child CAB/LEG/24.9/49 (1990). Adopted: 11/07/1990; EIF: 29/11/1999.

<sup>105</sup> United Nations Children's Emergency Fund "The African Charter on the Rights and Welfare of the Child" [http://www.unicef.org/esaro/children\\_youth\\_5930.html](http://www.unicef.org/esaro/children_youth_5930.html) (accessed 2015-10-10) 1.

<sup>106</sup> Ekundayo "Does the African Charter on the Rights and Welfare of the Child (ACRWC) only Underlines and Repeats the Convention on the Rights of the Child (CRC)'s Provisions?: Examining the Similarities and the Differences between the ACRWC and the CRC" 2015 5(7) 1 *International Journal of Humanities and Social Sciences* 143 143.

<sup>107</sup> Art 2 of the ACRWC reads as follows:  
"Definition of a Child: For the purposes of this Charter, a child means every human being below the age of 18 years."

<sup>108</sup> Ekundayo (2015 *International Journal of Humanities and Social Sciences* 147) writes: "One of the reasons for having an Africa Children's Charter was the feeling that Africa had been underrepresented during the drafting process of the CRC (only Algeria, Morocco, Senegal and Egypt participated meaningfully in the drafting process). A second reason was the thinking that Africa needed to have a charter for children which reflected the specifics of the African context."

<sup>109</sup> The Preamble of the ACRWC reads as follows:  
"The African Member States of the Organization of African Unity, Parties to the present Charter entitled 'African Charter on the Rights and Welfare of the Child', CONSIDERING that the Charter of the Organization of African Unity recognizes the paramountcy of Human Rights and the African Charter on Human and People's Rights proclaimed and agreed that everyone is entitled to all the rights and freedoms recognized and guaranteed therein, without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status,

prostitution, migration, early marriages, child-headed households, street children and extreme poverty.<sup>110</sup>

Earlier, this article addressed briefly how persons with albinism, including children with albinism, are victims of violence in the form of sexual exploitation, murder and being targeted for their body parts. An escalating number of children do not attend school or medical check-ups for fear of violence and discrimination. The ACRWC is an important instrument for the protection of the rights of children with albinism, as it emphasises the protection of children from violence, discrimination, ill-treatment, and negative social and cultural practices, including all forms of exploitation or sexual abuse and the kidnapping of and trafficking in children.

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RECALLING the Declaration on the Rights and Welfare of the African Child (AHG/ST.4 Rev.I) adopted by the Assembly of Heads of State and Government of the Organization of African Unity, at its Sixteenth Ordinary Session in Monrovia, Liberia from 17 to 20 July 1979, recognized the need to take appropriate measures to promote and protect the rights and welfare of the African Child, NOTING WITH CONCERN that the situation of most African children, remains critical due to the unique factors of their socio-economic, cultural, traditional and developmental circumstances, natural disasters, armed conflicts, exploitation and hunger, and on account of the child's physical and mental immaturity he/she needs special safeguards and care, RECOGNIZING that the child occupies a unique and privileged position in the African society and that for the full and harmonious development of his personality. the child should grow up in a family environment in an atmosphere of happiness, love and understanding, RECOGNIZING that the child, due to the needs of his physical and mental development requires particular care with regard to health, physical, mental, moral and social development, and requires legal protection in conditions of freedom, dignity and security, TAKING INTO CONSIDERATION the virtues of their cultural heritage, historical background and the values of the African civilization which should inspire and characterize their reflection on the concept of the rights and welfare of the child, CONSIDERING that the promotion and protection of the rights and welfare of the child also implies the performance of duties on the part of everyone, REAFFIRMING ADHERENCE to the principles of the rights and welfare of the child contained in the declaration, conventions and other instruments of the Organization of African Unity and in the United Nations and in particular the United Nations Convention on the Rights of the Child; and the OAU Heads of State and Government's Declaration on the Rights and Welfare of the African Child."

