

THE IDENTITY QUESTION VERSUS  
APPROPRIATENESS OF LEGAL ANTI-  
DISCRIMINATION MEASURES:  
ENDORISING THE DISABILITY RIGHTS  
APPROACH TO ALBINISM

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### Summary

*The marginalisation of persons with albinism has for years gone unnoticed. Recently various platforms have been used to combat reported harmful practices against persons with albinism, particularly in Africa. While it is currently accepted that albinism is a human rights agenda, the manner of its advocacy remains unresolved with respect to the 'appropriate legal approach' for protecting the rights of persons with albinism. When addressing this problem, two issues appear to be confused: identity (the 'who are we' question); and the appropriate legal anti-discrimination approach. Thus, the two issues are distinguished in this contribution by endorsing the 'appropriate legal anti-discrimination approach' in realising the rights of persons with albinism. It is worth noting that questions of identity are subjective and should not be confused with objective and empirical questions regarding the appropriate legal mechanisms designed to promote and protect the rights of a particular group. Without downplaying the significance of identity in the formation of the rights groups movement, which has proved vital to the development of human rights, this contribution argues that, while persons with albinism might have multiple identities, the 'disability rights approach', which is founded on the social model of disability that uses human rights as a path, is well placed to accommodate matters concerning the rights and equality of persons with albinism.*

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# 1 Introduction

Recent human rights discourse has been dominated by debates seeking to adopt preferable solutions for realising the rights of persons with albinism. Indeed, albinism is now widely acknowledged to be a human rights concern. However, the latest approaches deployed to address this concern conflict with one another and, at times, overlap. The question of identity has emerged, as has uncertainty over the best approach to adopt in attempting to realise the rights of persons with albinism.

Before unpacking the main issues in this area of concern, a general understanding of albinism is important. It is a rare, non-contagious, genetically-inherited condition present at birth. It is found in both genders, regardless of ethnicity, and in all countries of the world. The condition results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, most persons with albinism have varying levels of visual impairments (some may be legally blind) and are prone to developing skin cancer.<sup>1</sup> The medical approach to albinism is insufficient as it treats the condition as an illness or defect<sup>2</sup> – a ‘disease involving lack of pigmentation’.<sup>3</sup>

The prevalence of albinism varies across the world.<sup>4</sup> It is estimated that one in every 20 000 persons in North America and Europe has some form of albinism, while the reported frequency in sub-Saharan Africa ranges from one in 5 000 to one in 15 000, with prevalence rates of one in 1 000 to one in 1 500 for selected populations.<sup>5</sup> However, studies on the frequency of albinism often lack objectivity in their methodology or are incomplete, rendering the estimates guesses at best. According to World Health Organisation (WHO) estimates, there are tens of thousands of people living with albinism in Africa.<sup>6</sup>

Negative social perceptions are a major obstacle to the enjoyment of the right to equality and other human rights of persons with albinism.<sup>7</sup> The literature reveals a long history of widespread acts of stigma against

1 HRC *Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights* (2013) paras10 & 11.

2 J DiGennaro ‘Sex-specific characteristics as defences to criminal behaviour’ (1983) 6 *Criminal Justice Journal* 196; SAD Kanga ‘A call for a Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa’ (2013) 21 *African Journal of International and Comparative Law* 222; J Gillette ‘Pregnant and prejudiced: The constitutionality of sex and race-selective abortion restrictions’ (2013) 88 *Washington Law Review* 654.

3 S Scott ‘A new category of “colour”: Analysing albinism under Title VII and the Americans with Disabilities Act’ (1999) *The Journal of Gender, Race and Justice* 469.

4 HRC (n 1 above) para 14.

5 HRC *Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism* (2016) para 15.

6 HRC (n 1 above).

7 M Mswela ‘The “evil albino” stereotype: An impediment to the right to equality’ (2013) 32 *Medicine and Media* 89-92.

persons with albinism in different places throughout the world,<sup>8</sup> where they are viewed as inferior, bizarre and sinister,<sup>9</sup> and often subjected to ridicule.<sup>10</sup> There were even times when African Americans with albinism or those with vitiligo were exhibited in taverns, dime museums and circus sideshows.<sup>11</sup> The portrayal of albinism in some films and fiction has been viewed by activists to be mostly negative, and this supports and stimulates societal intolerance and discrimination against the group.<sup>12</sup> In some places, because of a lack of understanding about albinism, it is taken for granted that persons with albinism have perfect vision and, therefore, should not require assistance.<sup>13</sup>

The visibility of persons with albinism differs according to geographical location. In Western societies, where the populations are predominantly pale-skinned, persons with albinism often pass unnoticed, while in sub-Saharan Africa the condition is usually visible.<sup>14</sup>

In addition to the practical problems associated with albinism generally in Africa, an enduring challenge encountered by persons with albinism is the stigmatisation and ostracism they face.<sup>15</sup> Such treatment is often associated with a web of myths pertaining to the condition, which myths usually have negative connotations.<sup>16</sup> At the centre of all challenges confronting persons with albinism, women and children with albinism have always been most vulnerable in this regard. Children with albinism are at risk of abandonment, discrimination and exclusion<sup>17</sup> because of the existence of harmful traditional practices of infanticide against them, as is

8 S Bucaro 'A black market for magical bones: The current plight of East African albinos' (2010) 15 *Public Interest Law Reporter* 2.

9 Scott (n 3 above) 521.

10 MK Possi 'Stigma and people with disability: A review of stigma attached to people with albinism' (1998) 13 *International Journal of Special Education* 82; MK Possi 'Gender and education of people with disabilities in Tanzania' (1996) 3 *Utafiti (New Series)* 83; .

11 CD Martin *The white African-American body: A cultural and literary exploration* (2002) 1.

12 Mswela (n 7 above) 81.

13 N Wan 'Orange in a world of apples: The voices of albinism' (2003) 18 *Disability and Society* 287.

14 C Baker et al 'The myths surrounding people with albinism in South Africa and Zimbabwe' (2010) 22 *Journal of African Cultural Studies* 169.

15 Bucaro (n 8 above) 2.

16 See; Possi (n 10 above); HRC (n 1 above) paras 15-18. The common myths associated with albinism include the following: 'A person with albinism is born of a white and an African parent'; 'albinism is a disease'; 'a person with albinism was conceived while a woman was menstruating'; 'albinism is contagious'; 'the lack of pigmentation of a child with albinism can be cured by traditional healers or herbalists'; 'the skin of children with albinism is delicate at birth but can be "toughened" by exposure to the sun'; 'a child with albinism is a ghost or a substitute for a proper child by spirits'; 'persons with albinism are sorcerers, or devils'; 'a person with albinism is a curse'; 'contact with persons with albinism will bring bad luck, sickness or death'; 'persons with albinism are considered to simply vanish (they do not die)'; 'persons with albinism are apes and a source of money'; 'people with albinism have the power of seeing in the dark'; 'pulling out the hair of a person with albinism brings good luck'; and 'sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS'.

