

# Different in colour, equal in rights: Discrimination as a link to the violation of other rights of persons with albinism

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## Abstract

*Whereas it can be argued that generally, in Kenya, there exists cogent laws that guarantee all persons the enjoyment and protection of inherent fundamental rights and freedoms, this article submits that it is not a lived reality for persons with albinism. The article focuses on the freedom from discrimination where it argues that ignorance among members of Kenyan society is the main recipe for discrimination against persons with albinism. As will be evidenced in this article, such discrimination is cross cutting and it affects the enjoyment of the rights to dignity, education and employment. This article also discusses the gains and shortfalls of the legal regime under which the rights of such persons are anchored by making reference to; the Constitution of Kenya 2010, statutes such as the Persons with Disabilities Act, case law, and international instruments such as the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities*

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*in Africa, the Convention on the Rights of Persons with Disabilities among others. Moreover, it proposes measures to curb violations of the rights of persons with albinism such as efficient and widespread public education through the creation of awareness of the rights of persons with albinism.*

**Keywords;** albinism, colour, disabilities, discrimination, ignorance, rights, obligations; public education

## 1. Introduction

A quick reading of the international and national body of laws that give provisions regarding persons living with disabilities leads to the conclusion that persons with albinism fall within the category and definition of persons living with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD), the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa and the Persons with Disabilities Act of Kenya, substantiate this point. The Persons with Disabilities Act defines a disability as any physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which adversely impacts on social, economic or environmental participation.<sup>1</sup> On its part, the CRPD recognises disability as an evolving concept which results from the interaction between persons with impairments, and attitudinal and environmental barriers that hinder their full and effective participation in society.<sup>2</sup>

Kenyan courts have also rendered definitions of disability. In *Kinyua Felix v Ministry of Education* the Employment and Labour Relations Court adopted the following definition of disability:

a permanent physical or other impairment or condition that has, or is perceived by significant sectors of the community to have, a substantial or long-term effect on an individual's ability to carry out ordinary day to day activities.<sup>3</sup>

Albinism, which is the centre of focus in this paper, is defined as a rare non-contagious genetically inherited difference present at birth that results in the lack of pigmentation (melanin) in the hair, skin and eyes,

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<sup>1</sup> Persons with Disabilities Act (No 14 of 2003), Section 2.

<sup>2</sup> Convention on the Rights of Persons with Disabilities and Optional Protocol, Preamble.

<sup>3</sup> *Kinyua Felix v Ministry of Education and 2 others* (2021) eKLR. See also Public Service Commission Regulations 2020, see also *Margaret Martha Byama v Alice A Otwala and 3 others* (2016) eKLR para 15, *Macharia v Safaricom plc* (Petition 434 of 2019) [2021] KEHC 462 (KLR) (Constitutional and Human Rights) (8 July 2021) (Judgment). These authorities reinforce the above definition.

thus causing vulnerability to the sun and bright light.<sup>4</sup> The condition affects people worldwide regardless of race or ethnicity,<sup>5</sup> and is incurable.<sup>6</sup> The CRPD defines discrimination on the basis of disability as

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.<sup>7</sup>

The definition adopted by the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa is similar to the CRPD definition in form and context.<sup>8</sup>

Against this backdrop, the CRPD calls for the mainstreaming of disability issues as an integral part of relevant strategies of sustainable development.<sup>9</sup> Disability mainstreaming is a strategy through which concerns, needs and experiences of persons with disability are made an integral part or dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and social spheres so that persons with disability benefit equally and inequality is not perpetuated.<sup>10</sup>

A holistic approach to the reading of the Persons with Disabilities Act, the CPRD and the Protocol to the African Charter on Human

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<sup>4</sup> This is as defined by the Human Rights Council Report A/HRC/24/57, para 10.

<sup>5</sup> International Bar Association, *Waiting to disappear: International and regional standards for the protection and promotion of the human rights of persons with albinism*, June 2017.

<sup>6</sup> Under the Same Sun, *Children with albinism and the right to health: Summary report on Tanzania with implication for other parts of sub-Saharan Africa*, 31 August 2021, 2.

<sup>7</sup> Convention on the Rights of Persons with Disabilities, 13 December 2006, Article 2.

<sup>8</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, 29 January 2018, Article 1.

<sup>9</sup> Convention on the Rights of Persons with Disabilities, Preamble. See also, Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 4. Persons with Disabilities Act, Amendment Bill 2020, Section 2.

<sup>10</sup> Ministry of Labour and Social Protection, 'National Disability Mainstreaming Strategy (2018-2022); Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities on 27 April 2022.

and Peoples' Rights on the Rights of Persons with Disabilities in Africa makes it clear that individuals with albinism are indeed persons with disabilities. Therefore, any form of discrimination meted on them on the basis of their skin colour constitutes discrimination since it is based on their disability. To this end, the International Bar Association reports that there is a correlation between discrimination and the relative contrast in skin pigmentation of persons with albinism to that of the general community.<sup>11</sup>

Part I of this article is the introduction that defines discrimination as well as discrimination based on disability. Part II entails the various national and international laws that provide for rights of persons with disabilities and discusses the rights to dignity, freedom from discrimination, education, and employment. Part III evaluates the connection between ignorance and discrimination as factors that lead to the violation of other fundamental rights and freedoms of persons with albinism. Part IV of this article discusses how discrimination due to ignorance and stereotypes denies persons with albinism the enjoyment of the rights to human dignity, education and employment. Part V of this paper illustrates the position regarding the protection of the rights of persons with albinism in Kenya, and goes ahead to discuss steps taken by the government and the relevant agencies. Part VI makes recommendations, and proposes the way forward while Part VII gives a conclusion.

Given the limited availability of data and in-depth studies based on field research on the topic,<sup>12</sup> this paper does not aim to provide a final analysis of the issue but rather, it seeks to be indicative by presenting plausible root causes based on available data, and their analysis in order to facilitate subsequent conclusive work on the subject. It is important to note that throughout this article, persons with albinism are considered part of persons with disabilities.

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<sup>11</sup> International Bar Association, *Waiting to disappear: International and regional standards for the protection and promotion of the human rights of persons with albinism*, June 2017.

<sup>12</sup> International Labour Organisation, 'Inclusion of people with disabilities in Kenya', October 2009.

## 2. The domestic and international legal framework on the rights of persons with disabilities

### 2.1 The right to human dignity

The right to human dignity stipulates that one is worthy or deserving of respect by virtue of being human.<sup>13</sup> Dignity is intrinsic to each person, and it comprises of the deeply personal understanding we have of ourselves and our worth as individuals in our material and social context.<sup>14</sup> Aloy Ojilere and Muhammad Saleh observe that a meaningful life is well lived with dignity and when dignity is lost, human life becomes virtually worthless.<sup>15</sup> Under the Constitution, every person including a person with albinism has inherent dignity and the right to have their dignity respected and protected.<sup>16</sup> Notably, human dignity is a principle that must be taken into consideration while interpreting the Bill of Rights,<sup>17</sup> and in limiting the enjoyment of all other rights and fundamental freedoms.<sup>18</sup>

The right to inherent human dignity is a very important right since under the 2010 Constitution; the purpose of recognising and protecting human rights and fundamental freedoms is preserving the human dignity of individuals.<sup>19</sup> This undoubtedly applies to persons with albinism. Pursuant to the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, state parties have an obligation to take all appropriate and effective measures, including policy, legislative, administrative, institutional and budgetary

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<sup>13</sup> Jack Donnelly, 'Human dignity and human rights: Swiss initiative to commemorate the 60<sup>th</sup> anniversary of the UDHR,' June 2009.

<sup>14</sup> Edwin Cameron, 'Dignity and disgrace; Moral citizenship and constitutional protection', *Concourt.org.za*, 28 June 2012,

<sup>15</sup> A Ojilere, Musa M Saleh, 'Violation of dignity and life: Challenges and prospects for women and girls with albinism in Sub-Saharan Africa' 1(1) *Journal of Human Rights and Social Work* (2019).

<sup>16</sup> Constitution of Kenya (2010), Article 28.

<sup>17</sup> Constitution of Kenya (2010), Article 20(4).

<sup>18</sup> Constitution of Kenya (2010), Article 24(1).

