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**Social development**

## **Social development challenges faced by persons with albinism**

### **Report of the Secretary-General\***

#### *Summary*

Pursuant to General Assembly resolution [76/130](#), the present report contains an analysis of social development challenges faced by persons with albinism, taking into consideration the specific needs of women and children. It focuses on challenges in the areas of health, education and employment. The information contained in the report is based on information received by Member States, civil society and international organizations. The report, drawing upon the various submissions, in particular those received from persons with albinism, includes recommendations.

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\* The present report was submitted to the conference services for processing after the deadline so as to include the most recent information.



## I. Introduction

1. In its resolution [76/130](#), the General Assembly requested the Secretary-General to present a report on the various social development challenges faced by persons with albinism, taking into consideration the specific needs of women and children, including those related to social inclusion, health, education and employment, and measures taken, with recommendations for further action to be taken by Member States and other relevant stakeholders to address identified challenges.

2. At the seventy-second session, the Secretary-General presented to the General Assembly a comprehensive report on social development challenges faced by persons with albinism ([A/72/169](#)), which provided a framework for conceptualizing and removing barriers to social inclusion. At the seventy-fourth session, the Secretary-General presented to the Assembly a second report ([A/74/184](#)), focusing on the environmental and attitudinal barriers faced by persons with albinism worldwide. At the seventy-sixth session, the Secretary-General presented to the Assembly another report ([A/76/769](#)), which paid specific attention to the impact of the coronavirus disease (COVID-19) on persons with albinism. The issues raised and the information contained in those reports remain relevant. The present report supplements earlier reports with updated information on the challenges faced by persons with albinism and covers the period from 2021 to 2023.

3. In September 2023, a questionnaire was sent to Member States, non-governmental organizations (NGOs) and United Nations entities. Responses were received from eight Member States (Azerbaijan, Ecuador, Italy, Malawi, Malaysia, Mexico, Togo and Venezuela (Bolivarian Republic of)); five NGOs, civil society representatives and research institutes;<sup>1</sup> and 13 country offices of the United Nations Children's Fund (UNICEF).<sup>2</sup> At the request of some submitting entities, the submissions are not being published. The present report also draws upon information presented by the Independent Expert on the enjoyment of human rights by persons with albinism in her reports to the General Assembly and the Human Rights Council.

## II. Persons with albinism

### A. Persons with albinism

4. Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people worldwide, regardless of ethnicity or gender. It is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigments (see [A/HRC/24/57](#), paras. 10 and 11). There are two main types of albinism:

(a) **Oculocutaneous albinism.** This is the most common type. Melanin production in the skin, eyes, and hair is poor or absent because a person has inherited two copies of an altered gene, one from each parent;

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<sup>1</sup> Africa Albinism Network, in collaboration with albinism organizations from Ghana, South Africa, the United Republic of Tanzania and Zambia. The submission of Africa Albinism Network is based on contributions from the Ghana Association of Persons with Albinism, the National Albinism Taskforce of South Africa, the Tanzania Albinism Society and the Albinism Foundation of Zambia. Submissions were also received by the Association of Persons with Albinism in Malawi; the Centre for Human Rights, Faculty of Law, University of Pretoria; the Source of the Nile Union of Persons with Albinism; and the Women with Albinism Association.

<sup>2</sup> The following UNICEF offices provided input into the report: Angola, Comoros, Kenya, Lesotho, Madagascar, Malawi, Mozambique, Namibia, Rwanda, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.

(b) **Ocular albinism.** This mainly affects the eyes, causing vision problems. It is much less common than oculocutaneous albinism.<sup>3</sup>

5. Albinism results in two health conditions: visual impairment, to varying degrees, and high vulnerability to skin damage from ultraviolet rays, which can lead to skin cancer.<sup>4</sup>

6. A recent study, from July 2023, notes that the prevalence of the condition “varies widely between continents and population groups, and it is often influenced by local factors. ... The mean prevalence from four African countries was 1 in 4,264 (the range was from 1 in 1,755 to 1 in 7,900). Prevalence for three countries in Europe (mean, 1 in 12,000; range, 1 in 10,000 to 1 in 15,000) may be underestimated, as the phenotype, in fair-skinned populations, may be missed or misdiagnosed as ocular albinism or isolated visual impairment”.<sup>5</sup>

7. Data on the prevalence of albinism are generally lacking, as submissions to the present report show.<sup>6</sup> The Centre for Human Rights at the University of Pretoria noted, for example, that the former Independent Expert on the enjoyment of human rights by persons with albinism had recommended that a question on albinism be added to the next population census in South Africa, as, to date, no official statistics exist in that country.<sup>7</sup>

8. The Bolivarian Republic of Venezuela noted that it does not collect data on persons with albinism.<sup>8</sup> According to the Africa Albinism Network, there are no official statistics in Ghana; estimates are based on the number of members of the Ghana Association of Persons with Albinism, which currently stands at 2,533.<sup>9</sup> In Uganda, according to the submission of the Source of the Nile Union of Persons with Albinism, there are no national statistics available on the number of persons with albinism. The Union estimated that there could be between 15,000 and 30,000 persons with albinism living in the country.<sup>10</sup> The Uganda-based Women with Albinism Association explained that, according to the National Action Plan for Persons with Albinism, the estimated number of persons with albinism in Uganda is more than 20,000.<sup>11</sup>

9. Some countries, such as Kenya, Lesotho, Malawi and the United Republic of Tanzania, collect data on persons with albinism. According to the submission of UNICEF Kenya, according to the 2019 Kenya National Bureau of Statistics population census, the number of persons with albinism stands at 9,729, representing 0.02 per cent of the country’s population.<sup>12</sup> According to the 2016 population census of Lesotho, there are 4,756 men and 4,042 women with albinism (at total of 8,798 persons with albinism).<sup>13</sup> In Malawi, according to the Population and Housing Census

<sup>3</sup> Submission by Italy. For further information on albinism and human rights, please see [www.ohchr.org/en/topic/albinism](http://www.ohchr.org/en/topic/albinism).