<sup>110</sup> See the Preamble of the ACRWC. Art 27 of the Charter reads as follows:

Sexual Exploitation

- "1. States Parties to the present Charter shall undertake to protect the child from all forms of sexual exploitation and sexual abuse and shall in particular take measures to prevent:
- (a) the inducement, coercion or encouragement of a child to engage in any sexual activity;
  - (b) the use of children in prostitution or other sexual practices;
  - (c) the use of children in pornographic activities, performances and materials."

Art 27 of the Charter reads as follows:

Protection against Harmful Social and Cultural Practices

- "1. States Parties to the present Charter shall take all appropriate measures to eliminate harmful social and cultural practices affecting the welfare, dignity, normal growth and development of the child and in particular:
- (a) those customs and practices prejudicial to the health or life of the child; and
  - (b) those customs and practices discriminatory to the child on the grounds of sex or other status.
2. Child marriage and the betrothal of girls and boys shall be prohibited and effective action, including legislation, shall be taken to specify the minimum age of marriage to be 18 years and make registration of all marriages in an official registry compulsory."

Article 14 of the ACRWC states that every child has the right to enjoy the best attainable state of physical, mental and spiritual health. This includes the provision of nutritious food and safe drinking water, as well as adequate health care. Children with albinism's right to health is infringed when they are attacked physically and when they endure mental torture because of the consequences of the fear they undergo following an actual attack or an anticipated attack, as their safety is always at risk. Mental torture is also seen stemming from discrimination and persecution, which have harmful emotional and mental effects. Persons with albinism are noted as being either depressed, anxious, or experiencing other forms of psychological stress, from time to time.

Children with albinism are subjected to cultural and traditional practices that are harmful to their health and the ACRWC under article 24(3) provides that States Parties have to take appropriate measures to eliminate traditional practices that are harmful to the health of children, and this extends to children with albinism. The measures that should be taken by the South African government regarding the realisation of the right to health of children with albinism should be directed towards eliminating harmful practices against children with albinism, since such practices are detrimental to their health.

The adoption and coming into force of the Convention on the Rights of the Child (CRC) was an important historic event.<sup>111</sup> The philosophy underpinning the CRC derives from resistance to the nineteenth-century view of children as mere property, entirely submissive to their fathers and treasured only in economic terms.<sup>112</sup>

Before the adoption of this Convention, a number of international instruments and organisations expressed the need for an instrument that would regulate the rights of the child, which culminated in the drafting of the CRC.<sup>113</sup> One of these was the International Labour Organisation (ILO), which deals with issues such as minimum employment age, working hours and other conditions of employment for children and the protection of children who work under very dangerous conditions.<sup>114</sup> Various other multilateral agreements also protect the rights of children.<sup>115</sup>

The protection provided by the CRC applies to children *per se* and not children as constituent members of a family or other social group.<sup>116</sup> The rights referred to are not assumed to be held by any other person.<sup>117</sup> Under the Convention, a child is recognised as an independent person separate

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<sup>111</sup> UNGA Convention on the Rights of the Child 1577 UNTS 3 (1989). Adopted: 20/11/1989; EIF: 02/09/1990; and Verhellen *Convention on the Rights of the Child: Background, Motivation and Strategies* (2006) at back cover page.

<sup>112</sup> Mower *The Convention on the Rights of the Child: International Law Support for Children* (1997) 11.

<sup>113</sup> Mower *The Convention on the Rights of the Child: International Law Support for Children* 12.

<sup>114</sup> *Ibid.*

<sup>115</sup> *Ibid.*

<sup>116</sup> Verhellen *Convention on the Rights of the Child: Background, Motivation and Strategies* 4.