<sup>19</sup> Constitution of Kenya (2010), Article 19(2).

steps, to ensure the respect, promotion, protection and fulfilment of the rights and dignity of persons with disabilities.<sup>20</sup>

Article 15 of the CRPD also speaks against the degrading treatment of persons with disabilities. It asserts that no one shall be subjected to torture or cruel, inhuman or degrading treatment or punishment.<sup>21</sup> Besides the two authorities discussed above, the Universal Declaration of Human Rights (UDHR) calls upon all human beings to act towards one another in the spirit of brotherhood since all human beings are born free and equal in dignity and rights.<sup>22</sup> The UDHR obligates the state and the international community to promote the realisation of rights that are indispensable to a person with disability's dignity and the free development of their personality.<sup>23</sup>

## 2.2 Freedom from discrimination

When it comes to persons with albinism, the Constitution of Kenya, 2010 (2010 Constitution) provides that no person shall discriminate against another directly or indirectly on any ground including colour or disability.<sup>24</sup> Article 27 of the Constitution further affirms that equality includes the full and equal enjoyment of all rights and fundamental freedoms by all persons including those living with albinism.<sup>25</sup> The 2010 Constitution, the UDHR, the African Charter on Human and Peoples' Rights, the CRPD, and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa provide for the freedom from non-discrimination on any ground including colour and disability.<sup>26</sup>

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<sup>20</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 4.

<sup>21</sup> Convention on the Rights of Persons with Disabilities, Article 15.

<sup>22</sup> Universal Declaration of Human Rights 1948, Article 1.

<sup>23</sup> Universal Declaration of Human Rights, Article 22.

<sup>24</sup> Constitution of Kenya (2010), Article 27(4), (5).

<sup>25</sup> Constitution of Kenya (2010), Article 27. See Universal Declaration of Human Rights, Article 2.

<sup>26</sup> Constitution of Kenya (2010), Article 10(2)(b), see Convention on the Rights of Persons with Disabilities, Article 3; see also Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 3.

According to the CRPD, discrimination based on disability is a violation of the inherent human dignity and worth of the person living with albinism.<sup>27</sup> The African Charter on Human and Peoples' Rights props up this right since it prohibits discrimination based on colour when it comes to persons with albinism.<sup>28</sup> The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa provides that every person living with a disability shall be entitled to the enjoyment of rights and freedoms without distinction of any kind on any ground including colour or any status.<sup>29</sup> The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa further proffers that discrimination based on disability includes the denial of reasonable accommodation.<sup>30</sup> One outstanding feature of the UDHR is that it reiterates protection against discrimination, and any incitement to such discrimination.<sup>31</sup>

The CRPD in Article 4 lists the obligation of states when it comes to promoting the full realisation and enjoyment of all human rights by persons with albinism without discrimination on the basis of disabilities. These obligations include: the adoption of appropriate measures in administration and legislation to ensure the protection of all rights of persons living with disabilities, adoption of all appropriate measures to end discrimination by modifying or abolishing existing laws, regulations, or customs and practices that promote discrimination on the basis of disability. The obligations also include: taking into account the protection and promotion of all rights of persons with disabilities in all policy and programmes on development, promoting the training of professionals and staff in the rights of persons with disabilities to provide better assistance and services to them, and promoting the availability and use of new technologies including information on mobility aids,

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<sup>27</sup> Preamble of the Convention on Persons with Disabilities.

<sup>28</sup> African Charter on Human and Peoples' Rights, Article 2, 5.

<sup>29</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 5(1).

<sup>30</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 1.

<sup>31</sup> United Declaration of Human Rights, Article 7.



devices and assistive technologies, suitable for persons with disabilities while giving priority to technology at an affordable cost.<sup>32</sup>

The Convention further submits that an individual has a responsibility to strive for promotion of human rights for all persons.<sup>33</sup>

### 2.3 The right to education

The right to education is a globally recognised overarching right.<sup>34</sup> Various instruments encompass the right to education. At the domestic level, the 2010 Constitution, the Basic Education Act No 14 of 2013, the Children Act No 29 of 2022; and at the international level, the CRPD and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa. Kenya is party to both international instruments and is therefore under obligation to adhere to their provisions.

Under the 2010 Constitution, all persons including those living with albinism have a right to free and compulsory basic education.<sup>35</sup> Article 54 of the 2010 Constitution entitles persons with albinism to the right to access educational institutions for persons with disabilities that are integrated in society.<sup>36</sup> The Constitution mandates the state to take measures that guarantee the youth living with albinism the right to education through the access of relevant education and training.<sup>37</sup> The Constitution further reiterates that everyone shall enjoy the rights guar-

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<sup>32</sup> Convention on the Rights of Persons Living with Disabilities, Article 4.

<sup>33</sup> Preamble of the Convention on the Rights of Persons with Disabilities.

<sup>34</sup> T Mwoma, 'Education for children with special needs in Kenya: A review of related literature' 8(28) *Journal of Education and Practice* (2017) 188-200. See also Malasi Nyali Maghuwa Flora, Samuel Wanyonyi Juma 'The role of educational assessment resource centres in promoting inclusive education in Kenya' 7(1) *International Journal of Science and Research*, 885-889.

<sup>35</sup> Constitution of Kenya (2010), Article 43(1)(f), Article 53(b).

<sup>36</sup> Constitution of Kenya (2010), Article 54(1)(b).

<sup>37</sup> Constitution of Kenya (2010), Article 55(a), see Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 29(2).

anteed in the Bill of Rights to the greatest extent,<sup>38</sup> and such rights shall not be limited except through the law.<sup>39</sup>

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa also affirms that persons with disabilities have the right to education.<sup>40</sup> According to the Protocol, this right also encompasses free, quality and compulsory basic (primary) and secondary education, and access to general tertiary education, vocational training, adult education and lifelong learning by persons with disabilities.<sup>41</sup> The CRPD also recognises the right to education of persons with disabilities and goes ahead to provide that the education system should ensure the development of persons with disabilities in terms of their personality, talents, creativity as well as mental and physical abilities, to their fullest potential.<sup>42</sup> Undoubtedly, these guarantees also cover persons with albinism.

On its part, besides reiterating the right of every child including those living with disabilities to free and compulsory education, the Basic Education Act adds that persons with disabilities should not be denied admission to education institutions due to their disability.<sup>43</sup> Importantly, the Persons with Disabilities Act underscores the right of persons with disabilities to acquire substantial learning in any course provided they have the ability.<sup>44</sup>

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<sup>38</sup> Constitution of Kenya (2010), Article 20(2).

<sup>39</sup> Constitution of Kenya (2010), Article 24.

<sup>40</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 16(1),(2).

<sup>41</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 16(3)(a),(b).

<sup>42</sup> Convention on the Rights of Persons with Disabilities, Article 24(1)(b).

<sup>43</sup> Basic Education Act, Section 34(2), Persons with Disabilities Act (No 14 of 2003), Section 18(1).

<sup>44</sup> Persons with Disabilities Act (No 14 of 2003), Section 18(1). See also, Convention on the Rights of Persons with Disabilities, Article 24(2)(a); Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 16. The right to free and compulsory education is also provided under the Constitution and the Persons with Disabilities Act.

The state also has an obligation of ensuring that persons with disabilities can access inclusive, quality and free primary and secondary education in the communities in which they live.<sup>45</sup> This obligation comes with the need to support them through the provision of materials and support necessary for study. In line with this, the Basic Education Act points out that the national government should provide infrastructure, learning and teaching equipment, and appropriate financial resources to facilitate the right to education by students with disability.<sup>46</sup>

Under state responsibility, the cabinet secretary in charge of education should provide every learning institution with special needs learners with appropriately trained teachers, infrastructure, learning materials and equipment suitable for them.<sup>47</sup> The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa adds that the state responsibility encompasses the obligation of training education professionals and service providers on how to educate and interact with children with specific learning needs.<sup>48</sup> The CPRD also adopts this position and confers the state with the obligation of employing teachers, including teachers with disabilities who are qualified in sign language and braille.<sup>49</sup>

In support of the above discussion, the CPRD places an obligation on the state to ensure the provision of reasonable accommodation to facilitate enjoyment of the right to education by persons with disabilities.<sup>50</sup> Reasonable accommodation is any means necessary or any appropriate modifications needed in a particular case to ensure that persons with disabilities enjoy or exercise their human rights and freedoms on

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<sup>45</sup> Convention on the Rights of Persons with Disabilities, Article 24(2)(b).

<sup>46</sup> Basic Education Act (No 14 of 2013), Section 39(e).

<sup>47</sup> Basic Education Act (No 14 of 2013), Section 44(4); see also, Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 16(h).

<sup>48</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 16(i).