<sup>4</sup> See, for example, Joseph B. Mabula and others, “Skin cancers among albinos at a university teaching hospital in Northwestern Tanzania: a retrospective review of 64 cases”, *BMC Dermatology*, vol. 12, No. 5 (2012).

<sup>5</sup> Jennifer G. R. Kromberg, Kaitlyn A. Flynn and Robyn A. Kerr, “Determining a worldwide prevalence of oculocutaneous albinism: a systematic review”, *Investigative Ophthalmology and Visual Science*, vol. 64, No. 14 (July 2023).

<sup>6</sup> Submissions by UNICEF Angola and UNICEF Comoros.

<sup>7</sup> The recommendation is contained in her country visit report to South Africa ([A/HRC/43/42/Add.1](https://www.ohchr.org/en/hr-bodies/hrc/qa/2017/10/A/HRC/43/42/Add.1), paras. 36 and 93).

<sup>8</sup> Submission by the Bolivarian Republic of Venezuela.

<sup>9</sup> Submission by the Africa Albinism Network.

<sup>10</sup> Submission by the Source of the Nile Union of Persons with Albinism.

<sup>11</sup> Submission by the Women with Albinism Association.

<sup>12</sup> Submission by UNICEF Kenya.

<sup>13</sup> Submission by UNICEF Lesotho.

of 2018, there are 134,636 persons with albinism in the country, representing 0.8 per cent of the population.<sup>14</sup> According to non-official sources in the United Republic of Tanzania, the actual number of persons with albinism in that country might be significantly higher than officially determined, at 30,000 to 40,588.<sup>15</sup>

10. Other countries can extrapolate the approximate number of persons with albinism from their statistical material by referring to health databases that record albinism or the birth register. In Mexico, the birth register contains the number of children whose birth certificates recorded albinism status between 2014 and 2023 (one to three children per year).<sup>16</sup>

## **B. Social development challenges of persons with albinism**

11. Persons with albinism often face severe poverty due to potential health complications and rampant discrimination, notably in developing countries and least developed countries. They are also less likely to access high-quality health services, education and employment opportunities or to meaningfully participate in the community.<sup>17</sup>

12. While persons with albinism may face social development challenges in all regions of the world, the degree to which those challenges occur and their impact on individuals' lives vary from country to country depending on the general level of socioeconomic development, the availability of resources, social norms, their hypervisibility and climatic conditions, among other things.<sup>18</sup>

13. The submission of Malawi summarizes many social development challenges that persons with albinism may face, noting that a significant majority of persons – approximately 90 per cent – with albinism reside in rural areas with subpar living conditions and limited access to essential social services. Rural residents typically rely on agriculture for their livelihoods, but persons with albinism, due to the sensitivity of their skin, struggle to work effectively in the sun. Most persons with albinism therefore lack sustainable sources of income and live in chronic poverty.<sup>19</sup>

14. Aside from the health implications of albinism, persons with albinism often face discrimination, prejudice, stigma and social exclusion due to misconceptions and traditional beliefs that associate albinism with superstitions and witchcraft. These misconceptions have perpetuated harmful practices, such as the abduction and mutilation of persons with albinism for their body parts, which are believed to possess magical properties. The Africa Albinism Network noted in its submission that “owing to their distinctive appearance, persons with albinism also contend with harmful practices rooted in age-old beliefs about their looks. These practices encompass stigmatizing language, such as referring to persons with albinism as ‘ghosts’ in Tanzania or ‘monkeys’ in South Africa, ritual attacks, human trafficking, the trafficking of body parts, ritual banishment from specific communities, and more”.<sup>20</sup>

15. Malawi, in its submission, stressed that myths and misconceptions surrounding albinism have exposed individuals with albinism to abuse and violence, including killing, abduction and grave desecration, in the belief that their body parts bring good

<sup>14</sup> Submission by Malawi.

<sup>15</sup> The source of the submission received by the Secretariat cannot be disclosed.

<sup>16</sup> Submission by Mexico.

<sup>17</sup> See, for example, [A/72/169](#), para. 12, and [A/74/184](#), para. 8.

<sup>18</sup> See Ikponwosa Ero and others, *People with Albinism Worldwide: A Human Rights Perspective* (2021).

<sup>19</sup> Submission by the Women with Albinism Association.

<sup>20</sup> Submission by the Africa Albinism Network.

fortune. Consequently, they live in constant fear for their lives. The Women with Albinism Association echoed that point, noting that “the discrimination experienced by persons with albinism means they’re routinely excluded from formal employment and their enterprises are often shunned by potential customers who believe albinism is a curse”.

### III. Legal and policy frameworks

#### A. Relevant international human rights standards

16. Persons with albinism, like any other persons, have the fundamental rights recognized in the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The overarching general principle of equality and non-discrimination enshrined within these instruments guarantees the full enjoyment of human rights of persons with albinism on an equal basis with others and their full and effective participation in society. These instruments also safeguard various rights crucial for achieving the social development of persons with albinism.

17. The rights of persons with albinism are also guaranteed under other international human rights treaties. For example, the Committee on the Rights of Persons with Disabilities has confirmed that persons with albinism are covered under the definition of persons with disability and that their rights are guaranteed and protected under the Convention on the Rights of Persons with Disabilities (CRPD/C/18/D/22/2014, paras. 8.1–8.7 and CRPD/C/22/D/24/2014, para. 7.3).

18. The Committee on the Elimination of Racial Discrimination has noted that discrimination based on the pale skin colour associated with albinism amounts to racial discrimination based on colour (CERD/C/ZAF/CO/4-8, paras. 20 and 21). The Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child also contain provisions relevant to women and girls with albinism.