<sup>117</sup> *Ibid.*

from all other persons or groups of persons.<sup>118</sup> A child is not only recognised as possessing such rights but as having the capacity to assert such rights in national judicial and administrative proceedings.<sup>119</sup>

A self-governing body of experts monitors the CRC by assessing state reports, and in turn, compiling recommendations.<sup>120</sup> The CRC does not have an individual complaint mechanism.<sup>121</sup> The political will of the state party as reviewed by the committee of the CRC determines the enforcement of the Convention.<sup>122</sup>

Many children with albinism are victims of discrimination, as they are the most fragile and vulnerable.<sup>123</sup> Article 24 of the CRC explicitly mentions primary health care for children. Primary health care underlines the need to eliminate exclusion as well as social disparities in health, which involves organising health-related services around the needs as well as expectations of children.<sup>124</sup> So as to fully realise the right to health for all children, governments have a duty to ensure that the health of children is not undermined as a result of discrimination, which is a significant factor contributing to vulnerability.<sup>125</sup>

According to the CRC, children have a right to health and to be free from violence, abuse and neglect; yet many children with albinism are victims of violence, abuse, and neglect, and this has proven to cause far-reaching harm to their physical and mental health and development.

In November 2007, South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPWD)<sup>126</sup> The CRPWD is the most recent significant international human rights instrument relating to disability. The CRPWD came into force on 3 May 2008 with the purpose of protecting the fundamental rights and integrity of persons living with disabilities.

The CRPWD marked the beginning of a new era in disability rights and was the culmination of a 30-year struggle by people in the disability rights movement and advocates of human rights to gain acknowledgment that everyone, regardless of impairment, must enjoy all human rights and fundamental freedoms.<sup>127</sup> It altered the playing field for people universally by

<sup>118</sup> *Ibid.*

<sup>119</sup> *Ibid.*

<sup>120</sup> Alum, Gomez and Ruiz, "Hocus Pocus, Witchcraft, and Murder: The Plight of Tanzanian Albinos" 2009 *International Team Project* 1 42–44.

<sup>121</sup> Alum *et al* 2009 *International Team Project* 42–44.

<sup>122</sup> *Ibid.*

<sup>123</sup> Bukulupi "Child Sacrifice, Myth or Reality" 2014 30(1) *International Letters of Social and Humanistic Sciences* 1 2.

<sup>124</sup> UN CRC. General Comment No 15 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (Art 24) CRC/C/GC/15 (17 April 2013) page 3.

<sup>125</sup> General Comment No 15 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (Art 24) page 4

<sup>126</sup> UNGA Convention on the Rights of Persons with Disabilities (2007) 2515 UNTS 3; A/RES/61/106. Adopted: 24/01/2007; EIF: 03/05/2008.

<sup>127</sup> Rioux "Disability Rights and Change in a Global Perspective" 2011 14(9) *Sport in Society* 1094 1094.

giving official acknowledgment that disability is a rights issue<sup>128</sup> on the one hand, and a social development issue on the other.<sup>129</sup>

The CRPWD covers most aspects relating to the daily lives of children and adults with disabilities, such as the rights of children and adults to attend schools and to receive inclusive education. The Convention also requires that the State provide disabled children and adults with vocational education, rehabilitation, and the same range, quality and standard of free or affordable health services provided to other persons.

The CRPWD appears to take a middle road between the individual impairment model and the social model,<sup>130</sup> and it reflects a flexible and inclusive definition of disability.<sup>131</sup> The definition recognises that, while there might be myriad interpretations of disability, a juridical definition of disability for equality and non-discrimination purposes must at least imply impairment as a point of departure.<sup>132</sup> At the same time, the definition must be responsive to socio-economic barriers as constituent elements of disability.<sup>133</sup> The Convention accepts that impairment and the environment interact to produce the experience of disability when people with impairments cannot participate in society on an equal basis.

In order for disabled people to exercise their human rights, it is essential that there be constant dialogue and consensus about disability rights among the public, government and the private sector as well as a commitment to implement the spirit and moral intent of the CRPWD.<sup>134</sup> This dialogue has to accept how conventional philosophies around disability focused on individuals and their impairments as well as how this has fundamentally disadvantaged persons with disabilities. It must express solidarity with people who have been marginalised in their social participation.<sup>135</sup>

The CRPWD obliges states to take positive action to promote an extensive disability rights-based agenda.