<sup>49</sup> Convention on the Rights of Persons with Disabilities, Article 24(4).

<sup>50</sup> Convention on the Rights of Persons with Disabilities, Article 24(2)(c).

an equal basis with others.<sup>51</sup> Such modifications include enlarging print of reading materials, allowing students to use assistive technology or allowing a student more time to write tests and exams.<sup>52</sup>

In addition to providing support to facilitate the right to education of persons with disabilities, among whom include persons with albinism, the cabinet secretary in charge of education may establish special and integrated schools for learners living with albinism upon consultation with both the national and county education boards.<sup>53</sup> In cases where there are no special schools for such learners, educational institutions should take into account the special needs of persons with disability by considering the entry requirements, pass marks, curriculum examinations, class schedules, use of school facilities, and physical education requirements.<sup>54</sup> To underscore the foregoing, the cabinet secretary in charge of education should establish regulations that guarantee the learning and progression of learners with disabilities through the education system.<sup>55</sup> According to the Basic Education Act, learners with special needs include those with visual impairment therefore, learners with albinism fall under this category.<sup>56</sup>

Unlike the other authorities discussed above, the Basic Education Act also extends the obligation to guarantee the right to education of persons with disabilities to parents or guardians of such learners. In particular, it states that the parents or guardians of such learners shall ensure they present them to school for admission<sup>57</sup> and ensure that their children attend school regularly as pupils or learners.<sup>58</sup> Those who fail, commit an offence and are liable to a fine not exceeding Kshs 100,000,

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<sup>51</sup> Convention on the Rights of Persons with Disabilities, Article 2.

<sup>52</sup> UNICEF, 'Inclusive education: Understanding Article 24 of the Convention on the Rights of Persons with Disabilities', September 2017.

<sup>53</sup> Basic Education Act (No 14 of 2013), Section 28(1)(d).

<sup>54</sup> Persons with Disabilities Act (No 14 of 2013), Section 18(2).

<sup>55</sup> Basic Education Act (No 14 of 2013), Section 45(b).

<sup>56</sup> Basic Education Act (No 14 of 2013), Section 44(3).

<sup>57</sup> Basic Education Act (No 14 of 2013), Section 31(1).

<sup>58</sup> Basic Education Act (No 14 of 2013), Section 30(1).

imprisonment for one year or both.<sup>59</sup> Finally, the statute reiterates that learners should not be denied admission to public schools.<sup>60</sup>

## 2.4 The right to employment

The 2010 Constitution entitles every person to the right to fair labour practices.<sup>61</sup> The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa tenders that this right includes the right to decent, just and favourable conditions of work, protection against unemployment, protection against exploitation and protection from forced or compulsory labour.<sup>62</sup> The Persons with Disabilities Act stipulates that persons with disabilities who qualify as employees are entitled to the same terms, conditions, privileges, benefits, compensation, fringe benefits, incentives, and allowances as those enjoyed by qualified able-bodied employees.<sup>63</sup> This statute is also clear in prohibiting discrimination against persons with disabilities by employers. In particular, it encompasses instances under which an employer should not discriminate against a person with disability. These instances include: in the advertisement and recruitment of persons for employment, the recruitment for employment, the creation, classification or abolition of posts, the determination or allocation of wages, salaries, pensions, accommodation, leave or other benefits, the choice of persons for posts, training, advancement, apprenticeships, transfer, promotion or retrenchment and in the provision of facilities connected or related to employment.<sup>64</sup>

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<sup>59</sup> Basic Education Act (No 14 of 2013), Section 30(2),(3).

<sup>60</sup> Basic Education Act (No 14 of 2013), Section 34(5).

<sup>61</sup> Constitution of Kenya (2010), Article 41.

<sup>62</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 19(1).

<sup>63</sup> Persons with Disabilities Act (No 14 of 2003), Section 12(2).

<sup>64</sup> Persons with Disabilities Act (No 14 of 2003), Section 15. See Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 19(2)(a).

One other notable feature of the Persons with Disabilities Act is that it grants the person with disability the right to seek redress for any acts of discrimination meted out on them by the employer.<sup>65</sup>

The Employment Act also cements the right to employment and fair labour practices of persons with albinism. Under the Act, no employer shall discriminate against an employee or prospective employee who is a person with disability on any ground including colour and disability.<sup>66</sup> The Act also defines employees to include those applying for employment.<sup>67</sup> Of particular importance is that the Employment Act defines disability as any impairment that impacts adversely on a person's social and economic participation,<sup>68</sup> and goes ahead to reiterate that such a person shall not be denied access to opportunities for suitable employment.<sup>69</sup> However, the statute notes that any affirmative action taken to promote equality and eliminate discrimination will not amount to discrimination.<sup>70</sup>

Courts have also addressed the right to employment. For instance, in *Kenya Union of Domestic, Hotels, Educational Institutions, Hospitals and Allied Workers v Association for the Physically Disabled of Kenya*,<sup>71</sup> while addressing the right to work and seek employment by persons with disabilities, the Court reiterated that the State has an obligation to safeguard and promote the realisation of the rights of persons with disabilities. Additionally, in *Fredrick Gitau Kimani v Attorney General & 2 Others*,<sup>72</sup> the petitioner being a person with disabilities also successfully challenged the violation of his labour rights by the State in accordance with the Constitution and the Persons with Disabilities Act. In this case, the Respondent had forced the Petitioner into early retirement at the age of

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<sup>65</sup> Persons with Disabilities Act (No 14 of 2003), Section 15(3).

<sup>66</sup> Employment Act (2007), Section 5(3).

<sup>67</sup> Employment Act (2007), Section 5(7).

<sup>68</sup> Employment Act (2007), Section 2.

<sup>69</sup> Employment Act (2007), Section 2.

<sup>70</sup> Employment Act (2007), Section 5(4).

<sup>71</sup> *Kenya Union of Domestic, Hotels, Educational Institutions, Hospitals and Allied Workers v Association for the Physically Disabled of Kenya* (2015) eKLR.

<sup>72</sup> *Fredrick Gitau Kimani v Attorney General and 2 others* (2012) eKLR.

55 years, instead of the age of 60 years as Section 15(6) of the Persons with Disabilities Act provides. Upon the determination of the matter, the Court agreed that the petitioner had been discriminated on the basis of disability and went ahead to grant him compensation.

Aside from the legislations relied on above, courts have also been at the forefront in addressing issues regarding persons with disabilities. Courts have ruled that for one to benefit and be recognised as a person with disability, they must be registered with the National Council for Persons with Disabilities. In the case of *Esau Rodgers Mumia v Central Bank of Kenya*, the Petitioner, a person with disability was subjected to early retirement at the age of 55 years instead of the stipulated retirement at the age of 60 years as is provided by statute. While addressing the rights of the Petitioner the Employment and Labour Relations Court held that for one to benefit from the rights and privileges under the Persons with Disabilities Act, then they ought to register with the National Council for Persons with Disabilities as provided by Section 7 of the Persons with Disabilities Act.<sup>73</sup> The Employment and Labour Relations Court further went on to add that disability as defined in the Persons with Disabilities Act is not an internal matter between an employee and their employer.<sup>74</sup>

In the matter of *Suleman Angolo & another v Executive Officer Teachers Service Commission*, the Court stated that persons with disabilities enjoy certain rights such as tax exemption as provided in the Persons with Disabilities (Income Tax Deductions and Exemptions) Order.<sup>75</sup> The Court reiterated that one must register with the National Council for Persons with Disabilities to enjoy such benefits.<sup>76</sup>

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<sup>73</sup> *Esau Rodgers Mumia v Central Bank of Kenya* (2017) eKLR.

<sup>74</sup> *Esau Rodgers Mumia v Central Bank of Kenya*.

<sup>75</sup> *Suleman Angolo and another v Executive Officer Teachers Service Commission* (2015) eKLR.

<sup>76</sup> *Suleman Angolo and another v Executive Officer Teachers Service Commission*.