17 HRC (n 1 above) para 42.

commonly reported in some African communities.<sup>18</sup> General problems of marginalisation in education and employment also affect persons with albinism.<sup>19</sup> Their lack of education results in high unemployment rates which ultimately give rise to them experiencing the additional problems associated with low income and poverty. As a result, many persons with albinism in Africa cannot afford the cost of what they particularly need, such as proper sun screen lotions,<sup>20</sup> and, therefore, are at greater risk of developing skin cancer. The level of discrimination and the prevalence of myths have gone as far as ‘promoting’ the ritual killing of persons with albinism and the trade in their organs, the trafficking of their persons and the sale of children with albinism, often motivated by the myth that the ‘body parts of persons with albinism possess magical powers capable of bringing riches and power’.<sup>21</sup>

As stated above, while it is not in doubt that albinism currently is a human rights concern, the question of the ‘appropriate legal approach’ for realising the rights of persons with albinism appears not to have been conclusively answered. Thus, this contribution investigates the appropriate human rights approach for safeguarding the rights of persons with albinism and endorses the view that the disability rights approach appropriately accommodates matters concerning the rights and equality of persons with albinism.

This contribution contains six sections. The first is a general introductory section, which is followed by an assessment of the current international and regional approaches to protecting the rights of persons with albinism. The third section reveals some concerns surrounding the grounds of discrimination which have a bearing on advancing the rights of persons with this condition. The disability approach to albinism, which forms the central concern of this work, is analysed in section four. The approach endorsed still faces some challenges, which the article identifies in section five. Lastly, section six contains concluding remarks.

## **2 International and regional approaches to albinism**

The second half of 2013 witnessed several landmark developments in advancing the rights of persons with albinism. International and regional human rights institutions took centre stage in this process. At the United Nations (UN), the Resolution on Attacks and Discrimination against

18 HRC para 43.

19 I Nzagi ‘Securing the rights of people with albinism in Tanzania mainland: The fight against social exclusion’ unpublished MA dissertation, International Institute of Social Studies, The Hague, 2009 34-35.

20 Nzagi (n 19 above) 36.

21 HRC (n 1 above) para 20.

Persons with Albinism<sup>22</sup> was adopted by the Human Rights Council in June 2013. Later, in September 2013, the Office of the UN Human Rights Commissioner issued the Preliminary Report on Persons with Albinism.<sup>23</sup> Fourteen days after the publication of this report, the Human Rights Council adopted a Resolution on Technical Co-operation for the Prevention of Attacks Against Persons with Albinism.<sup>24</sup> Recent achievements at the UN were the proclamation of 13 June as the International Albinism Awareness Day;<sup>25</sup> the issuing of the Human Rights Council's Advisory Committee Report on a Study on the Situation of Human Rights of Persons with Albinism;<sup>26</sup> and the appointment of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism,<sup>27</sup> who issued her first report on 18 January 2016.<sup>28</sup>

Amongst the steps taken by the African Union (AU) through the intervention of African human rights institutions were the adoption of the Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism,<sup>29</sup> and a Declaration on Ending Discrimination and Violence against Girls in Africa.<sup>30</sup> There has also been an investigative mission with respect to the situation of children with albinism.<sup>31</sup>

While the Human Rights Council Resolution on Attacks and Discrimination against Persons with Albinism<sup>32</sup> does not mention disability, the African Commission Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism, which in many respects is similar to the UN Albinism Resolution, directly adopts a disability approach to albinism. Not only does the Albinism Resolution of the African Commission on Human and Peoples' Rights (African Commission) refer to article 18(4) of the African Charter on Human and Peoples' Rights (African Charter), which provides for the rights of persons

22 Resolution on Attacks and Discrimination against Persons with Albinism, Human Rights Council Resolution 23/13 of 2013.

23 HRC (n 1 above); United Nations Convention on the Rights of Persons with Disabilities, General Assembly Resolution A/RES/61/106 of 2006.

24 Resolution on Technical Co-operation for the Prevention of Attacks Against Persons with Albinism, Human Rights Council Resolution 24/33 of 2013.

25 Resolution on International Albinism Awareness Day, Human Rights Council Resolution 69/170 of 2014.

26 HRC *Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism* (2015).

27 Resolution on the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Human Rights Council Resolution 28/6 of 2015.

28 HRC (n 5 above).

29 Resolution on the Prevention of Attacks and Discrimination against Persons with Albinism, African Commission on Human and Peoples' Rights Resolution 263 of 2013.

30 Addis Ababa Declaration on Ending Discrimination and Violence against Girls in Africa, adopted at the 22nd session of the African Committee of Experts on the Rights and Welfare of the Child, 5 November 2013.

31 Report on Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters – Tanzania, African Children's Committee, 2016, <http://www.acerwc.org/investigation/> (accessed 24 June 2016).

32 Resolution 23/13 of 2013 (n 22 above).

with disabilities to special measures of protection in keeping with their physical or moral needs, but article 7 of the Albinism Resolution also invites its Working Group on Older Persons and People with Disabilities to include guarantees of the rights of persons with albinism in the envisaged Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol). However, the Declaration on Ending Discrimination and Violence against Girls in Africa appears to treat albinism and disability as distinct issues, for example, when it requires member states to

take urgent and appropriate measures to support and provide for the needs of girls, particularly those in vulnerable circumstances, such as *girls with disabilities*, girls with *albinism*, girls in disasters ...

This kind of distinction (girls with disabilities and girls with albinism) appears four times in the declaration, which suggests that it was not accidental.

The latest international and regional developments set the stage for the adoption of the right approach to realising the rights of persons with albinism, while also raising relevant questions for consideration with respect to the appropriate approach. In fact, there are similarities between persons with albinism and those belonging to groups internationally accepted as minorities, or other groups that have suffered from marginalisation on whatever grounds. Nevertheless, it is necessary to study the situation and come up with a precise understanding of the phenomenon, since overgeneralisation runs the risk of obfuscating particular aspects of the condition that ought to be considered if real equality is to be realised. This makes it necessary to debate the appropriateness or otherwise of the disability approach to albinism. However, it is necessary first to determine how to categorise albinism as a cause of discrimination, which is done in the next section.

### **3 Albinism and the problem of categorising the basis of discrimination**

While it is clear that persons with albinism experience marginalisation and discrimination, there seem to be some difficulties or contradictions in identifying the category into which they fall on the basis of discrimination. It appears that there are conflicting opinions as to how discrimination against persons with albinism should be dealt with, namely, whether the orthodox civil rights approach, based on colour (independently from the grounds of race and ethnic origin)<sup>33</sup> should be adopted, or the disability

33 Nzagi (n 19 above); Scott (n 3 above) 517.

rights approach.<sup>34</sup> A closer examination of the arguments for these approaches follows.