The question whether PWA ought to contest their health-related discrimination on the basis of disability is a question that should be founded on a clear understanding of what disability is.

South Africa has no centralised disability legislation since it is generally assumed that the range of diverse statutes and state department policies regulating disability matters are sufficient. Our courts have interpreted disability by adopting an excessively narrow guiding principle in terms of who qualifies as disabled. It is clear that this definition of disability is centered on the existence of an actual impairment and on the degree of impairment. To

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<sup>128</sup> Rioux 2011 *Sport in Society* 1094.

<sup>129</sup> *Ibid.*

<sup>130</sup> Dupper and Garbers *Equality in the Workplace: Reflections From South Africa and Beyond* (2009) 94.

<sup>131</sup> *Ibid.*

<sup>132</sup> Dupper and Garbers *Equality in the Workplace: Reflections From South Africa and Beyond* 195.

<sup>133</sup> *Ibid.*

<sup>134</sup> Rioux 2011 *Sport in Society* 90.

<sup>135</sup> *Ibid.*

qualify under the protected class, such impairment must significantly restrict a person's ability to conduct normal activities. Such proof involves a detailed medical inquiry. The key enquiry is then how intensely a person is affected by albinism.

The current working definition of disability stems from the case of *IMATU v City of Cape Town*.<sup>136</sup> South Africa's narrow approach to disability, as pointed out, excludes many disabled people from protection on the grounds that their impairment is not severe enough in itself, or that they are coping so satisfactorily with the impairment that they no longer require protection from discrimination.

South Africa's narrow approach to disability excludes several PWA from protection on the grounds that their impairment is not severe enough in itself, or that they are coping so satisfactorily with the impairment that they no longer require protection from discrimination. This position stands irrespective of the merits of the victim's claim of discrimination. This has had the adverse effect that persons who can mitigate their disabilities and evidently are capable of working are unable to rely, for example, on the Employment Equity Act<sup>137</sup> or Social Assistance Act.<sup>138</sup>

The Convention asserts the social construction of disability by stipulating that the definition of disability ought to be advanced not from the viewpoint of the supposed medical condition of an individual, but from those perspectives of society that disable persons by generating attitudinal and physical barriers preventing them from effectively contributing to society. The Convention thus goes beyond the question of "access to the physical environment" and tackles the broader concerns of equality and elimination of legal, social and attitudinal obstructions to the participation of people with disabilities. An employee with albinism should therefore be protected from discrimination emanating from misconceptions, myths and stereotypes about their condition.

Article 25 of the CRPWD specifies that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability". The measures taken by the South African government regarding the realisation of the right to health of children with albinism should be directed towards maximum inclusion in the receiving of health services. It is also vital that persons with albinism are aware of their human rights as provided in article 25 of the CRPWD when accessing health care services. In addition, it is correspondingly important for health care professionals to comprehend their responsibilities in terms of the CRPWD.

#### **4 CONCLUSION**

The Department of Health's Strategic Plan 2020/21–2024/25 is determinedly grounded on strengthening the South African health system. Twelve of the

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<sup>136</sup> 2005 (11) BLLR 1084 (LC) 1091.

<sup>137</sup> 55 of 1998.

<sup>138</sup> 13 of 2004.

eighteen outcomes prioritised by the Department of Health are geared towards strengthening the health system, as well as improving quality of care, with the remaining five outcomes responding to the quadruple burden of disease in South Africa. The Department of Health's Strategic Plan for 2020/21–2024/25 covers a range of critical health issues, including developing the national health insurance scheme, ending the epidemics of AIDS, malaria and neglected tropical diseases, combating hepatitis and making access to universal sexual reproductive health a reality.<sup>139</sup> The study recommends that the health concerns of PWA be added to the list of critical health issues.