### 3. The interplay between discrimination and ignorance

In many cases discrimination results from negative attitudes, perception, misconception, misunderstanding and lack of awareness.<sup>77</sup> A persistent lack of awareness and ignorance about the condition has contributed immensely to stigmatisation, stereotyping and prejudice against persons with albinism.<sup>78</sup> The myths and misconceptions that arise from ignorance provide a rationale for discriminating against them.<sup>79</sup> According to the Albinism Society of Kenya, ignorance by law and policy makers, the public, and the community about albinism also sustains discrimination against person with albinism.<sup>80</sup>

The Kenya National Commission on Human Rights submits that the Kenyan government recognises that discrimination against persons with disabilities is entrenched in stereotypes prevailing in Kenyan society.<sup>81</sup> Such stereotypes and ignorance are said to lead to cases in which other persons with disabilities develop perceptions that those with albinism are not disabled enough to be covered in their programmes, pushing persons with albinism into a dilemma of ability against disability.<sup>82</sup>

The UN Independent Expert on the enjoyment of human rights by persons with albinism agrees that lack of public education on albinism is closely linked to widespread myths regarding the condition.<sup>83</sup> The Independent Expert adds that there is need to establish initiatives for

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<sup>77</sup> United Nations, 'Introducing the United Nations Convention on the Rights of Persons with Disabilities: Toolkit on disability in Africa', *United Nations. Org*, 2 May 2022.

<sup>78</sup> Ikponwosa Ero, Samer Muscati, Anne-Rachelle Boulanger and India Annamanthadoo, *People with albinism worldwide: A human rights perspective*, 2021, 24.

<sup>79</sup> UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, *Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism*. UN Doc A/72/131, 14 July 2017.

<sup>80</sup> Albinism Society of Kenya, *Albinism Report 2019*, 4.

<sup>81</sup> Kenya National Commission on Human Rights, *Compendium on Convention on the Rights of Persons with Disabilities*, 2016.

<sup>82</sup> Albinism Society of Kenya, *Albinism report 2019*, 4.

<sup>83</sup> Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, *A preliminary survey on the root causes of attacks and discrimination against persons with albinism*, A/71/255, 29 July 2016.



sustained awareness raising among the public.<sup>84</sup> Even where the laws address disability rights, a lack of societal awareness about albinism renders these guarantees ineffective or meaningless despite the existence of cogent laws that guarantee all persons the enjoyment of fundamental rights and freedoms.<sup>85</sup>

The lack of understanding, misinformation and myths on albinism fuels discrimination against children with albinism. Ikponwosa Ero posits that in some cases, the parents of children with albinism may have difficulty accepting them or fully embracing them as their children.<sup>86</sup> In addition, adults fuel the exclusion of children with albinism by warning their children not to interact with them.<sup>87</sup> In other cases, boys with albinism are expected to tolerate bullying and discrimination ‘as men’.<sup>88</sup>

The Albinism Society of Kenya notes that ignorance and lack of awareness about albinism has led to the emergence of myths in some communities in Kenya such as the Maasai and the Luhya. These communities believe that women who give birth to children with albinism are unfaithful and have children out of wedlock with white men.<sup>89</sup> Grace Nzomo, a young person living with albinism and a psychology graduate, supports this claim and adds that it is common for children with albinism in such communities to end up in single parent families, as the father disowns the mother alleging that the wife had been unfaithful with a white man.<sup>90</sup>

From the above conceptualisation, it is necessary to point out that discrimination and ignorance are intertwining factors. It is necessary to take steps to root out ignorance and existing stereotypes in society in order to give effect to the freedom from discrimination.

<sup>84</sup> UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, *Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism*.

<sup>85</sup> Ero, Muscati, Boulanger and Annamanthadoo, *People with albinism worldwide*.

<sup>86</sup> Ero, Muscati, Boulanger and Annamanthadoo, *People with albinism worldwide*, 25.

<sup>87</sup> Ero, Muscati, Boulanger and Annamanthadoo, *People with albinism worldwide*, 25.

<sup>88</sup> Ero, Muscati, Boulanger and Annamanthadoo, *People with albinism worldwide*, 25.

<sup>89</sup> Albinism Society of Kenya, *Albinism Report 2019*.

<sup>90</sup> Aidex Voices, ‘Living positively with albinism in Kenya: Grace’s story,’ 14 June 2018.

#### 4. Discrimination as a plausible link to the violation of other fundamental rights and freedoms

*Black's Law Dictionary* defines the term 'violation' as an infraction or breach of law, or the contravention of a right or duty.<sup>91</sup> Lawrence Mute asserts that persons living with disabilities contend that it is society rather than their bodies that makes them disabled. To them, it is not the disabled person that bears the pathology nor is it the diseased ear, eye, leg or mind that disables but rather, it is society that carries the pathology and disables by its stigma, prejudice and discrimination.<sup>92</sup> The Albinism Society of Kenya agrees in its 2019 report that indeed, persons with albinism in Kenya continue to face stigma, discrimination, abuse, dehumanisation and brutal killings. This is despite significant progress in the development of a progressive legislative and policy framework to address the economic, social, cultural, political and civil rights of persons with disabilities.<sup>93</sup>

##### 4.1 The right to human dignity

The claim of human dignity is that simply being human makes one worthy or deserving of respect.<sup>94</sup> According to the Kenya National Commission on Human Rights, even the persons with albinism who manage to beat the odds in society are not spared from public derision.<sup>95</sup> Not even those in prominent political positions are spared! For instance, former nominated Senator Isaac Mwaura who is a person with albinism is one such victim who experienced the violation of his right to inherent dignity because of his different skin colour. In 2021, he was verbally attacked by fellow legislator Mr Junet Mohammed in a statement made at

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<sup>91</sup> *Black's Law Dictionary*, 8<sup>th</sup> edition.

<sup>92</sup> Lawrence M Mute, 'Difference and distinct identities: Are constitutional provisions for persons with disabilities being implemented?' *The Elephant.info*, 20 August 2020.

<sup>93</sup> B Rohwerder, *Disability inclusive development: Kenya situational analysis, June 2020 update*, Inclusive Futures/Institute of Development Studies, 2020.

<sup>94</sup> Donnelly, 'Human dignity and human rights'.

<sup>95</sup> KNCHR and others, 'The human rights of persons with albinism in Kenya. A report submitted to the UN Office of the High Commissioner for Human Rights', 2014, para 26.

a political rally, where the legislator claimed that Senator Mwaura had bleached his skin in order to be nominated to Parliament (to represent persons with disability).<sup>96</sup> The Kenya National Commission on Human Rights condemned the comments that elicited public outcry stating that the comments not only ridiculed Senator Mwaura's albinism but are also the epitome of the stigmatisation of disability.<sup>97</sup> The Commission was quick to note that such comments indeed violated Article 54 of the Constitution of Kenya, 2010 that requires the treatment of persons with disabilities with dignity and respect and requires them to be addressed and referred to in a manner that is not demeaning.<sup>98</sup>

The Commission also reiterated the fact that leaders have a crucial role in ending stigma and discrimination, and that it was very unfortunate that a person in a position of power could perpetuate such vices against persons living with disabilities. It also added that such negative utterances could evoke dehumanisation, negative attitudes, and violence against these individuals.<sup>99</sup> Through a press statement, the Commission condemned the discriminatory remarks by the legislator and added that such remarks were not only an affront to the person and character of Senator Mwaura but also an abuse on the dignity of all persons living with disabilities.<sup>100</sup>

Following the outcry elicited by his comments, Mr Mohammed apologised to all persons with albinism but still went ahead to state that his comments were directed at the rotten character of Isaac Mwaura who he said exploited his disability for personal gain and the incitement of violence.<sup>101</sup>

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<sup>96</sup> Mercy Asamba, 'Suna East MP Junet criticised over remarks against Senator Mwaura' *The Standard*, 7 February 2021.

<sup>97</sup> Kenya National Commission on Human Rights (KNCHR), 'Press statement in response to Hon MP Junet Mohamed's disability comments against Senator Dr Isaac Mwaura', 9 February 2021.

<sup>98</sup> KNCHR, 'Press statement in response to Hon MP Junet Mohamed'.

<sup>99</sup> KNCHR, 'Press statement in response to Hon MP Junet Mohamed'.

<sup>100</sup> KNCHR, 'Press statement in response to Hon MP Junet Mohamed'.

<sup>101</sup> Star Reporter, 'Junet under fire over derogatory remark on Isaac Mwaura' *The Star*, 7 February 2021.

In the same year 2021, KTN NEWS featured former Jubilee Party Vice Chairman Mr David Murathe, on live television claiming that albinism was not a disability and it should not be exploited for political gain.<sup>102</sup> Mr Murathe stated that they will look into the legal definition of persons living with disability in future.<sup>103</sup> Following this statement, the Albinism Society of Kenya called out Mr Murathe and stated that Senator Mwaura is a role model and mentor to many persons with disabilities and questioning his disability subsequently questions the disability of all persons with albinism and those that he identifies with and represents.<sup>104</sup> Although the above cases show that influential persons in the society are among the most ignorant persons when it comes to rights of persons with albinism, the society has made some effort in calling out such cases.