#### B. Regional policy initiatives

19. The African Union has been actively engaged in addressing the challenges faced by persons with albinism on the continent by organizing awareness campaigns, combatting discrimination and violence against persons with albinism and promoting inclusion. The African Union has recognized albinism as a human rights issue and has urged its member States to protect the rights and dignity of individuals with albinism. Furthermore, it has called for the elimination of harmful cultural practices and stereotypes surrounding albinism. The African Union has also supported research and data collection to better understand the specific needs of this community and has developed evidence-based policies.<sup>21</sup>

20. At its thirty-first session, held in 2019, the Executive Council of the African Union considered the Regional Action Plan on Albinism in Africa (2017–2021) (see A/HRC/37/57/Add.3). The Regional Action Plan was endorsed by the African Commission through a resolution<sup>22</sup> and followed by a continent-wide policy known as the Plan of Action to End Attacks and Other Human Rights Violations Targeting

<sup>21</sup> See examples at [www.ohchr.org/en/special-procedures/ie-albinism/albinism-africa](http://www.ohchr.org/en/special-procedures/ie-albinism/albinism-africa).

<sup>22</sup> African Commission on Human and Peoples’ Rights, resolution 373 (LX) 2017.

Persons with Albinism in Africa (2021–2031).<sup>23</sup> At the same session, the African Union decided that a special envoy would be appointed to ensure the implementation of the Plan of Action.

21. Member States are called upon to implement the Plan of Action at the national level through the creation of national action plans.

### C. National policy initiatives and laws

22. A few countries have adopted laws, policies and other measures that specifically guarantee the human rights of persons with albinism (A/74/190, paras. 8, 43, 68 and 99–103 and A/75/170, para. 67). Persons with albinism are protected by existing international instruments that guarantee the fundamental human rights principles of equality and non-discrimination as well as by specific legislation on disability, health, inclusive education, employment and rare diseases and conditions. Some Member States, including Argentina, Brazil, Guinea, Kenya, Malawi, Nigeria, Panama and Uganda, have taken steps to make specific reference to persons with albinism in their legislation (A/74/190, para. 9 and A/75/170, para. 67). National action plans containing specific measures promoting the enjoyment of human rights by persons with albinism have been developed in several countries, including Kenya, Malawi, Mozambique, Nigeria, South Africa and the United Republic of Tanzania (A/74/190, para. 11).

23. In several countries, such as South Africa and Uganda, albinism is officially acknowledged as a disability. In contrast, others, including Ecuador, Malaysia and Venezuela (Bolivarian Republic of), do not categorize albinism as a disability. However, in Ecuador and Malaysia, if albinism has a significant impact on a person's overall health, the national health authority assesses and determines the disability type and percentage. Ecuador noted in its submission that the Disability Law enables individuals with albinism who have a disability to access various benefits, including those related to health care, taxation, employment and education.<sup>24</sup>

24. In Angola, the Council of Ministers approved a plan for the support and protection of persons with albinism (2023–2027) in August 2023.<sup>25</sup> Other countries have introduced specific national action plans on albinism (and Malawi has also adopted a related national strategy on inclusive education) that address the social development challenges of persons with albinism.<sup>26</sup> In Uganda, laws with specific references to persons with albinism include the Persons with Disabilities Act, amended in 2020.<sup>27</sup>

## IV. Selected social development challenges

### A. Health

25. The lack of melanin affecting persons with albinism can lead to health conditions, which mainly affect the skin and eyesight. Individuals with albinism often encounter significant health challenges related to visual impairment. Low visual acuity, a common feature, hampers their ability to see fine details, which affects daily

<sup>23</sup> African Union, “Implementation matrix of the plan of action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031)”, 2019.

<sup>24</sup> Submission by Malaysia and submission by Ecuador.

<sup>25</sup> Submission by UNICEF Angola.

<sup>26</sup> Submission by Malawi.

<sup>27</sup> See also Office of the United Nations High Commissioner for Human Rights (OHCHR), “Uganda: action plan gives hope to people with albinism”, 5 October 2022.

activities such as reading or recognizing faces. Photophobia, an increased sensitivity to light, exacerbates discomfort in bright environments, while conditions such as nystagmus and strabismus contribute to involuntary eye movements or misalignment, intensifying the complexity of visual challenges for those with albinism.<sup>28</sup>

26. Persons with albinism are also highly vulnerable to developing skin cancer, which has become a significant threat to their longevity.<sup>29</sup> Access to basic health-care products and services, such as sunscreen lotion and skin cancer screening and treatment, for those living in rural areas can be particularly challenging. In some countries, most persons with albinism die from skin cancer between 30 and 40 years of age. Skin cancer can be preventable if detected early enough, which is possible when persons with albinism enjoy access to health care, including access to regular health checks for detection and intervention, and have access to sunscreen, sunglasses and sun-protective clothing.<sup>30</sup> Unfortunately, such life-saving measures often remain unavailable to many. The discrimination and stigma that persons with albinism can face due to their skin colour can limit their access to health services. Furthermore, the Independent Expert on the enjoyment of human rights by persons with albinism and the Africa Albinism Network have warned that climate change places persons with albinism at grave risk, as climate change intensifies exposure to ultraviolet radiation.<sup>31</sup>

27. Essential health services that could avert premature death are often unavailable to persons with albinism. As noted by the Centre for Human Rights at the University of Pretoria,

studies have found that throughout South Africa's different provinces, there is an inconsistent supply of dermatological and ophthalmological services. Provinces such as Gauteng and the Western Cape have more funding and resources than provinces such as Eastern Cape, KwaZulu Natal, Limpopo and Mpumalanga. Hence, persons with albinism in provinces such as Limpopo and Mpumalanga ... do generally not have access to products such as sunscreen or other essential dermatological products. Furthermore, studies have revealed that persons with albinism are treated as low priority patients at hospitals; meaning that healthcare professionals tend to treat other patients first due to their reluctance to treat persons with albinism.<sup>32</sup>