Against the backdrop of the right to health care services enshrined in the South African Constitution, this article proposes that lobby groups should take the first step and approach the court to challenge the government's failure to progressively realise their right of access to health care services by neglecting to provide preventative services such as dermatological skin checks, eye checks and protective sunscreen lotion, as well as vision aids, and eye correction surgery, within its available resources. Although one can argue that PWA are no different from other classes of persons with health risks, such as diabetics or persons with hypertension, this article submits that none of these other health conditions cause their sufferers to be targeted in the very unique way that PWA are. The stigmatisation of and discrimination against HIV-positive persons is severe but not as dangerous as those relating to PWA who have special needs, such as for focused trauma counselling for victims of assault, discrimination, rape and amputation in addition to cancer.

Over the years, we have seen several noteworthy policy achievements at national level, in for example, public health, where the outcome of advocacy was by lobby groups. To mention but one example, the Treatment Action Campaign (TAC) advocated for the right to a prevention-of-mother-to-child (PMTCT) programme, demanded a national antiretroviral treatment plan and went further than just demanding that government comply with abstract legal obligations.<sup>140</sup> The TAC was launched in South Africa on 10 December 1998, on International Human Rights Day, by a small group of political activists.<sup>141</sup> The fundamental consensus within the group was that equitable access to health care, particularly medicines for HIV, is a human right.<sup>142</sup> By doing this, the TAC assimilated moral and legal strength from the South African Constitution, which embeds rights to equality, life and dignity.<sup>143</sup> The goal of the founders of the TAC was to popularise and enforce what was lightly described as “the right of access to treatment” through an

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<sup>139</sup> The Department of Health, National Strategic Plan for 2020/21–2024/25 <https://www.health.gov.za/wp-content/uploads/2020/11/depthhealthstrategicplanfinal2020-21-to-2024-25-1.pdf> (accessed 2021-10-10).

<sup>140</sup> The Humanitarian “A Timeline of HIV/AIDS Activism” <https://www.thenewhumanitarian.org/report/93877/south-africa-timeline-hiv-aids-activism> (accessed 2021-08-10).

<sup>141</sup> Heywood “South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health” 2009 1 *Journal of Human Rights Practice* 14.

<sup>142</sup> *Ibid.*

<sup>143</sup> *Ibid.*

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amalgamation of protest, mobilisation, and legal action.<sup>144</sup> The TAC also worked with scientists and researchers to develop plans as well as policy proposals with which the government was supposed to comply.<sup>145</sup>

The successes of the TAC exemplify how this can be done effectively. The same is proposed for the health concerns of PWA. It is important for lobby groups to ensure that PWA are included visibly in promoting and protecting their rights, benefits and common welfare. Such lobby groups should be officially launched to raise political consciousness and put emphasis on the health-related barriers facing PWA. Strategies for advocacy at the national level must consider proposing policies that influence governmental budgets to prioritise albinism-related spending priorities. Such advocacy should particularly propose that policymakers must reframe health-spending priorities to include albinism-related needs.

Although we have seen albinism-related campaigns, several of these efforts have not thrived, as the fairly recent passage of protests and action initiatives by PWA proves.<sup>146</sup> By speaking out for PWA, lobby groups can keep the health issues facing PWA alive in the media and increase or create public consciousness at a time when their needs are being overlooked in the political arena. Legislative lobbying can serve diverse purposes beyond influencing or obstructing a particular Bill. It can complement the service-delivery objectives of participating organisations by providing increased funding for health-related programmes.

The South African government must understand the variations in human genetics and find effective solutions towards the health problems that stem from mutated heredities.

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<sup>144</sup> *Ibid.*

<sup>145</sup> *Ibid.*

<sup>146</sup> SABC News “People With Albinism Still Face Many Forms of Discrimination” <https://www.sabcnews.com/sabcnews/people-with-albinism-still-face-many-forms-of-discrimination/> (accessed 2021-09-28).