In addition to the above cases, persons with albinism have been subjected to attacks that have deprived them of their dignity as human beings. To substantiate this point, the Expert on the enjoyment of human rights by persons with albinism, Ms Ero observes that there is need for protection measures in some parts of Kenya such as Migori, Taita Taveta and other border counties where attacks on persons with albinism remain high.<sup>105</sup> The Expert added that in rural areas stereotypes have intensified the attacks.<sup>106</sup> In light of the observations by the Independent Expert, the Albinism Foundation of East Africa, the Kenya National Commission on Human Rights and other albinism rights advocacy groups, in a joint statement note that that several attacks against persons with albinism have been

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<sup>102</sup> Gordon Osen, 'Albinism lobby wants Murathe to apologize over remark on Mwaura' *The Star*, 22 May 2021.

<sup>103</sup> Osen, 'Albinism lobby wants Murathe to apologize over remark on Mwaura'.

<sup>104</sup> Osen, 'Albinism lobby wants Murathe to apologize over remark on Mwaura'; see also Wycliffe Nyamasage, 'Albinism Society calls out Murathe over offensive TV utterances' *KahawaTungu*, July 2021.

<sup>105</sup> UN News, 'Kenya makes progress in supporting people with albinism, but 'much remains to be done' says UN expert' *UN News*, 18 September 2018.

<sup>106</sup> UN News, 'Kenya makes progress in supporting people with albinism, but 'much remains to be done' says UN expert

documented.<sup>107</sup> This report points out that in many cases attacks go unreported.<sup>108</sup>

Among the documented attacks, persons with albinism were murdered for their body parts pursuant to the beliefs that such parts could be used to generate wealth and bring luck.<sup>109</sup> The report added that in other cases, these body parts are sold in the black market for thousands of dollars.<sup>110</sup> Esther Moraa, a four-month old baby was killed by the mother due to threats of divorce from her husband who termed the baby as a bad omen and a disgrace to the family.<sup>111</sup> On the other hand, two other victims, Margaret and Joyce, were abducted, murdered and parts of their bodies chopped off.<sup>112</sup> Further, other persons with albinism were attacked but they managed to escape.<sup>113</sup> The report documents the stories of Robinson Mukwahana and A Bettlyn, who were abducted by people who tried to sell them but were unsuccessful.<sup>114</sup> These findings highlight that the struggle of persons with albinism to live in an equal and safe society in Kenya remains far from achievement.

#### 4.2 The right to education

In her report, the Independent Expert on the enjoyment of human rights by persons with albinism observes there still exist challenges that hinder the enjoyment of the right to education of children with albinism despite the guarantee of access to education in the same manner as other children.<sup>115</sup> While considering cases from Kenya and other Af-

<sup>107</sup> Albinism Foundation of East Africa (AFEA), Albinism Society of Kenya (ASK), Kenya National Commission on Human Rights (KNCHR), Under the Same Sun (USS), 'The human rights of persons with albinism in Kenya; Universal Periodic Review', June 2014, *Repository on Disability Rights in Africa(RODRA)*, July 2022.

<sup>108</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>109</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>110</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>111</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>112</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>113</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>114</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>115</sup> Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Women and children impacted by albinism, Human Rights Council (43<sup>rd</sup>

rican countries, the Independent Expert also notes that when it comes to education, children with albinism face rejection by school authorities based on the misconception that they are unable to study in mainstream schools.<sup>116</sup> Several studies also point out that children with disabilities have not been 'fully integrated into the education system in Kenya' despite policies and other legal instruments supporting inclusive education.<sup>117</sup>

This assertion is also affirmed by the Albinism Society of Kenya which reports that learners with albinism are sometimes turned away from schools due to assumptions held by the school community that they are all blind, and are thus designated to learn in special schools for the blind and to use braille. This affects their employability and productivity.<sup>118</sup> The Albinism Society of Kenya further adds that at present, around 70% of Kenyan children with albinism attend schools for the visually impaired where both those who are blind and those who are not are forced to learn braille.<sup>119</sup> Grace Nzomo, a person with albinism adds that using braille while doing mathematics during her years in school was like teaching the Greek language to non-speakers.<sup>120</sup> Although she is not blind, she adds that the forceful use of braille made her feel blind.<sup>121</sup>

The Independent Expert further reports that in some cases teachers lack sufficient knowledge on how to provide reasonable accommodation or a generally supportive environment for children with albinism. Furthermore, in other cases teachers receive training on how to support children with visual impairments only as opposed to supporting chil-

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Session), A/HRC/43/42, 24 December 2019.

<sup>116</sup> UN News, 'Kenya makes progress in supporting people with albinism, but 'much remains to be done' says UN expert'.

<sup>117</sup> T Mwoma, 'Education for children with special needs in Kenya: A review of related literature' 8(28) *Journal of Education and Practice*, (2017) 188-200. See also Malasi Nyali Maghuwa Flora, Samuel Wanyonyi Juma 'The role of educational assessment resource centres in promoting inclusive education in Kenya' 7(1) *International Journal of Science and Research*, 885-889.

<sup>118</sup> Albinism Society of Kenya, *Albinism Report 2019*, 2.

<sup>119</sup> Aidex Voices, 'Living positively with albinism in Kenya'.

<sup>120</sup> Aidex Voices, 'Living positively with albinism in Kenya'.

<sup>121</sup> Aidex Voices, 'Living positively with albinism in Kenya'.

dren on the entire spectrum of albinism. Ashley Julia Robertson posits that it takes only a trained eye to observe the challenges faced by these children and as such, regular teachers may not realise that the child is struggling.<sup>122</sup>

In addition to the above instances, in some cases families neglect the education of children with albinism as they see their child as a source of shame and believe their education is unnecessary.<sup>123</sup> Olanike Adhlakun and Maryann Ajayi posit that in some cases African parents shy away from sending their children with albinism to schools due to the erroneous belief that children with albinism cannot compete successfully with their peers and therefore cannot prosper in life.<sup>124</sup>

Grace Nzomo adds that most children with albinism remain hidden from society causing them to develop low self-esteem. This affects their development and progress as individuals, in school and in other fields of life.<sup>125</sup>

On tertiary education, there is little data with regards to persons with albinism. Ikponwosa Ero attributes this to discrimination and lack of reasonable accommodation that contributes to poor academic performance, demotivation, low school attendance and high dropout rates among learners living with albinism, so much so that many do not get to the tertiary level of education.<sup>126</sup>

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<sup>122</sup> Julia Robertson Ashley, 'Improving teacher and caregiver strategies for meeting the special needs of children with the visual disability of ocular albinism or oculocutaneous albinism (birth to age 14)' A practicum II report presented to the Ed.D. program in early middle childhood in partial fulfilment of the requirements for the Degree of Doctor of Education, (1992).

<sup>123</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>124</sup> Olanike S Adhlakun, Maryann O Ajayi, 'Eliminating discrimination and enhancing equality: A case for inclusive basic education rights of children with albinism in Africa' 29(2) *Nigerian Journal of Medicine* (April-June 2020), citing RJ Gaigher, PM Lund, E Makuya, 'A sociological study of children with albinism at a special school in the Limpopo province' 25 *Curatonia* (2002) 4-11.

<sup>125</sup> Aidex Voices, 'Living positively with albinism in Kenya'.

<sup>126</sup> Ero, Muscati, Boulanger and Annamantadoo, *People with albinism worldwide*, 24.

From the discussion above, two facts come out clearly. First is that ignorance is deeply entrenched in the society leading to discrimination from parents and the society in guaranteeing the right to education of persons with albinism. Second, the lack of training for teachers on how to handle learners living with albinism makes such learners vulnerable to discrimination in the learning institutions.