The Preliminary Report of the Office of the UN High Commissioner for Human Rights on the Attacks and Discrimination against Persons with Albinism called for further analysis and consultations to determine the category into which persons with albinism may fall and the basis for discrimination against these persons.<sup>35</sup> On the question of whether persons with albinism should be categorised as persons with disabilities, the Report noted:<sup>36</sup>

In some of the written submissions received from associations working with persons with albinism, they are considered persons with disabilities. Others refer to discrimination on the ground of skin colour.<sup>37</sup>

According to the Convention on the Rights of Persons with Disabilities (CRPD), persons with albinism could be considered persons with disabilities. According to information received, the laws of some states recognise albinism and the associated visual impairment as a disability. An additional review of the national legislation on disability needs to be conducted, and consultations with persons with albinism are required on the issue of self-identification.<sup>38</sup>

The report also considered other grounds of discrimination that could be used to protect persons with albinism, such as race, minority status or 'other status', and stated:

The Committee on the Elimination of Racial Discrimination has not yet examined the issue of discrimination on the basis of colour with respect to persons with albinism.<sup>39</sup>

The Independent Expert on minority issues has stated that '[p]eople living with albinism do not fall under the internationally accepted definition of minorities ... However, their stigma, the lifelong social exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour.'<sup>40</sup>

Organisations working with persons with albinism advocate for considering them as a group requiring special attention, as the discrimination and attacks they are exposed to are mainly rooted in erroneous beliefs and myths that must be addressed.<sup>41</sup>

34 M Mswela & M Nöthling-Slabbert 'Colour discrimination against persons with albinism in South Africa' (2013) 6 *South African Journal of Bioethics and Law* 27; Scott (n 3 above) 508.

35 HRC (n 1 above) para 77.

36 HRC para 77.

37 HRC para 77.

38 HRC para 78.

39 HRC para 80.

40 HRC para 81.

41 HRC para 83.

The Human Rights Council's Advisory Committee Report on a Study on the Situation of Human Rights of Persons with Albinism states *inter alia*.<sup>42</sup>

Human rights challenges associated with albinism are multi-layered and are not currently being addressed in a comprehensive and sustainable manner by any human rights mechanism. In addition to the fact that they do not fall within the scope of the current definition of minorities, persons with albinism often suffer from poor eyesight and are prone to developing skin cancer, but cannot or would not want to be classified as persons with disabilities, as that would mean adding another layer of labelling and discrimination to which they may be subjected.

The Independent Expert's first report on albinism connects disability only with the visual impairment effects of albinism.<sup>43</sup> This is also the opinion of some in Europe and North America.<sup>44</sup> There is also the view that the problems with vision associated with albinism may not on their own be sufficient to constitute an impairment which substantially limits a major life activity.<sup>45</sup> Therefore, the 'perceived disability' approach has been proposed, which puts the focus on (another's) perception of the individual as 'disabled' without requiring the individual to view himself or herself as 'disabled'.<sup>46</sup>

In an effort to determine the 'appropriate legal approach' to realising the rights of persons with albinism, conflicting views often emerge in relation to the question of identity as a construction of 'self' and the question of the appropriate legal anti-discrimination approach. This could be complicated by any attempt to 'universalise' albinism, thereby overlooking some issues, such as the evolving concept of disability. Much as issues of albinism cannot be 'universalised', the thesis of this contribution is that questions of identity are subjective and should not be weighed against objective and empirical questions regarding the appropriate legal mechanisms designed to promote and protect the rights of particular groups. This requires a closer look at identity, its formation and rejection, on the one hand, and the nature and purpose of legal terms, on the other.

The understanding of one's 'self' is a step forward in the development of group identity, which has been used as a political tool for marginalised

42 HRC para 59(f).

43 HRC paras 34-36.

44 See Scott (n 3 above) 516 and some of the responses to the HRC Advisory Committee's questionnaire (to States, NHRIs and NGOs) on the situation of human rights of persons with albinism, prepared pursuant to Resolution 24/33 of 2013 (n 24 above).

45 Scott (n 3 above).

46 Scott 517.

groups<sup>47</sup> such as persons with albinism. Every human being is aware of his or her individuality, and this awareness enables us to reflect on who we are, whom we choose to identify with, and what we choose to do as matters of choice, not compulsion.<sup>48</sup> Identity is empowering when self-ascribed, but can be delimiting when identity is ascribed to one by others.<sup>49</sup> Identity is a subjective experience and 'fluid', being subjected to the fluctuations of self and society;<sup>50</sup> and time, space and relationality are all important in identity formation and the achievement of a self-concept.<sup>51</sup>

People may accept or reject identities merely because of a variety of perceptions in their societies. For example, when disability identity is perceived as inferior, some persons with disabilities may try to conceal social markers of impairment to avoid the stigma of disability,<sup>52</sup> and may feel the need to overcompensate for their impairments; that is, the need to succeed at levels higher than their colleagues without disabilities, which may lead to their developing a stressful lifestyle.<sup>53</sup> Others may try to shift the focus of their impairment through denial. This is what has been referred to as 'disability passing'.<sup>54</sup> In other words, the disability label may have offered some persons an opportunity to limit the freedom and independence of others, and a significant number of persons with disabilities may resolve to make everyone think that they do not have a disability,<sup>55</sup> or even develop negative attitudes towards others with disabilities in an effort to pass as 'normal'.<sup>56</sup> In the circumstances, certain persons with albinism may reject a particular identity such as a disability identity. This is not because they do not have an impairment, but because of the effects linked to societal perceptions that 'disability is a bad thing'.<sup>57</sup> Therefore, stigmatisation may have the result that some persons with albinism may internalise the harmful reactions that are generated by ignorance, cultural beliefs and myths, hence prompting a loss of self-esteem, which may possibly make them conclude that they have little to be proud of, either as persons with disabilities, in general, or as persons with albinism, in particular.<sup>58</sup> On the other hand, the shift from medical to social approaches to disability has situated disability as a 'valued concept'

47 CJ Johnstone 'Disability and identity: Personal constructions and formalised supports' (2004) 24 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/880/1055> (accessed 22 September 2017).

48 MW Murugami 'Disability and identity' (2009) 29 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/979/1173> (accessed 22 September 2017).

49 Johnstone (n 47 above).

50 As above.

51 Murugami (n 48 above).

52 JA Brune & DJ Wilson 'Introduction' in JA Brune & DJ Wilson (eds) *Disability and passing: Blurring the lines of identity* (2013) 1.