This assessment was echoed in the submission by the Africa Albinism Network, which notes that, in South Africa, "there are dermatology and ophthalmology services in major cities. These services are not available in all nine provinces. Also, those in remote areas do not have access to these services. Skin cancer is widespread among those in remote regions of the country due to lack of access to dermatological services".<sup>33</sup>

28. Based on submissions received in relation to Angola, Ghana, Kenya, Uganda, the United Republic of Tanzania and Zambia, health-care services for persons with albinism are often out of reach. In Angola, there are not enough dermatologists in the country (only 7 out of the 18 provinces have dermatologists) and there is a need for doctors specialized in issues common to persons with albinism.<sup>34</sup>

<sup>28</sup> Rokiah Omar and others, "Management of visual disturbances in albinism: a case report", *Journal of Medical Case Reports*, vol. 6, article No. 316 (2012).

<sup>29</sup> Submission by Malawi.

<sup>30</sup> See [www.un.org/en/observances/albinism-day](http://www.un.org/en/observances/albinism-day).

<sup>31</sup> Submission by the Africa Albinism Network. See also the report of the Independent Expert on the enjoyment of human rights by persons with albinism, climate change and persons with albinism (A/78/167) and the respective press release.

<sup>32</sup> Submission by the Centre for Human Rights, University of Pretoria, South Africa.

<sup>33</sup> Submission by the Africa Albinism Network.

<sup>34</sup> Submission by UNICEF Angola.

29. According to the Africa Albinism Network, in Ghana, “there are a few dermatologists and most of them are based in the big cities. These services are not readily available especially in the remote parts of the country. Persons with albinism must pay to access these services as they are not covered by the national health insurance scheme”.<sup>35</sup> UNICEF Kenya noted that, while the Government of Kenya had launched a free sunscreen programme aimed at providing sunscreen to all persons with albinism, sunscreen lotions are provided within centralized facilities. This means that a single distribution centre serves about three or more sub-counties. Persons with albinism from remote areas are therefore required to travel long distances monthly to access the lotion. Key services, such as skin cancer management and care, are provided at the Kenyatta National Hospital, in the capital. This means that persons with albinism from all over the country in need of this service must travel to Nairobi for skin cancer treatment.<sup>36</sup>

30. The Africa Albinism Network reported scarcity of services in some countries, often paired with a lack of information on albinism-related health issues. It noted that many households with children with albinism lack knowledge about skin cancer prevention, with children often wearing nothing more than short trousers when exposed to the sun. It further noted that statistics from parts of Africa indicate that persons with albinism often succumb to skin cancer at an early age. According to the Network, this suggests that cancer could be the leading cause of death for persons with albinism, who often do not reach their fortieth birthday.<sup>37</sup>

31. The Source of the Nile Union of Persons with Albinism reports that, in Uganda, generally, dermatology and ophthalmology services are not readily accessible for persons with albinism across the country. There are fewer than three active dermatologists, and two of those provide dermatology services through the skin clinic organized by them. Similarly, there are no ophthalmologists specifically serving persons with albinism.<sup>38</sup>

32. The same organization reported that, in Zambia, dermatology and ophthalmology services are not readily accessible. For example, there is only one skin cancer hospital, located in Lusaka; it is reported that persons with albinism must undertake long journeys to Lusaka to receive treatment for skin cancer. Sunscreens are also not easily available to persons with albinism, and many persons with albinism struggle to afford the few services that do exist.<sup>39</sup>

33. In addition to the physical availability of health services, financial affordability is an issue in some countries. UNICEF Madagascar reported, for example, that treatment and medication, sun cream and sunglasses are not accessible to all persons with albinism due to their unaffordability.<sup>40</sup>

34. As an example of a promising practice, UNICEF reported that, in Mozambique, persons with albinism have free access to dermatological services in central hospitals in Beira, Inhambane, Maputo and Nampula. In addition, some hospitals run specific dermatology clinics, whose facilities include priority service for persons with albinism, who do not need to schedule an appointment, and consultations are free.<sup>41</sup>

<sup>35</sup> Submission by the Africa Albinism Network.

<sup>36</sup> Submission by UNICEF Kenya.

<sup>37</sup> Submission by the Africa Albinism Network.

<sup>38</sup> Submission by the Source of the Nile Union of Persons with Albinism.

<sup>39</sup> Ibid.

<sup>40</sup> As an indication, a 100 ml tube of sun cream costs around \$23 and is sufficient for only a half a month of use. A consultation with a dermatologist costs \$89. (Submission by UNICEF Madagascar.)

<sup>41</sup> Submission by UNICEF Mozambique.



35. The prevention of skin cancer and information on its health risks are of high importance. According to information received for the present report, many persons with albinism neither know what causes the condition nor are they aware of the corresponding health risks.<sup>42</sup>

36. Various means are used to inform persons with albinism about health issues associated with albinism and about available resources. According to the Source of the Nile Union of Persons with Albinism, in Uganda, radio and television programmes, social media platforms, community gatherings and the celebration of International Albinism Awareness Day are used to spread this information.<sup>43</sup> In most countries in the sub-Saharan region, civil society plays a key role in the dissemination of information.<sup>44</sup>