#### 4.3 *The right to employment*

Rohwerder submits that despite significant progress in the development of policies and laws which recognise the right of persons with disabilities to work, their impact on the real situation of persons with disabilities access to work and employment opportunities has been minimal.<sup>127</sup> Some studies point out that in Kenya, the employment rate for persons with disabilities is about 1% compared to 73.8% for the general population.<sup>128</sup>

According to the Albinism Society of Kenya, persons with albinism continue to suffer double discrimination as employers assume that their capacity to deliver within the workplace is below par.<sup>129</sup> This has denied them equal opportunities for their economic empowerment. The Kenya National Commission on Human Rights adds that besides the discrimination on face value in the workplace, persons with albinism suffer discrimination in the education system that results in high dropout rates from school, which in turn leaves most of them unskilled and unequipped for jobs.<sup>130</sup> In a study of 30 people with disabilities, almost all cited their inability to attain higher education as a major factor limiting

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<sup>127</sup> Rohwerder, 'Kenya situational analysis: Inclusion works' (2020) citing A Kingiri, W Khaemba, J Olenja, A Gitonga, W Oloo, E Nyariki & S Wafula, 'Policy brief: The labour market situation in Kenya - promoting right to work and employment for persons with disabilities' (2017).

<sup>128</sup> ID Ebuenyi, AJ van der Ham, JFG Bunders-Aelen & BJ Regeer, 'Expectations management: Employer perspectives on opportunities for improved employment of persons with mental disabilities in Kenya' 42(12) *Disability Rehabilitation* (June 2020), 1687-1696.

<sup>129</sup> Albinism Society of Kenya, *Albinism report 2019*, 2.

<sup>130</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.



their access to employment.<sup>131</sup> Interestingly, some people who incurred disability after they had received their education felt that the education enabled them secure jobs.<sup>132</sup>

Further, the Kenya National Commission on Human Rights posits that in employment opportunities, other persons with disabilities receive more consideration than persons with albinism.<sup>133</sup> This discrimination flows from the fact that most employers do not regard persons with albinism as persons with disabilities.<sup>134</sup> Such discrimination in the workplace and in school leaves them only with the option of menial jobs which subject them to hostile conditions such as sunlight or bright light, which in turn puts them at risk of skin cancer or sight impairment.<sup>135</sup> One of the notable myths that exists is that people with albinism are inferior and incapable of completing normal mental and physical tasks.<sup>136</sup> The Human Rights Council's Advisory Committee indicates that states should launch and sustain education and awareness campaigns aimed at combating the underlying causes of discrimination, which include stereotypes and misconceptions against people with albinism.<sup>137</sup>

## 5. Steps Kenya has taken so far: The status quo regarding persons with disabilities

Article 21 of the 2010 Constitution reiterates the government's duty to observe, respect, protect, promote, and fulfil rights and funda-

<sup>131</sup> Rohwerder, *Kenya situational analysis, June 2020 update* citing MP Opoku, WM Mprah, JA Dogbe, JN Moitui, & E Badu, 'Access to employment in Kenya: The voices of persons with disabilities' 16(1) *International Journal on Disability and Human Development* (2016).

<sup>132</sup> Rohwerder, *Kenya situational analysis, June 2020 update* citing A Kingiri, W Khaemba, J Olenja, A Gitonga, W Oloo, E Nyariki, S Wafula, 'Policy brief: The labour market situation in Kenya: promoting right to work and employment for persons with disabilities' (2017).

<sup>133</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>134</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>135</sup> Albinism Society of Kenya, *Albinism report 2019*; see also AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

<sup>136</sup> Ero, Muscati, Boulanger and Annamanthadoo, *People with albinism worldwide*. 24.

<sup>137</sup> Ero, Muscati, Boulanger and Annamanthadoo, *People with albinism worldwide*. 24.

mental freedoms in the Bill of Rights. This obligation encompasses the government's commitment to the progressive realisation of the rights of all Kenyans including persons with disabilities.<sup>138</sup> In light of this, the Government is quick to note that following the progress made in the implementation of its obligations under the law concerning persons with disabilities, there has been a slow but noticeable improvement in public perception towards the treatment of persons with disabilities.<sup>139</sup>

The United Nations Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, also welcomed some of Kenya's unique achievements, saying the country was set to become one of the leaders on the issue in the region.<sup>140</sup> The Independent Expert acknowledged Kenya's successes that include the allocation of a substantial annual budget geared towards encompassing specific measures for the protection of persons with albinism, who had historically been left out of key sectors such as health and education and had fallen prey to ritual attacks and consequent insecurities.<sup>141</sup> However, the Expert also noted that much remains to be done including undertaking an intense and widespread sensitisation campaign across the country, particularly in rural communities, to ensure that the conditions that create attacks and discrimination in the first place are dealt with.<sup>142</sup>

### 5.1 Domestic institutional schema with respect to persons with albinism

Under the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, states parties are expected to establish or designate national mechanisms, including forming independent national institutions, to monitor the implemen-

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<sup>138</sup> Constitution of Kenya (2010), Article 21.

<sup>139</sup> KNCHR, *Compendium on submissions to the Committee on the Rights of Persons with Disabilities* (2016).

<sup>140</sup> OHCHR, 'Persons with albinism: Kenya on the way to becoming regional champion,' (2018), *United Nations Human Rights Office of the High Commissioner*, 7 May 2022.

<sup>141</sup> OHCHR, 'Persons with albinism: Kenya on the way to becoming regional champion'.

<sup>142</sup> OHCHR, 'Persons with albinism: Kenya on the way to becoming regional champion'.

tation of the rights of persons with disabilities.<sup>143</sup> To give effect to this provision Kenya has made key initiatives such as establishing the Kenya National Commission on Human Rights, the National Gender and Equality Commission, the National Council for Persons with Disabilities and the State Department for Social Protection.

#### *5.1.1 Kenya National Commission on Human Rights (KNCHR)*

The KNCHR was established pursuant to Article 59 of the 2010 Constitution as an independent commission and the principal institution of the state in ensuring compliance with human rights treaties and conventions.<sup>144</sup> Its functions include: promoting respect for human rights and developing a culture of human rights in the republic, monitoring, investigating and reporting on the observance of human rights in all spheres of life in Kenya, promoting the protection and observance of human rights in public and private institutions, receiving and investigating complaints about alleged abuses of human rights and taking steps to secure appropriate redress where human rights have been violated. Additionally, the KNCHR may institute investigations into allegations of violations of human rights on its own initiative or upon a complaint. Under this function, any person including a person with albinism has a right to complain to the Commission alleging that their right(s) or fundamental freedom(s) in the Bill of Rights has been denied, violated, infringed or is threatened.<sup>145</sup>

Against this backdrop, the Commission has made steps in discharging its functions of monitoring, investigating and reporting on the violation of rights of persons with albinism in Kenya. This is evidenced in Part III of this article which has cited some of the Commission's documented reports on various violations of the rights to dignity, employment and education of persons with albinism.<sup>146</sup> Further, in the dis-

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<sup>143</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, Article 34(2).

<sup>144</sup> Constitution of Kenya (2010), Article 59.

<sup>145</sup> Constitution of Kenya (2010), Article 59(3).

<sup>146</sup> AFEA, ASK, KNCHR, USS, 'The human rights of persons with albinism in Kenya.

charge of its function to promote respect for the rights of persons with albinism, the Commission prides itself in facilitating the inclusion of persons with albinism in the 2019 Kenya Population and Housing Census, which according to the Commission sets the stage for planning and intervention to advance the rights of persons with albinism.<sup>147</sup> Additionally, the Commission observes that it is collaborating with persons with albinism, their representative organisations, and other stakeholders towards the development of a Kenya Plan of Action to end attacks and other human rights violations targeting persons with albinism.<sup>148</sup> This plan falls in line with the recommendations of Ikponwosa Ero's and the African Commission on Human and Peoples' Rights of creating a brief but comprehensive national action plan to end violence and violations against persons with albinism.<sup>149</sup>

Going forward, the Commission calls upon the state, at both levels of government to increase public awareness on albinism and the human rights violations faced by persons with albinism.<sup>150</sup>

### *5.1.2 National Gender and Equality Commission (NGEC)*

The National Gender and Equality Commission Act establishes NGEC as a successor to the Kenya National Human Rights and Equality Commission in the discharge of functions assigned to it pursuant to the 2010 Constitution.<sup>151</sup> Its functions include: to promote gender equality and freedom from discrimination in accordance with Article 27 of the 2010 Constitution, to monitor, facilitate and advise on the integration of the principles of equality and freedom from discrimination in

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<sup>147</sup> KNCHR, 'Press Statement: Commemoration of International Albinism Awareness Day,' 13 June 2021.

<sup>148</sup> KNCHR, 'Press Statement: Commemoration of International Albinism Awareness Day'.

<sup>149</sup> UN News, 'Kenya makes progress in supporting people with albinism, but 'much remains to be done' says UN expert'.

<sup>150</sup> KNCHR, 'Press Statement: Commemoration of International Albinism Awareness Day'.