53 As above; Johnstone (n 47 above).

54 Brune & Wilson (n 52 above).

55 JA Brune 'The multiple layers of disability passing in life' in Brune & Wilson (n 52 above) 38.

56 Johnstone (n 47 above).

57 Consider some African societies where disability is perceived as a curse.

58 Mswela (n 7 above) 89-90.

in identity formation and, in this way, the adoption of a disability identity is seen as the 'reclaiming of the body' from approaches that have diminished the value of persons with disabilities.<sup>59</sup>

When a particular concept is used in a legal sense, its meaning is not always subjected to an individual being's perceptions or desires. Any legal term in a statute serves a particular purpose in that statute. The concept of disability, for example, is capable of being construed in either the context of identity as above, or in the legal sense. Used in a legal context, it has a 'gate-keeping function' since it denotes the class of people entitled to special benefits, or those who qualify for reasonable accommodation and protection against discrimination.<sup>60</sup> To achieve this purpose, disability has to be objectively interpreted, as against disability as a subjective, individual (self)-construction. When it is construed with respect to the perception of self, disability may not necessarily produce the same results as when the term is used in a purely legal sense. It is also a fact that certain conditions may have 'multiple' identities and could well fit in with specific legal concepts defining particular groups. Where the same meaning is produced in both the subjective and objective construction of a particular concept, this should be more of a coincidence than a matter of pure logic.

This rejection of over-emphasising the construction of self in determining the basis of discrimination should not be construed as ignoring the significance of identity in the formation of a rights group movement and, for the purposes of this contribution, the 'albinism movement'. It is not in doubt that the recognition of one group in society by others comes about only with self-awareness within that group of its differences and strengths.<sup>61</sup> The main point here is that identity issues and prohibited grounds of discrimination are not necessarily the same thing.

The perceived difficulty of defining the type of discrimination that occurs against persons with albinism, or the conflation of the question of identity as a construction of 'self' with the question of an appropriate approach to legal anti-discrimination measures, may well have arisen as a result of overlooking the potential of the disability approach to albinism, which is explored in the following section.

## **4 Disability approach to albinism**

When contemplating the disability approach to albinism, one cannot ignore the complex relationship and, at times, the overlap, between the disability identity and the legal, human rights concept of disability.

59 Johnstone (n 47 above).

60 SR Bagenstos 'Comparative disability employment law from an American perspective' (2003) 24 *Comparative Labour Law and Policy Journal* 656.

61 <http://dsq-sds.org/article/view/343/433> (accessed 22 September 2017).

Furthermore, as there cannot be a universal legal definition of disability, it is inappropriate to narrow the definition and exclude any possibility of having some flexibility in interpreting the term. We expound the disability approach to albinism first by stating the extent to which disability as a matter of identity differs from disability in the legal context, and proceed to emphasise the broad concept of disability, considering the possibility of catering for albinism in domestic disability legislation. The disability approach to albinism is preferred, as this approach is better able to address the concerns of persons with albinism in Africa.

#### 4.1 Coincidence of construction of self and a legal concept

As already stated, disability may be perceived as a matter of self-construct or as a legal construct, and an understanding of the difference between the two is vital to the general understanding of albinism as a disability, not only because of the concomitant visual impairment, but also because of the lack of pigmentation. However, there is a thin margin separating developments in disability identity and the current human rights approach to disability to be found in legal texts.

Disability as a matter of identity pervades the history of disability activism and scholarship.<sup>62</sup> Persons with disabilities have the capability of constructing a self-identity not constituted in impairment but rather independent of it, and of accepting impairment as a reality that they live with without losing a sense of self.<sup>63</sup> The people in this group share a common history and experience of ‘oppression’ and a common bond of resilience,<sup>64</sup> the commonalities of which have produced a common way of expressing their shared experiences of negotiating disability in a world oriented largely for (and by) able-bodied people.<sup>65</sup> Disability identity, thus, is a political tool; and the legitimising language of the ‘politicised’ disability identity serves as a communicative tool that asserts that a marginalised disability group has equal rights in the larger society.<sup>66</sup>

Disability identity has significantly influenced the approach of the CRPD<sup>67</sup> and disability legislation that rejects the medical approach to disability. The past legal definitions of disability were influenced by the medical or welfare approach to disability, in which the term ‘disability’ was used interchangeably with the term ‘impairment’ – a biological

62 C Kelly ‘Wrestling with group identity: Disability activism and direct funding’ (2010) 30 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/1279/1307> (accessed 22 September 2017).

63 Murugami (n 48 above).

64 SE Brown ‘What is disability culture?’ <http://www.independentliving.org> (accessed 27 September 2017).

65 Johnstone (n 47 above).

66 As above.

67 General Assembly Resolution A/RES/61/106 of 2006 (n 23 above).

condition – or some functional characteristics, without reference to externalities such as stigma or the inaccessibility of the environment.

## 4.2 No universal definition of disability

The CRPD does not expressly define ‘disability’, but recognises it as ‘an evolving concept’, and states that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’.<sup>68</sup> The reason for withdrawing the definition of disability was the disagreement in the *Ad Hoc* Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities with regard to whether or not the CRPD should include a definition of disability.<sup>69</sup> While, on the one hand, there was a concern that not including a specific definition of disability in the CRPD could lead to excluding persons with certain impairments,<sup>70</sup> on the other, an argument was raised that any disability would inevitably derive from the medical model, which would also lead to the involvement of some people and the exclusion of others.<sup>71</sup> The view which seems to accord with the current approach is that the definition may change to make room for the inclusion of people who may not now be considered persons with disabilities<sup>72</sup> and, furthermore, that any definition would also risk ignoring variations amongst societies – by ‘imposing a Western view of disability on non-Western cultural systems’,<sup>73</sup> or by compelling states to accept the existence in their societies of a large number of impairment groups not traditionally understood as persons with disabilities.<sup>74</sup> By not specifically defining disability, the CRPD enabled states and regions to contextualise disability issues within their realities.<sup>75</sup>

Since the CRPD recognises attitudinal and environmental barriers as hindering the full and effective participation in society of persons with disabilities, it is evident that such barriers cannot be the same throughout the world, a fact which should make it understandable that some people

68 Preamble CRPD.

69 AS Kanter ‘The promise and challenge of the United Nations Convention on the Rights of Persons with Disabilities’ (2007) 34 *Syracuse Journal of International Law and Commerce* 291; R Kayess & P French ‘Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8 *Human Rights Law Review* 23.

70 Kanter (n 69 above) 292.

71 As above.

72 As above; AC Hendriks ‘Different definition – same problems – one way out?’ in ML Breslin & S Yee (eds) *Disability rights law and policy: International and national perspectives* (2002) 195.

73 Kanter (n 69 above) 292.

74 Kayess & French (n 69 above) 23.

75 EO Adebitan & YJ Job ‘Addressing the hotels facility and service needs of persons living with disabilities within Bauchi metropolis of Bauchi state, Nigeria’ (2014) *Proceedings of the Multi-disciplinary Academic Conference on Sustainable Development Vol 2 No 1*.

with certain forms of impairment may not be perceived as persons with disabilities in certain areas. Persons with albinism belong to one such category. A cross-cultural work in anthropology and disability studies has also highlighted the fact that the Western definition of disability does not necessarily clearly correspond to the way in which people define disability in other parts of the world.<sup>76</sup> This could explain not only the differences in the general perceptions across continents, but also the differences in the policy and legislative approaches regarding whether certain conditions, such as a lack of skin pigmentation, are sufficient to constitute an impairment necessary for the definition of disability in a particular jurisdiction.