37. Some countries have also established special programmes that cater to this population group. To make health services more accessible, some Governments, such as the Government of Malawi, provide special programmes. Its Ministry of Health, in collaboration with public and private partners, is implementing several dermatology and ophthalmology initiatives to address the health-care needs of persons with albinism. They include the national skin cancer prevention programme, which is aimed at reducing skin cancer risk among persons with albinism through capacity-building, outreach clinics and the promotion of sunscreen lotion accessibility in approximately 75 per cent of districts. Low vision clinics focus on eye screening and the provision of appropriate eyeglasses for students with albinism, while skin screening clinics provide cancer prevention services and sunscreen. In its submission, Malawi reported that central hospitals conduct weekly skin cancer clinics and engagement meetings with relevant stakeholders and ensure the availability of sunscreen lotion. In addition, Malawi is in the process of establishing a local sunscreen lotion production plant. Information is disseminated on albinism-related health concerns through various channels, including health talks at district clinics, through community, radio and television awareness programmes and through engagement meetings with the Association of Persons with Albinism in Malawi.<sup>45</sup>

38. Persons with albinism can be confronted with significant mental health issues in addition to their physical health issues. The prevalence of myths and superstitions in their communities fosters stigmatization, bullying and discrimination, which can result in low self-esteem, social isolation, loneliness, anxiety and distress.<sup>46</sup> The myths and superstitions described in paragraph 14 have even resulted in rape, with associated unwanted pregnancies and sexually transmitted diseases, or other forms of violence, thus further harming the psychological well-being of persons with albinism.<sup>47</sup>

## B. Education

39. Individuals with albinism can be subject to prejudice, discrimination and even violence, which in some regions makes it unsafe for students with albinism to access education. Furthermore, discrimination, coupled with long journeys to reach school and exposure to the sun, can lead to high absenteeism and dropout rates. The Women with Albinism Association reported, for example, that, while the educational status of

<sup>42</sup> Submission by the Women with Albinism Association.

<sup>43</sup> Submission by the Source of the Nile Union of Persons with Albinism.

<sup>44</sup> Submission by the Women with Albinism Association.

<sup>45</sup> Submission by Malawi.

<sup>46</sup> Shangwe H. Kiluwa, Sophie Yohani and Samuel Likindikoki, "Accumulated social vulnerability and experiences of psycho-trauma among women living with albinism in Tanzania", *Disability and Society*, vol. 39, No. 2 (2024).

<sup>47</sup> See, Ero and others, *People with Albinism Worldwide*, p. 75.

persons with albinism has been improving in Uganda, with around 70 per cent of persons with albinism attending primary school, still only 10 per cent have completed secondary education.

40. The Source of the Nile Union of Persons with Albinism reported that, although statistics are not readily available, numerous students with albinism withdraw from school. The organization observed that the lack of safety surrounding albinism stems from dangerous myths and misconceptions about the condition, along with widespread reports of abductions of individuals with albinism. This leads parents to exhibit protectiveness towards students with albinism, which can impede their ability to access education.

41. Even if students manage to avoid dropping out, teachers and schools often lack the necessary resources, equipment or knowledge to cater to the specific needs of students with albinism. This relates primarily to their sensitivity to sun exposure and potential vision impairment, which makes it more difficult for students to follow classes. These factors undermine the ability of many persons with albinism to access education on an equal basis with their peers.<sup>48</sup>

42. When access to education proves challenging, modest alterations in policies and behaviour can yield notable differences. For example, in Malawi, several schools have granted approval for individuals with albinism to wear long-sleeved uniforms and wide-brimmed hats during school hours, a practice also adopted in Uganda. Moreover, students with albinism can be permitted to occupy seats in the front row. Nevertheless, critical resources such as large-print materials and low vision aids are frequently not readily accessible within educational institutions.<sup>49</sup>

43. In its submission, Malawi reported that children with albinism are enrolled at all levels of education, from early childhood to tertiary education institutions. At primary school, most learners with albinism are accommodated in resource centres with boarding facilities. The same applies to secondary school learners, who also automatically get selected to attend schools with boarding facilities, for safety purposes. Furthermore, secondary school learners can receive scholarships that cover school fees and allowances.<sup>50</sup>

44. Notwithstanding this approach, the Government of Malawi identified the following factors as significant impediments to providing education for students with albinism: (i) kidnapping, which is a traumatic ordeal with enduring consequences, as it induces a perpetual state of fear among both parents and children; and (ii) discrimination and adverse attitudes, as schools have yet to fully embrace students with albinism as an integral part of their diverse student bodies. Malawi reported that some educators and students continue to harbour negative attitudes towards students with albinism, hampering their participation and integration.<sup>51</sup> As one civil society organization pointed out:

Teachers lack knowledge of albinism and are unaware of the needs of learners with albinism. This is exacerbated by the fact that all primary school teachers have limited education in special needs as part of their pre-service training course at Teacher Training Colleges. ... Lecturers follow a handbook provided by the Ministry of Education that, however, has very little content on albinism or on educating children with this condition. This leads teachers to believe that

<sup>48</sup> Ibid., p. 51.

<sup>49</sup> Submission by the Source of the Nile Union of Persons with Albinism and submission by Malawi.

<sup>50</sup> Submission by Malawi.

<sup>51</sup> Ibid.

albinism is a mental disability refusing to teach learners with albinism and violating their right to education.<sup>52</sup>

### C. Employment

45. Member States noted in their submissions that persons with albinism are protected by labour laws that prohibit discrimination.<sup>53</sup> Ecuador, for example, stated that “All persons have the right to participate in equal opportunities and be free of discrimination of any kind in personnel selection processes in the public and private sector”.<sup>54</sup> In Panama, persons with albinism are protected against discrimination in the workplace by a special law.<sup>55</sup>

46. Employment statistics on persons with albinism are seldom available. There is, however, information provided by various stakeholders that indicates that the challenges encountered in employment by persons with albinism, in particular in Sub-Saharan Africa, where agriculture and therefore sun exposure play an important role, are dire. The Source of the Nile Union of Persons with Albinism noted, for example, that employers have not fully embraced the potential of individuals with albinism who possess employable skills. Furthermore, submissions indicate that the employment of individuals with albinism in government institutions is rare.<sup>56</sup>