<sup>151</sup> National Gender and Equality Commission Act (2011), Section 3. See Constitution of Kenya (2010), Article 59(5).

...all national and county policies, laws, and administrative regulations in all public and private institutions, to act as the principal organ of the state in ensuring compliance with all treaties and conventions ratified by Kenya relating to issues of equality and freedom from discrimination and relating to special interest groups....

This certainly includes persons with albinism.

Additionally, NGEC has a mandate of coordinating and facilitating the mainstreaming of issues of persons with albinism and advising the government on all aspects concerning this. The Commission also has the mandate of investigating on its own initiative or on the basis of complaints, any matter in respect of any violations of the principle of equality and freedom from discrimination, coordinating and advising on public education programmes for the creation of a culture of respect for the principles of equality and freedom from discrimination, and preparation and submission of annual reports to Parliament.<sup>152</sup>

However, NGEC does not have adequate resources to do comprehensive audits and enforce the provisions of the law.<sup>153</sup> So far, there is little data reported on the progress made by the NGEC in facilitating protection and enjoyment of the rights of persons with albinism as it has majorly focused on addressing gender equality and non-discrimination.<sup>154</sup>

### 5.1.3 National Council for Persons with Disabilities (NCPWD)

Section 3 of the Persons with Disabilities Act establishes this body and its functions include:<sup>155</sup> registering persons with disabilities, providing to the maximum extent possible assistive devices, appliances and other equipment to persons with disabilities, making provisions for assistance to students with disabilities in the form of scholarships, loan programmes, fee subsidies and other similar forms of assistance in both public and private institutions. The Council also formulates and develops measures and policies designed to achieve equal opportunities for persons with disabilities by ensuring that they obtain education

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<sup>152</sup> National Gender and Equality Commission Act (2011), Section 8.

<sup>153</sup> Rohwerder, *Kenya situational analysis, June 2020 update*.

<sup>154</sup> National Gender and Equality Commission, *2017-2018 annual report*.

<sup>155</sup> Persons with Disabilities Act (2011), Section 3, 7.

and employment opportunities to the maximum extent possible. Furthermore, the Council formulates and develops measures and policies designed to co-ordinate services provided in Kenya for the welfare and rehabilitation of persons with disabilities and implements programmes for vocational guidance and counselling. In addition to these functions, the Council formulates and develop measures and policies designed to recommend measures to prevent discrimination against persons with disabilities, and formulate and develops measures and policies designed to put into operation schemes and projects for self-employment or regular or sheltered employment for the generation of income by persons with disabilities.<sup>156</sup>

In the discharge of its statutory functions, the Council has been implementing the National Persons with Albinism Sunscreen Support Programme that is currently providing sunscreen lotion to over 4000 persons with albinism.<sup>157</sup> This programme is designed to carry out awareness and offer lip care and after sun lotion and other services for all persons with albinism in the country which cushions them from the effects of harmful sunrays that cause skin cancer.<sup>158</sup>

In May 2022, the Kenya Medical Supplies Authority (KEMSA) and the National Council for Persons with Disabilities flagged-off a consignment of sunscreen agents worth KSh 54 million destined for more than 192 public health facilities, to address these needs of persons with albinism in 45 counties.<sup>159</sup> Speaking at the flag-off event, KEMSA Acting Chief Executive Officer (CEO), John Kabuchi said that KEMSA and the NCPWD have been ensuring that these sunscreen agents are delivered promptly to all health facilities, to ensure the comfort of persons with albinism.<sup>160</sup>

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<sup>156</sup> Persons with Disabilities Act (2011), Section 3, 7.

<sup>157</sup> National Council for Persons with Disabilities, 'Albinism support program' *National Council for Persons with Disability*, 29 April 2022.

<sup>158</sup> National Council for Persons with Disabilities, 'Albinism support program'; Kenya Disability Resource, 'Kenya Government disability services,' *Kenya Disability Resource*, 1 May 2022.

<sup>159</sup> Hamdi Mohamud, 'KEMSA flags-off sunscreen agents for persons living with albinism,' *Kenya News*, Friday 13 May 2022.

<sup>160</sup> Mohamud, 'KEMSA flags-off sunscreen agents for persons living with albinism'.

One of the recommendations of the experts on the prevention of skin cancer is the provision of protective clothing and avoidance of prolonged exposure to the sun.<sup>161</sup> Besides providing skin care products to persons with albinism, the Council also provides them with protective clothing with the aim of preventing skin cancer.<sup>162</sup> The Council has also set aside funds to provide comprehensive eye care for all persons with albinism.<sup>163</sup> On this, the Council identified a service provider who will support it in providing comprehensive eye care for persons with albinism in the entire country.<sup>164</sup> The Council also pays for full eye check-up including the cost for eye glasses.<sup>165</sup>

Besides procuring sunscreen, body lotions and other assistive products, the NCPWD prides itself for developing the National Plan of Action on Accessibility for Persons with Disabilities, taking steps to review the Persons with Disabilities Act<sup>166</sup> and all other legislations affecting the rights of persons with disabilities, and the development of the Affirmative Action Policy for Persons with Disabilities.<sup>167</sup> Additionally, the Council has set aside a legal service department that provides professional legal services to persons with disabilities, relevant government ministries and departments, stakeholders and the general public with the aim of assisting the Council deliver on its statutory mandate.<sup>168</sup> This department serves persons with disabilities and the public on a walk-in-walk-out basis with the aim of protecting and promoting the interests of persons with disabilities.<sup>169</sup>

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<sup>161</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>162</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>163</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>164</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>165</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>166</sup> Persons with Disabilities Amendment Bill 2020.

<sup>167</sup> National Council for Persons with Disabilities, 'Achievements of the Council' *National Council for Persons with Disability*, 4 June 2022.

<sup>168</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>169</sup> Kenya Disability Resource, 'Kenya Government disability services'.

#### 5.1.4 State Department for Social Protection

Executive Order No 1 (14) of 2018 issued by the president created the State Department for Social Protection to coordinate the formulation of policies and legislation on disability and oversee the implementation of various disability development programmes and rehabilitative services among other social development programmes.<sup>170</sup> In the discharge of its mandate, the department developed a Disability Awareness Booklet with the aim of demystifying disability to reduce stigma and discrimination, and enhance social inclusion of persons with disabilities.<sup>171</sup> Additionally, this booklet aims to raise public awareness on the needs, aspirations and capacities of persons with disabilities in order to enhance their acceptance, participation and inclusion in society.<sup>172</sup>

Although this looks like step in the right direction, the mere publishing of laws does not guarantee legal awareness.<sup>173</sup> Arnold Nciko, notes that in fact many scholars posit that the rule of law could easily be brought to naught if the mere publication of laws is not taken a step further.<sup>174</sup>

## 5.2 Other measures taken by the state of Kenya

### 5.2.1 The National Development Fund for Persons with Disabilities

The National Development Fund for Persons with Disabilities (NDFPWD) supports the provision of assistive devices and services to persons with disabilities in Kenya to enable these individuals to function in society.<sup>175</sup> The Fund gives priority to those individuals requiring assistance to function in a learning, training or work environment.<sup>176</sup>

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<sup>170</sup> The Presidency, 'Executive Order No 1 of 2018: Organisation of the Government of the Republic of Kenya', June 2018, Government Printer.

<sup>171</sup> Ministry of Labour and Social Protection, *Disability awareness creation booklet*, 50.

<sup>172</sup> Ministry of Labour and Social Protection, *Disability awareness creation booklet*, 50.

<sup>173</sup> Arnold Nciko, 'Ignorance of the law is no defence: Street law as a means to reconcile this maxim with the rule of law,' 3(1) *Strathmore Law Review* (2018), 36.

<sup>174</sup> Nciko, 'Ignorance of the law is no defence', 36.

<sup>175</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>176</sup> Kenya Disability Resource, 'Kenya Government disability services'.