In 2014, when responding to a questionnaire distributed by the Human Rights Council Advisory Committee, and particularly regarding the question of whether albinism is regarded as a disability, there were some notable differences in approaches or perceptions across countries, which could be attributed to a variety of factors in different countries. Responses from the human rights commissions of Malawi, Rwanda and South Africa<sup>77</sup> made it clear that persons with albinism are considered persons with disabilities in those countries. In countries such as Denmark, Spain, France and Germany, albinism was 'qualified' as a disability only with respect to visual impairment.<sup>78</sup> A similar view was expressed in China and Australia,<sup>79</sup> although there was also the view that there could be various categories for persons with albinism relating to non-discrimination laws on the basis of sensory impairment and physical appearance.<sup>80</sup>

The responses to the questionnaire reinforce the view that perceptions of difference or the visibility of 'disability' attached to the skin are more frequent in places where albinism appears more visible, as in sub-Saharan Africa. In Nigeria, for instance, according to one non-governmental organisation (NGO), persons with albinism are considered 'the

76 G Brocco 'Labelling albinism: Language and discourse surrounding people with albinism in Tanzania' (2015) *Disability and Society* 1146.

77 Responses to the questionnaire (n 44 above) by the National Human Rights Organisations for Malawi, Rwanda and South Africa <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

78 Responses to the questionnaire (n 44 above) by the Danish Institute for Human Rights, Asociación española de Ayuda a Personas con Albinismo (Spain), Genespoir (France), and NOAH - Albinismus Selbsthilfegruppe Germany <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

79 Chinese Organisation for Albinism, Albinism Fellowship of Australia.

80 Responses to the questionnaire (n 44 above) by the Albinism Fellowship of Australia, <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

unfortunate lot who are ill-coloured'.<sup>81</sup> An NGO in Germany presented a different picture.<sup>82</sup>

Due to the fact that Germans are Caucasians, PWA often are not recognised [as persons with disabilities] by fellow citizens. This is due to two facts: lack of knowledge on albinism in the general population and the fact that their complexion (which may vary from white to strawberry-blond to light brown) does not differ too much from that of the other citizens.

There is growing recognition and acceptance in Africa that persons with albinism are persons with disabilities.<sup>83</sup> In a disabling society, so described because of the non-inclusion of persons with albinism, defining a certain person as a person with a disability constitutes a way for persons with albinism to explain to other individuals why they cannot do certain things which people without disabilities can do.<sup>84</sup> Their rights are violated on the basis of their disability status.<sup>85</sup> In addition to the negative social perceptions, the inaccessibility of basic requirements for persons with albinism, such as sunscreen lotions, proper skincare, large print information or magnifying glasses, has seriously contributed to the marginalisation of persons with albinism in sub-Saharan African countries. A tropical climate and the predominance of an agricultural economy means that the choices of employment opportunities of persons with albinism are limited, considering the susceptibility to skin cancer which may result from long-time exposure to sunlight. Under the circumstances, sunscreen and visual aids should be treated in the same way as wheelchairs and crutches for people with physical disabilities.<sup>86</sup>

### 4.3 Albinism in domestic disability legislation

Generally, a human rights approach in disability legislation would mean that persons with albinism, especially in the African community, qualify for the protection and benefit of disability legislation. It would be difficult to sufficiently accommodate the issues of interest to persons with albinism in disability legislation where the definition of disability, for example, is focused on substantial limitations in obtaining employment or obtaining

81 As above.

82 Responses to the questionnaire (n 44 above) by the Albinismus Selbsthilfegruppe Germany, <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx> (accessed 24 June 2016).

83 J Burke et al 'Media analysis of albino killings in Tanzania: A social work and human rights perspective' (2014) 8 *Ethics and Social Welfare* 119.

84 Brocco (n 76 above) 1153.

85 Kamga (n 2 above) 230.

86 SH Braathen & B Ingstad 'Albinism in Malawi: Knowledge and beliefs from an African setting' (2006) 21 *Disability and Society* 610.

work,<sup>87</sup> which would mean that only certain persons with albinism qualified for the benefits of that legislation.

Many countries in Africa have ratified the CRPD. This has resulted in the enactment of new disability laws in some countries, which progress is expected to be emulated by other countries. In Tanzania, for example, the Persons with Disabilities Act<sup>88</sup> defines disability in relation to an individual to mean a loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors. The Act also adopts a definition of a person with a disability like that of the CRPD, recognising a person with a disability to be 'a person with a physical, intellectual, sensory or mental impairment and whose functional capacity is limited by encountering attitudinal, environmental and institutional barriers'.<sup>89</sup> Also, the Zanzibar Persons with Disabilities (Rights and Privileges) Act<sup>90</sup> shifts from the medical approach to disability and, in addition, groups ultraviolet sun glasses and sun creams together with 'assistive devices and appliances'.<sup>91</sup> Namibia, Zambia and Zimbabwe are also amongst the states with a non-medical definition of disability or a person with a disability,<sup>92</sup> reflecting the CRPD's context, according to which a person with albinism should qualify as a person with a disability. Although there could be question as to the legal definition of a person with a disability under South African statutes, a recent study on the 'knowledge of disability rights and the social

87 Sec 2 of Disabled Persons (Employment) Act Cap 184 RE 2002 defines a person with disability (using the term 'disabled person') as 'a person who, on account of injury, disease or congenital deformity, is substantially handicapped in obtaining employment, or in undertaking work on his own account, of a kind which apart from that injury, disease or deformity would be suited to his age, experience and qualification'.

88 Persons with Disabilities Act 9 of 2010.

89 Persons with Disabilities Act (n 88 above) sec 3.

90 Persons with Disabilities (Rights and Privileges) Act 9 of 2006.

91 According to sec 29(1) of the Act, among the functions of the Zanzibar Disability Council is the provision of assistive devices, appliances, UV sunglasses and sun creams and other equipment to persons with disabilities to the maximum extent possible.