47. UNICEF reported that, in Malawi, key impediments to the full employment of persons with albinism include (i) misconceptions regarding the employability and productivity of individuals with albinism; (ii) poor educational opportunities and achievements; and (iii) the threat of violence, which has resulted in persons with albinism not accessing job opportunities. Because of the rise in attacks, kidnappings and murders over the past few years, persons with albinism are forced to stay hidden out of fear for their safety. Insecurity therefore remains an obstacle encountered by this population group in accessing employment, in both the formal and the informal sectors, or engaging in self-employment.<sup>57</sup>

48. In this connection, the Government of Malawi reported that it is implementing a job placement programme that facilitates access to employment. Through the programme, opportunities for internships or placements are provided to persons with disabilities, including persons with albinism, in various companies and organizations. In addition, the Government provides vocational skills training to young persons with disabilities to enhance their employability.<sup>58</sup>

### D. Women and children

49. Women and girls in some countries are especially affected by harmful practices linked to albinism. The Africa Albinism Network reports that women are often abandoned by their spouses when they give birth to children with albinism. Typically, children reside with their grandparents or single parents (usually mothers) in rural areas, where they have limited opportunities to access education. These challenges

<sup>52</sup> Submission by the Association of Persons with Albinism in Malawi.

<sup>53</sup> Submission by Azerbaijan.

<sup>54</sup> Submission by Ecuador.

<sup>55</sup> See OHCHR, “Panama: fast-track implementation of the law on albinism, urges UN expert”, 8 September 2023; and Independent Expert on the enjoyment of human rights by persons with albinism, “Official visit to the Republic of Panama, 28 August to 7 September 2023: preliminary findings”, September 2023.

<sup>56</sup> Submission by the Source of the Nile Union of Persons with Albinism.

<sup>57</sup> Submission by UNICEF Malawi.

<sup>58</sup> Submission by Malawi.

are further exacerbated by their visual impairments and the necessity for protection against the sun.

50. Women and girls with albinism, as well as mothers of children with albinism, are also more likely than other women and girls to become targets of sexual and physical violence and related health concerns, including sexually transmitted diseases and HIV/AIDS.<sup>59</sup> One reason is the gender dimension of certain beliefs,<sup>60</sup> such as that a man can be cured of HIV/AIDS if he has sex with a woman with albinism.<sup>61</sup>

51. Women with albinism and mothers of children with albinism are already highly susceptible to isolation and poverty and are consequently likely to encounter even greater challenges in securing a livelihood for themselves and their children. Children with albinism are usually at higher risk of attacks for witchcraft and ritual practices because of the belief that the innocence of the victim increases the potency of the witchcraft (A/76/769, para. 38).

52. A report published in 2021 highlighted the disproportionate challenges faced by women and children with albinism in various regions, including Africa, South America and South Asia. It noted that women often experience blame, abandonment and isolation after giving birth to a child with albinism due to misconceptions and societal stigmas. Such abandonment leads to poverty and increased vulnerability to various risks, including health issues and sexual violence. Furthermore, women and children with albinism are at heightened risk of attacks and reprisals for seeking justice. Perpetrators often enjoy impunity. Displacement among persons with albinism is also common, with many seeking temporary shelter due to safety concerns and facing inadequate support. Overall, these factors underscore the urgent need for awareness, support and protection for women and children with albinism to ensure their full enjoyment of human rights.<sup>62</sup>

## V. Policies to support persons with albinism

### A. Health

53. **Prioritizing prevention and awareness.** In crafting a robust policy framework for the health of individuals with albinism, prevention and awareness must be at the forefront. Prevention measures should ensure that individuals with albinism are shielded from the heightened risks they face, particularly in terms of skin cancer and vision impairments. Governments should mandate regular skin cancer screening programmes and facilitate the distribution of sunscreen lotions and eye care services to individuals with albinism. Concurrently, awareness campaigns are essential components for educating the public, health-care providers and families about the unique challenges presented by albinism. These campaigns should emphasize the importance of preventive measures, such as sun-protective clothing and safe sun practices, as critical elements in reducing health risks. By integrating prevention with awareness, these policies can create a safer and more informed environment for individuals with albinism.

54. **Ensuring affordable, available, accessible, acceptable and good quality health-care infrastructure.** Another fundamental element of a comprehensive health policy framework for individuals with albinism is ensuring the availability and accessibility of specialized health-care services. It is imperative that individuals with

<sup>59</sup> See Ero and others, *People with Albinism Worldwide*, p. 93.

<sup>60</sup> Submission by the Africa Albinism Network.

<sup>61</sup> Submission by the Women with Albinism Association.

<sup>62</sup> See Ero and others, *People with Albinism Worldwide*, p. 89.

albinism have access to dermatological and ophthalmological screening and treatment, as well as visual assistive devices tailored to their unique needs, without discrimination. To eliminate financial barriers, these services and products (e.g. assistive devices) should be made available free of charge or at reduced costs, given that these treatments and support measures are vital for the health and well-being of this community. Moreover, mobile clinics and sunscreen lotion should be made available to persons with albinism. Adopting innovative measures to reach individuals with albinism effectively and ensure that they receive appropriate care, especially in remote areas, should be a key priority in order to bridge the health-care gap and provide equitable access to the necessary specialized services.

**55. Combating all forms of discrimination and inequalities.** Training and awareness-raising programmes for health-care providers are crucial in combating discrimination and biases that individuals with albinism may encounter within the health-care system. Awareness campaigns should also empower families and caregivers with information and support upon the birth of a child with albinism.

## **B. Education**

**56. Ensuring safety and non-discrimination.** A comprehensive policy framework for education for persons with albinism should prioritize safety and non-discrimination. It is critical that policies explicitly prohibit any form of discrimination against students with albinism and promote a culture of inclusivity within educational institutions. They should include awareness-raising campaigns that address stereotypes and misconceptions. Furthermore, these policies should mandate the establishment of safe and secure environments, both within schools and during the daily commute, by addressing the unique security concerns of individuals with albinism, who are often at risk of abduction and violence. For these measures to be effective in ensuring the safety and well-being of students with albinism, they should involve collaboration between educational authorities, law enforcement and relevant community organizations.