Expensive items, such as cars and business equipment like sewing machines or laptops are not included.<sup>177</sup> In cases of expensive assistive devices, the individual is directed to ask their work place or education institution to contact the Fund Programme Office directly and make an application for equipment that can then be shared and accessed by multiple students or staff members with disabilities.<sup>178</sup> For assistive services, the funding given is used to train individuals working in an institution like a school or hospital in sign language.<sup>179</sup> The Fund also provides grants to community and self-help groups made up of persons with disabilities for economic empowerment and fund schemes.<sup>180</sup> These grants aim to help persons with disabilities gain self-sufficiency in generating income and enables them to access the loans required to grow their business.<sup>181</sup>

Besides providing support for assistive devices and economic empowerment, the Fund also provides financial support to persons with disabilities from primary school, secondary school, college, vocational training school and university.<sup>182</sup> These education grants aim to empower persons with disabilities by enhancing opportunities for them in education, training and rehabilitation institutions.<sup>183</sup> The Fund covers up to 75% of course fees but in exceptional circumstances, it may cover 100% of fees, if the applicant can provide additional evidence of extreme poverty.<sup>184</sup> The NDFPWD sends funding to the educational institution directly, not to the beneficiary. The funds may cover all levels of education except the doctorate level.<sup>185</sup>

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<sup>177</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>178</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>179</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>180</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>181</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>182</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>183</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>184</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>185</sup> Kenya Disability Resource, 'Kenya Government disability services'.

### 5.2.2 Job placement

Besides the National Development Fund for Persons with Disabilities, the government has also established a Job Placement Portal where persons with disabilities can access job vacancies some of which are from partners of the National Council for Persons with Disabilities.<sup>186</sup>

In addition to providing job opportunities, the career portal also contains special courses for persons with disabilities aimed at helping them improve and enrich their skills.<sup>187</sup> So far, over 1000 persons with disabilities have registered in the portal while over 15 corporate organisations have signed up to help provide employment opportunities for persons with disabilities.<sup>188</sup> Going forward, the NCPWD estimates that the portal would benefit over 3,000 persons of a working-age with disabilities.<sup>189</sup>

### 5.3 Steps taken by county governments

Counties are also at the forefront of promoting and protecting the rights of persons with disabilities. The Kisumu County Government, for instance, has enacted the Kisumu County Persons with Disability Act.<sup>190</sup> Besides the Act, the County Government has taken further steps such as creating a Youth, Women and Persons with Disability Fund, and ensuring the inclusion of persons with disabilities in trade funds.<sup>191</sup> Furthermore, there is a special delivery unit in the County that oversees the implementation of the CRPD and the Kisumu County Persons with Disability Act.<sup>192</sup> To this end, *Business Today* newspaper reports that Kisumu County government is a front-runner in the localisation of the

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<sup>186</sup> Kenya Disability Resource, 'Kenya Government disability services'.

<sup>187</sup> National Council for Persons with Disabilities, 'NCPWD career portal', 3 June 2022.

<sup>188</sup> National Council for Persons with Disabilities, 'NCPWD career portal'.

<sup>189</sup> National Council for Persons with Disabilities, 'NCPWD career portal'.

<sup>190</sup> Business Today editorial team, 'Kisumu County feted for enacting law on disability' *Business Today*, 6 November 2018.

<sup>191</sup> 'Kisumu County feted for enacting law on disability'.

<sup>192</sup> 'Kisumu County feted for enacting law on disability'.

CRPD among county governments in Kenya.<sup>193</sup> Other counties such as Kilifi, Kiambu and Bungoma have formulated legislation that protects and promotes the rights of persons with disabilities in their counties.<sup>194</sup> In common, these authorities have established a Youth, Women and Persons with Disabilities Enterprise Development Fund, to promote the establishment and development of micro and small businesses and industries by the youth, women and persons with disabilities in the respective counties.<sup>195</sup> These Funds have been instrumental in assisting persons with disabilities to realise their fundamental rights and freedoms.<sup>196</sup>

## 6. The way forward

Pursuant to the National Gender and Equality Commission Act, one of the core mandates of the Commission is to co-ordinate and advice on public education programmes for the creation of a culture of respect for the principles of equality and freedom from discrimination.<sup>197</sup> The National Council for Persons with Disabilities also has a mandate of spreading awareness on the rights of persons with disabilities to the public.<sup>198</sup> A 2016 report by NGENC explains that according to local chiefs, there is need for public sensitisation to break cultural taboos and help people understand better the needs of children with disabilities.<sup>199</sup> In the report, head teachers called for regular refresher courses for all teachers on how to handle children with disabilities.<sup>200</sup>

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<sup>193</sup> 'Kisumu County feted for enacting law on disability'.

<sup>194</sup> Bungoma County Youth, Women and Persons with Disabilities Enterprise Development Fund Bill, 2014; Kiambu County Youth, Women and Persons with Disabilities Enterprise Development Fund Act, 2014; Kilifi County Persons with Disabilities Bill, 2021.

<sup>195</sup> Rohwerder, *Kenya situational analysis, June 2020 update*.

<sup>196</sup> Rohwerder, *Kenya situational analysis, June 2020 update*.

<sup>197</sup> National Gender and Equality Commission Act (2011), Section 8(h).

<sup>198</sup> Persons with Disabilities Act (No 14 of 2013), Section 7(1)(i).

<sup>199</sup> National Gender and Equality Commission, *Access to basic education by children with disability in Kenya*, 2016.

<sup>200</sup> National Gender and Equality Commission, *Access to basic education by children with disability in Kenya*.

Findings in a nationwide survey by the Kenya Institute of Special Education also point out to the fact that there has been inadequate advocacy, sensitisation and mobilisation on the needs of children with disabilities in education at the grassroots, and that parents are not actively involved in the education of their children with disabilities.<sup>201</sup> The Social Protection Department of the Kenyan Government further reports that creating awareness reduces stigma and discrimination which enhances social inclusion,<sup>202</sup> and perhaps the mainstreaming of disability issues. The Department adds that raising awareness on the needs, aspirations and capacities of persons with disabilities enhances their acceptance, participation and inclusion in society.<sup>203</sup>

As such, to fully support the wellbeing of persons with disabilities, there needs to be public re-education on disability.<sup>204</sup> All Kenyans need to be taught about disability, and the old mantra that ‘disability is not inability’ needs to be taught to all.<sup>205</sup> Such foundation needs to be laid from the home to nursery schools, primary schools, secondary schools and all the way to colleges, workplaces and public places.<sup>206</sup> However, such re-education needs to be informative and practical.<sup>207</sup>

A programme tailored to influence community groups in Kilifi County, found that as a result of the intervention their beliefs about disability changed, this led to increased support and inclusion of persons with disabilities and their families.<sup>208</sup> Additionally, awareness should be cross cutting when it comes to persons with disabilities. This is so because, a survey by the Kenya Institute of Special Education found that

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<sup>201</sup> Kenya Institute of Special Education, *National survey on children with disabilities and special needs in education*, 2018.

<sup>202</sup> Ministry of Labour and Social Protection, *Disability awareness creation booklet*, 2021, 50.

<sup>203</sup> Ministry of Labour and Social Protection, *Disability awareness creation booklet*, 2021, 50.

<sup>204</sup> Tom Odhiambo, ‘We have ignored the plight of persons with disabilities,’ *Nation*, 2 April 2022.

<sup>205</sup> Odhiambo, ‘We have ignored the plight of persons with disabilities.’

<sup>206</sup> Odhiambo, ‘We have ignored the plight of persons with disabilities.’

<sup>207</sup> Odhiambo, ‘We have ignored the plight of persons with disabilities.’

<sup>208</sup> Rohwerder, *Kenya situational analysis, June 2020 update*, citing CR Bauer, L Mbonani & J Charles, ‘Changing cultural perception on disability through empowerment of families and local leaders’, 2019.

barriers to access to education included lack of information on education opportunities for children with disabilities.<sup>209</sup>

## 7. Conclusion

From the foregoing, it is evident that persons with albinism suffer significantly when discriminated based on their disability. As seen, such discrimination mostly emanates from stereotypes and myths, and stretches to other aspects of the lives of persons with albinism, thereby threatening their enjoyment of other rights and fundamental freedoms. Although the government has taken numerous steps and measures to protect the rights of persons with albinism through the establishment of relevant institutions, provision of sunscreen, protective clothing and reasonable accommodation; much still remains to be done when it comes to debunking myths and misconceptions which have had a profound negative effect on the lives of persons with albinism.

However commendable the efforts by the government are, they have proven insufficient in addressing existing myths and stereotypes since they are calculated towards the provision of material support to persons with albinism and other persons with disabilities, thereby neglecting and scarcely addressing the violations that result from myths and stereotypes. This calls for sufficient, effective and efficacious public education and creation of awareness among the Kenyan people about the rights and fundamental freedoms of persons with albinism.

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<sup>209</sup> Kenya Institute of Special Education, *National survey on children with disabilities and special needs in education*.