92 According to sec 1 of Namibia's National Disability Council Act 26 of 2004, disability is defined to mean 'a physical, mental or sensory impairment that alone, or in combination with social or environmental barriers, affects the ability of the person concerned to take part in educational, vocational, or recreational activities'. In Zambia, disability is legally defined as 'a permanent physical, mental, intellectual or sensory impairment that alone, or in a combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in society on an equal basis with others'. 'A person with disability is a person with a permanent physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder that person to fully and effectively participate in society on an equal basis with others' (Persons with Disabilities Act 6 of 2012 sec 2). In Zimbabwe, the law defines a 'disabled person' as being 'a person with a physical, mental or sensory disability, including a visual, hearing or speech functional disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society' (Disabled Persons Act 5 of 1992 sec 2).

encounters of students with disabilities in tertiary institutions' included persons with albinism as participants.<sup>93</sup> In 2010 there was a move to include 'albinism' in the legal definition of disability in Kenya,<sup>94</sup> although this move should be looked at in the context of the problem of defining disability in Kenya since, should a broader human rights definition of disability be adopted, it is not necessary to specifically list all kinds of impairments for the purpose of establishing that one's condition fits into any of the categories listed in the definition.<sup>95</sup>

#### 4.4 Weighing other non-discrimination approaches

Being marginalised and discriminated against is a common experience of persons with albinism in Africa, which they share with other marginalised groups. It is indeed possible, either because of the construction of the self, or the substantive nature of the anti-discrimination laws of certain jurisdictions, that persons with albinism could fall under different groups. It is for this reason that the discussion on albinism has involved other issues – notably issues of colour, of being in a minority, and of belonging to a particular social group. None of these issues can sufficiently address albinism issues in Africa, in terms of both visual impairment and a lack of skin pigmentation, in the manner the disability approach does.

##### 4.4.1 Colour

There is no definition of 'colour' in human rights instruments. However, it is generally recognised that 'colour' implies skin colour.<sup>96</sup> Twenty-seven African constitutions identify 'colour' and 'race' as distinct prohibited grounds of discrimination,<sup>97</sup> whereas 25 African constitutions do not list

93 AK Tugli et al 'Knowledge of disability rights and the social encounters of students with disabilities in a tertiary institution in South Africa' (2014) 28 *Journal of Social Sciences* 147.

94 Persons with Disabilities (Amendment) Bill 2010.

95 See GO Onyango 'A socio-legal critique of the legal framework for the promotion of rights of persons with disabilities in Kenya' unpublished MA dissertation, International Institute of Social Studies, The Hague, 2012 23.

96 WJ Aceves 'Two stories about skin colour and international human rights advocacy' (2015) 14 *Washington University Global Studies Law Review* 563. .

97 Constitution of the Republic of Angola 2010 art 21(h); Constitution of Botswana 1966 art 15(3); Constitution of Burkina Faso 1991 art 1; Post-Transition Interim Constitution of the Republic of Burundi 2005 art 22; Constitution of the Arab Republic of Egypt 2014 art 21; Constitution of Eritrea 1997 art 14(2); Constitution of the Federal Democratic Republic of Ethiopia 1995 art 25; Constitution of the Republic of The Gambia 1997 art 33(4); Constitution of the Republic of Ghana 1992 art 12(2); Constitution of Kenya, 2010 art 27(4); Constitution of Lesotho 1993 art 18(3); Constitution of the Republic of Malawi 1994 art 20(1); Constitution of the Republic of Mali 1992 art 2; Constitution of Mauritius 1968, arts 3, 16(3) & (5); Constitution of the Republic of Mozambique 2004 art 39; Constitution of the Republic of Namibia 1990 art 10(2); Constitution of the Republic of Rwanda 2003 art 11; Constitution of Sierra Leone 1991 art 27(3); Constitution of the Federal Republic of Somalia 2012 art 11(3); Constitution of the Republic of South Africa, 1996 art 9(3); Transitional Constitution of

'colour' as a prohibited ground of discrimination.<sup>98</sup> Morocco and the Seychelles have adopted the 'classical' juridical equality stipulations by protecting the right of all to equality, but without mentioning any prohibited ground of discrimination.<sup>99</sup> The Tanzanian Constitution identifies 'colour' as a prohibited ground of discrimination, but does not include 'race' or 'ethnic origin' in the list,<sup>100</sup> suggesting that the term 'colour' could also be extended to cover race. However, using race as a proxy for colour poses some concerns of its own, since the two are in fact distinct phenomena,<sup>101</sup> although they sometime overlap.<sup>102</sup> This situation raises the following questions: Did the drafters of those constitutions that mention 'colour' as a prohibited ground of discrimination have persons with albinism in mind? Can the word 'colour', given the current situation, be extended to address albinism? Are persons with albinism in Africa stigmatised merely because of their colour?

Some have championed for 'colour/colourism' to be recognised as a distinct form of discrimination, which should cover persons with albinism, where the equality clause prohibits discrimination on the ground of colour independently from the grounds of race and ethnic origin.<sup>103</sup> As already stated, although the term 'colour' in human rights anti-discrimination

the Republic of South Sudan 2011 art 14; Interim National Constitution of the Republic of the Sudan 2005 art 31; Constitution of the Kingdom of Swaziland Act 2005 art 20(1); Constitution of the Republic of Uganda 1995 art 21(3); Constitution of Zambia Act 1991 art 40; and Constitution of Zimbabwe 2013 art 56(3).

- 98 Constitution of the People's Democratic Republic of Algeria 1989 art 29; Constitution of the Republic of Benin 1990 art 26; Constitution of Cameroon 1996 art premier; Constitution of the Republic of Cape Verde 1992 arts 1(2) & 24; Constitution of Central African Republic 2004 art 5; Constitution of the Republic of Chad 1996 art 14(i); Constitution of Comoros 2001 Preamble; Constitution of the Democratic Republic of the Congo 2006 arts 13 & 45; Constitution of the Republic of Djibouti 1992 art premier, arts 3 & 6; Constitution of the Republic of Equatorial Guinea 1991 art 15; Constitution of Gabon 1991 art 2; Constitution of the Republic of Guinea Bissau 1984 art 24; Constitution of the Republic of Guinea 1990 arts 1 & 8; Constitution of Côte d'Ivoire 2000 arts 17 & 30; Constitution of the Republic of Liberia 1986 art 11(b); Interim Constitutional Declaration 2011 art 6; Constitution of the Republic of Madagascar 1992 art 8; Constitution of the Islamic Republic of Mauritania 1991 art premier; Constitution of the Republic of Niger 1999 art 8; Constitution of the Federal Republic of Nigeria 1999 art 15(2); Constitution of the Republic of Congo 2002 art 8; Constitution of the Democratic Republic of São Tomé and Príncipe 1975 art 16(1); Constitution of the Republic of Senegal 2001 art premier; Constitution of Tunisia 1959 art 6. The Constitution was superseded by the Decree-Law 2011-14 on 23 March 2011, relating to the provisional organisation of the public authorities. The said decree does not contain a clear anti-discrimination provision. There have been negotiations for a new constitution. Constitution of the IVth Republic of Togo 1992 art 2. Morocco and the Seychelles have adopted the 'classical' juridical equality stipulations by protecting the right of all to equality, but without mentioning any prohibited grounds of discrimination. See Constitution of the Kingdom of Morocco 1996 art 5; Constitution of the Republic of Seychelles 1993 art 27(1).
- 99 See Constitution of the Kingdom of Morocco 1996 art 5; Constitution of the Republic of Seychelles 1993 art 27(1).
- 100 Constitution of the United Republic of Tanzania 1977 art 13(5). The same position reappears in the Proposed New Constitution 2014.
- 101 T Jones 'Shades of brown: The law of skin colour' (2000) 49 *Duke Law Journal* 1493; Aceves (n 96 above) 583.
- 102 Jones (n 101 above) 1493.
- 103 Mswela & Nöthling-Slabbert (n 34 above) 27.