**57. Providing adequate support measures.** To provide an effective and inclusive education for individuals with albinism, it is imperative that policies address their specific needs. This includes adequate sun protection measures and vision impairment support. The policy framework should ensure that sunscreen lotions are readily available in schools and encourage students with albinism to use them. It should also ensure that they are taught about their importance. In addition, policies should mandate the provision of visual assistive devices and services, such as large print materials and specialized teaching techniques, to remove the barriers that persons with albinism face in education.

**58. Support and inclusivity.** Support and inclusivity should be at the core of any policy framework for education for persons with albinism. It is essential to provide ongoing teacher training on albinism-related issues to reduce prejudice and bias and ensure that educators can accommodate the unique learning requirements of these students. Moreover, support services, such as counselling and peer mentoring, should be readily available within schools to address the social and psychological challenges that students with albinism may face.

**59.** Policymakers should also consider allocating resources for scholarships and financial aid to mitigate the economic barriers that hinder their access to inclusive quality education. This comprehensive approach ensures that students with albinism not only receive a safe and discrimination-free education, but that they are also fully supported in reaching their full academic potential, contributing to a more inclusive and equitable educational landscape.

## C. Employment

60. **Ensuring equal employment opportunities and non-discrimination in the workplace.** A comprehensive policy framework for employment of persons with albinism is needed to ensure equal employment opportunities and non-discrimination in the workplace. This involves implementing stringent anti-discrimination laws and regulations to prohibit any form of prejudice based on albinism. Policymakers should actively promote diversity and inclusivity in the workplace, fostering a culture wherein individuals with albinism are valued for their skills and contributions rather than judged on the basis of their physical appearance. In addition, awareness-raising campaigns should be conducted to educate employers and co-workers about albinism, dispelling myths and stereotypes. To ensure equal employment opportunities and non-discrimination in the workplace, these policies must also establish mechanisms for individuals with albinism to report discrimination and ensure that persons with albinism have legal recourse in cases of discriminatory and unjust treatment.

61. **Addressing reasonable accommodation in the workplace and in professional or vocational training.** To empower persons with albinism in the workforce, policies should address their specific needs. This includes ensuring access to shaded areas and sun-protective clothing, as well as offering visual assistive devices and larger print materials to facilitate their work. Moreover, a key aspect of the policy framework should be academic, professional or vocational training and skills development programmes tailored to the specific strengths and capabilities of individuals with albinism. These training initiatives should prepare them for a wide range of job opportunities and equip them with the skills necessary to thrive in various industries and professions.

62. **Incentives for employers and support mechanisms.** The policy framework should include incentives for employers to hire individuals with albinism. These incentives could take the form of tax breaks, subsidies for accommodations or grants for vocational training programmes. By incentivizing employers to create inclusive work environments, these policies can stimulate the recruitment and retention of individuals with albinism in the workforce. Furthermore, support mechanisms should be put in place to assist individuals with albinism in their career development. This could involve mentorship programmes, career counselling or access to accessible transportation. By establishing a supportive infrastructure, the policy framework ensures that persons with albinism have the resources and guidance necessary to thrive in their chosen professions.

## D. Protection and non-discrimination

63. Persons with albinism experience multiple and intersecting forms of discrimination because of their sex, age, gender identity, sexual orientation, ethnicity and race, location, legal status and economic status, among other factors. Policies should therefore respond to the multiple and intersecting forms of discrimination faced by persons with albinism.

64. Member States should strengthen their efforts to address the root causes of discrimination against persons with albinism through awareness-raising campaigns and education. Awareness-raising campaigns should engage with people, including at the community level, and be adapted to local socio-cultural contexts. Persons with albinism should be involved in the design of these campaigns.

65. Persons with albinism have been at heightened risk of attacks and verbal abuse, especially women and children.<sup>63</sup> It is essential that Member States ensure that reporting mechanisms, hotlines, emergency shelters and other forms of assistance are accessible to persons with albinism. They should also consider increasing police patrols in reported hotspots for attacks against persons with albinism. Persons with albinism who have been victims of human rights violations or abuses have a right to access justice and effective remedies.

## **E. Meaningful participation and inclusion**

66. Persons with albinism, like everyone else, have the right to participate fully and effectively in decisions that affect their lives. Member States should ensure that persons with albinism and their representative organizations are meaningfully consulted and actively involved in the planning and implementation of any policy measure that concerns them.

67. Participation and inclusion also require that measures are taken to ensure that information and communications are accessible to all persons with albinism, including those living in remote areas. Any information concerning persons with albinism should therefore be disseminated using the greatest variety of communication means available, be provided in formats accessible to persons with visual impairment (e.g. captioning and easy-to-read formats) and in languages spoken by them.

## **F. Data collection, analysis and dissemination**

68. Data on persons with albinism are indispensable for framing effective policies to support this community as they provide an understanding of their specific needs, challenges and the extent of discrimination they face.<sup>64</sup> Accurate data allow policymakers to develop targeted interventions, allocate resources effectively and design inclusive programmes that cater to the unique needs of individuals with albinism. In addition, data help in monitoring progress, measuring the impact of policy initiatives and adapting strategies as circumstances evolve. By gathering, analysing and disseminating data, Governments can create policies that not only protect the rights and well-being of persons with albinism, but also contribute to a more inclusive and equitable society, fostering a stronger sense of belonging and acceptance for this often-marginalized community.

## **G. Climate change**

69. For persons with albinism, who face heightened vulnerability due to their sun-sensitive skin, climate change, paired with ozone depletion, exacerbates their exposure to ultraviolet radiation and, thereby, the incidence of skin cancer.<sup>65</sup> In developing countries, where many people with albinism depend on agriculture, changes to agriculture caused by climate change might also force persons with albinism to spend more time outside to sustain their livelihoods, thereby increasing their exposure to ultraviolet radiation. Addressing the threat of increased sun exposure caused by climate change and ozone depletion to persons with albinism necessitates

<sup>63</sup> See OHCHR, “Attacks against people with albinism are hate crimes – UN albinism expert”, 30 March 2022.

<sup>64</sup> For further information, see OHCHR, “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development”, 2018.

<sup>65</sup> See, for example, Brian Diffey, “Climate change, ozone depletion and the impact on ultraviolet exposure of human skin”, *Physics in Medicine and Biology*, vol. 49, No. 1 (January 2004).

comprehensive policies and strategies at the local, national, regional and international levels in the light of the unique vulnerabilities this community faces due to their condition and the rapidly changing climate.<sup>66</sup>

## H. Equitable sharing of scientific progress and international cooperation

70. Progress in dermatology and related fields of science may improve the quality of life for individuals with albinism. Dermatological research has led to the development of advanced sunscreen formulations tailored to their specific needs, offering better protection against harmful ultraviolet rays, and to the creation of a synthetic version of melanin, called “super melanin”, that, when applied as a skin cream, nearly doubles the speed of skin healing following injury.<sup>67</sup> If science, as it continues to advance, is shared and made accessible, it can significantly contribute to the physical health of persons with albinism.

71. Ongoing advancements in medical science have the potential to lead to innovative treatment methods. Action at both the national and international levels is needed to ensure that the benefits of such technological progress are shared in a fair and equitable manner.

72. Addressing the wide-ranging specific needs of persons with albinism remains a major challenge, especially for developing countries with limited capacities. At the same time, as the present report illustrates, there are several low-cost, high-impact measures, such as allowing students to wear clothes that protect their skin or ensuring that information on the prevention of skin cancer is widely shared, that all Member States can take. Such measures could have a positive impact on the lives of people with albinism. Furthermore, international cooperation could make an important contribution in supporting countries, especially those with limited capacities.

## VI. Conclusions and recommendations

73. **Addressing the challenges faced by persons with albinism requires a whole-of-Government and whole-of-society effort, as well as support from the international community. On the basis of the suggestions contained in the submissions received for the present report, I encourage Member States to consider the following recommendations:**

74. **Protection: implement policies to end all form of violence, including sexual violence and harmful practices, such as witchcraft and ritual attacks, against persons with albinism.**

75. **National action plans and coordination and monitoring mechanisms:**

(a) **Develop comprehensive national action plans on albinism that help to reinforce legal and policy frameworks to promote inclusion of people with albinism. Persons with albinism should engage meaningfully in all mechanisms, as well as in the elaboration and implementation of programmes, policies, and laws affecting them;**

(b) **Establish coordination and monitoring mechanisms focusing on vulnerable populations, including persons with albinism, in line with the commitment of the 2030 Agenda for Sustainable Development to leave no one**

<sup>66</sup> Submission by Malawi.

<sup>67</sup> Robert F. Service, “Synthetic ‘super melanin’ speeds skin repair”, *Science*, 2 November 2023.



behind. Such mechanisms should consist of relevant ministries and involve other relevant actors, including civil society and national human rights institutions, as applicable;

(c) Collect data on persons with albinism, using a human rights-based approach to ensure that policymaking and resource allocation advance the realization of the full range of their rights.

**76. Health care:**

(a) Ensure that health care, including mental health-care services, is available, affordable, physically accessible, acceptable and of good quality for all persons with albinism, especially as it relates to skin cancer prevention and treatment and access to ophthalmological services;

(b) Ensure access to information on proper skin and eye care for persons with albinism and promote health-seeking behaviours. Member States are also encouraged to ensure affordability of health care for persons with albinism, including through health insurance covering skin and eye care and by subsidizing the costs of ophthalmologist, skin cancer prevention, and treatment services;

(c) Consider investing in dermatology and ophthalmology training to ensure the availability of health care and establish mobile clinics for skin cancer detection and prevention and eye care to secure access to health services everywhere, including in remote areas. Moreover, accessibility of mental health-care services, as well as provision of psychological support structures in communities and schools, should be ensured;

(d) Ensure the provision of sunscreen for persons with albinism. Sunscreen should be made available at affordable prices or free of charge.

**77. Education:**

(a) Implement education policies that provide inclusive, accessible and quality education for students with albinism, including assistive devices and reasonable accommodations;

(b) Strengthen efforts to educate parents and communities in order to dispel myths about children with albinism and encourage their enrolment and retention in school;

(c) Implement basic health-care measures in schools, including sun-protective dress codes and shaded areas. Member States are also encouraged to allocate funds for assistive devices, such as sunglasses, magnifiers and large-print materials for students with albinism. Guidelines for teachers and educators on how to support children with albinism should be developed and widely disseminated.

**78. Employment and skills development:**

(a) Enact and enforce anti-discrimination laws that explicitly prohibit discrimination against persons with albinism or the parents or guardians of children with albinism in employment and in the workplace;

(b) Take measures to incentivize employers to hire individuals with albinism, including by providing them with tax breaks and subsidies;

(c) Consider developing and providing quality vocational training programmes for individuals with albinism that are aimed at equipping them with the skills necessary to thrive in various industries and professions;

**(d) Create and promote employment opportunities for persons with albinism, including through entrepreneurship skills development.**

**79. Climate change: given that persons with albinism are particularly adversely impacted by climate change, Member States should consider adopting policies aimed at protecting them from its negative impacts.**

**80. I further recommend that the international community foster scientific progress to support persons with albinism and ensure that its benefits are shared and made accessible and available in an equitable and fair manner.**

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