discourse refers to skin colour,<sup>104</sup> it cannot be stated with certainty that the drafters had albinism in mind, and perhaps the insertion of colour as a prohibited ground of discrimination was an easy way of navigating through the complications associated with race/colour definitions. In explaining discrimination against persons with albinism, ‘skin colour matters’.<sup>105</sup> However, colour *per se* is not the cause of stigma directed at persons with albinism in Africa. Persons with albinism also face discrimination because of the impairments associated with the condition of albinism, such as photophobia; decreased visual acuity; extreme sun sensitivity; and skin cancer.<sup>106</sup> Therefore, colour alone, as a prohibited ground of discrimination, does not address the actual impairment consequences affecting the skin of persons with albinism. If colour were the main cause of stigma, the stigma directed at persons with albinism in Africa could also have extended to other ‘white’ persons, namely, persons of European origin in Africa.

#### 4.4.2 *Minority*

Persons with albinism do not fall under the internationally-accepted definition of minorities, which is limited to national, ethnic, religious or linguistic minorities.<sup>107</sup> However, social attitudes toward persons with albinism are often similar to those experienced by other disability and minority groups.<sup>108</sup> It is for this reason that persons with albinism may be regarded as belonging to the ‘minority’ group – when the term is used in its generic form.<sup>109</sup> Used in its generic form, the term ‘minority’ then becomes too broad, and capable of including almost all marginalised groups. For example, viewed as a social construct, disability is a culturally-constructed minority identity,<sup>110</sup> and persons with disabilities have been defined as the ‘largest minority’ in the world.<sup>111</sup>

While the minority approach to albinism may be similar to the ‘disability rights approach’, in the sense that both approaches reject the medical conception of albinism/disability, the minority approach risks ignoring the specific ‘disability-related rights’ with respect to persons with albinism. At this point it is perhaps important to take note of the argument that achieving equality for persons with disabilities is a more complex and

104 Aceves (n 96 above) 563.

105 Aceves 583.

106 Mswela (n 7 above) 89 91.

107 United Nations Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, General Assembly resolution 47/135 of 1992.

108 J Waugh ‘Social and emotional aspects of albinism’ <http://www.tsbvi.edu/seehear/winter99/albinism.htm> (accessed 4 October 2017).

109 A Fayoyin & N Ihebuzor ‘Advocacy for minorities in Africa: Issues and lessons in advancing the rights of albinos in Tanzania and osus in Nigeria’ (2014) *I Asia Pacific Journal of Research* 113.

110 Wan (n 13 above) 283.

111 See eg UN Enable *UN Convention on the Rights of Persons with Disabilities: Some facts about persons with disabilities* (2006).

difficult process than achieving equality for minorities.<sup>112</sup> In the circumstances, the impairment aspect of albinism makes it preferable to deal with it from a disability rights perspective. It may also be argued that the term 'minority' carries with it the same problems as the phrase 'a particular social group' (discussed immediately below), since it is so broad, and cannot in itself exclude persons with albinism from the 'disability' or 'other status' categories.

#### 4.4.3 *A 'particular social group' or 'other status'*

Several African constitutions have the phrase 'other status' as a prohibited ground of discrimination. The term 'other status' envisages prohibited grounds of discrimination which are not clearly listed or addressed in the current international or regional instruments or domestic anti-discrimination laws. However, the phrase seems to be more a speculative than a practical tool, given the fact that most of the concrete policy or legislative measures aimed at addressing discrimination are focused on particular groups mentioned in the relevant laws.

Some could have attempted to classify persons with albinism as belonging to a particular social group.<sup>113</sup> However, this expression is itself too broad to be useful, although it could be adequate to cover persons with disabilities<sup>114</sup> or persons with albinism, where these groups of persons (or either of them) are not expressly covered in a particular legal or policy instrument.

Therefore, it follows that the expressions 'a particular social group' and 'other status' are unnecessarily expansive, and do not necessarily preclude persons with albinism from the protection of disability legislation. Relying solely on this approach may also lead to difficulties in ascertaining specific measures aimed at addressing the impairment aspects of albinism.

#### 4.4.4 *Albinism and the question of intersectionality*

Intersectionality connotes that different identity categories can intersect and co-exist in the same individual in a way that creates a qualitatively different experience when compared with the experience of any of the characteristics separately.<sup>115</sup> In this sense, intersectionality denies that

112 .T Shakespeare *Disability rights and wrongs* (2006) 65.

113 S Larson 'Magic, mutilation, and murder: A case for granting asylum to Tanzanian nationals with albinism' (2011) 2 25.

114 See United States Court of Appeals, 9th Circuit '*Tchoukhrova v Gonzales*' (2015).

115 B Smith 'Intersectional discrimination and substantive equality: A comparative and theoretical perspective' (2016) 16 *The Equal Rights Review* 73.

identity can be dissected into ‘mutually exclusive categories of experience and analysis’.<sup>116</sup> Therefore, the grounds for discrimination should (in the appropriate circumstances) be defined in such a way that they reinforce one another.<sup>117</sup> Therefore, a truly intersectional approach, for example, would state that the level of discrimination that a woman with albinism experiences is different from that faced by other women and distinct from that suffered by other persons with albinism. This is like stating that, because the CRPD covers albinism, the discrimination a woman with a disability experiences is different from that faced by other women and different from that suffered by other persons with disabilities. This article does not reject the notion of the intersectional nature of discrimination. Even within the larger disability group, it may be argued that only recently have there been louder voices for persons with albinism, meaning that the significance of intersectionality as regards albinism is that it exposes the differences in categories, including the disability category, bringing to attention the individuals at the intersections who are ignored by the current orthodoxy.<sup>118</sup>

The intersectional nature of discrimination is neither peculiar to persons with albinism, nor peculiar to persons belonging to any other ‘identities’. The core question in this article has been whether or not disability covers albinism, which we answer in the affirmative. Furthermore, the synergistic nature of intersectional discrimination requires one to identify some grounds of discrimination which, taken separately, would not seem to be discriminatory,<sup>119</sup> and what these are with respect to albinism. Are persons with albinism discriminated against because of both colour and impairment? Which impairment – visual or a lack of skin pigmentation? Is it merely a question of colour or is the impact attached to the lack of skin pigmentation? These questions would take one back to the issues already covered in this article: visual issues which would require assistive devices, or an inability to work for long hours in the sun, which may require that workers with albinism be given reasonable office accommodation. Coupled with discrimination against the individual concerned, these factors are sufficient to constitute disability.

Intersectionality plays an important role in defining some unique instances of discrimination, but its overgeneralisation may lead to the incorrect assumption that intersectional discrimination is the only form of discrimination, or the only form of discrimination worthy of being addressed. This kind of assumption would create new and harmful

116 Smith (n 115 above) 76; D Schiek ‘Intersectionality and the notion of disability in EU discrimination law’ (2016) 53 *Common Market Law Review* 62.

117 As above.

118 Smith (n 115 above) 101.

119 S Fredman *Intersectional discrimination in EU gender equality and non-discrimination law* (2016) 28.

stereotypes, such as that all persons with albinism are victims of intersectional subordination.<sup>120</sup>

#### **4.5 Multiple identities and intersectionality not excluding the disability approach**

Persons with albinism may have multiple identities, and there could be a number of suggestions regarding measures aimed at improving their human rights situation. Nevertheless, despite the multiple identity nature of albinism, the stigma surrounding albinism is not based purely on colour, and other seemingly broader descriptions or approaches to albinism, such as those attached to 'minorities' or 'particular social groups', sound as they may appear to be, may not be able to answer some specific issues of concern for persons with albinism in Africa. Therefore, it is important to recognise the fact that the impairment-related issues linked to albinism are fully covered under the CRPD and can be fully addressed under any domestic legislation following the CRPD model.

### **5 Potential challenges to the disability approach to albinism**

The broad human rights approach to disability properly addresses albinism issues, especially in Africa, with respect to both visual impairment and skin pigmentation. However, there are still those who do not appear to fully appreciate the disability rights approach to albinism. This may be the case for a number of reasons, such as the continued existence of the vestiges of the medical approach to disability, weaknesses within the African albinism movement, and faulty attempts at universalising albinism, amongst others.

There are numerous policies and pieces of legislation in various countries that maintain the medical approach to disability, making it tedious to progressively address the concerns of albinism. For example, Uganda's definition of disability is tied to 'a substantial functional limitation of daily life activities'.<sup>121</sup> Although there are some references to environmental barriers, the legislation contains the 'disability coding' which not only reflects the medical approach to disability but also excludes persons with albinism.<sup>122</sup> Some other examples of the medical approach to

120 See T Makkonen *Multiple, compound and intersectional discrimination: Bringing the experiences of the most marginalised to the fore* (2002) 58.

121 Sec 2 of the Persons with Disabilities Act of 2006 defines disability as 'a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation'.

122 The codings which are in the First Schedule to the Act include, among others, 'skin diseases' and '[e]ye 'defects''. While albinism is not a disease, the visual issues are not the only challenges to persons with albinism. The codings exist for the purposes of determining 'whether an impairment has a substantial functional limitation of daily life

disability or the medical definition thereof can be seen in the disability legislation of Rwanda<sup>123</sup> and Sierra Leone.<sup>124</sup> In South Africa, although the Constitution as a whole is widely deemed (amongst some scholars) to be admirable, some uncertainties remain in defining persons with disabilities. Different pieces of legislation define disability for different purposes, such as employment and social security.<sup>125</sup> None of these definitions incorporates persons with albinism. In Ghana, the Persons with Disability Act<sup>126</sup> defines neither disability nor a person with a disability, making it problematic not only for persons with albinism who may seek to benefit from the said legislation, but also for other persons who may fall within the disability group. We take note, though, that the fact that the respective countries have ratified the CRPD is itself a progressive step towards a more inclusive approach to disability.

The medical approach to disability is likely to lead to persons with albinism being categorised as being 'impaired', which leads to stigmatisation and disempowerment. The construction of diametrically-opposed identities, the good against the bad, the strong against the weak, or the desirable against the undesirable, is fundamental to the oppression of persons with disabilities.<sup>127</sup> When this is the perception of disability amongst individuals with albinism, it is not possible to easily support the disability approach to albinism, since they too would perceive disability as a 'bad thing'. In other words, the rejection of the disability approach to albinism by some persons with albinism could well be caused by the fact that they too, perhaps unknowingly, also stigmatise persons with other forms of impairment.

The rejection of the disability approach to albinism by some individuals with albinism may influence them to look for a different way of characterising the nature or cause of discrimination against persons with albinism. When this happens in an environment where the African albinism movement lacks the ability to venture separately into the international arena, there is a risk of falling into the old trap of treating some conditions as universal from the perspective of Western rights movements. This observation should not be regarded as intended to

activities; or whether an impairment has a long-term effect on a person' (secs 4(1)(a) & (b) of the Persons with Disabilities Act (n 121 above)).

123 Law Relating to the Protection of Disabled Persons in General 1 of 2007.

124 Persons with Disability Act 3 of 2011 sec 2.

125 According to the Employment Equity Act 55 of 1998, 'people with disabilities' means 'people who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into, or advancement in, employment'. According to the Social Assistance Act 13 of 2004, a person with a disability is one who is 'owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance'.

126 Persons with Disability Act 715 of 2006.

127 R Galvin 'The making of the disabled identity: A linguistic analysis of marginalisation' (2003) 23 *Disability Studies Quarterly* <http://dsq-sds.org/article/view/421> (accessed 22 September 2017).

discredit the tremendous efforts being made by some Western albinism rights activists who have worked tirelessly to promote the albinism agenda in the international human rights fraternity.<sup>128</sup> The point is that the weakness of the albinism movement in Africa has been the cause of inadequate dialogue amongst albinism organisations on the continent, a situation which has made it impossible to present a stronger albinism voice within the disability movement, even in jurisdictions where albinism is generally accepted as a disability. This has created the further possibility of developing the idea that the rights approach to albinism can be uniform and universalised.

## 6 Conclusion

A lack of pigmentation constitutes an impairment, which forms one part of the definition of a person with a disability. Despite the existence of this impairment, albinism is not universally characterised as a disability in legal terms. This alone must not prevent or discourage persons with albinism from pursuing their rights under the disability rights mechanism, considering the fact that even the term 'disability' itself does not have a universal definition. Thus, this contribution puts forward the view that in Africa, and probably in some other parts of the world, albinism can be legally construed as a disability with respect to both visual impairment and a lack of skin pigmentation. The task ahead is to ensure that the specific needs of persons with albinism are exhaustively addressed in future policies and programmes so as to cater for the full realisation of their rights.

128 Credit must be given to Under the Same Sun (UTSS), a Canadian-based organisation, also registered in Tanzania, as the only organisation for persons with albinism, which has been at the forefront campaigning internationally for the rights of persons with albinism. The organisation was registered in Tanzania shortly after the reports of the killings of persons with albinism had emerged.