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**Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms**

## **Protection of human rights of persons with albinism**

### **Note by the Secretary-General**

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, in accordance with Human Rights Council resolutions [28/6](#) and [37/5](#).

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\* [A/75/150](#).



## **Report of the Independent Expert on the enjoyment of human rights of persons with albinism, Ikponwosa Ero**

### *Summary*

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, provides guidance to Member States on measures and best practices to ensure the protection of the rights of persons with albinism worldwide. Measures are grouped into four clusters: protection, prevention, accountability and equality and non-discrimination. Concrete measures and guidelines in the present report do not only address protection and redress, but also serve as the basis of an adaptable template for designing national action plans on albinism between now and 2030 in all countries, irrespective of reported attacks against persons with albinism. This is to ensure that no one is left behind in the context of the timeline of the 2030 Agenda for Sustainable Development.

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## I. Introduction

1. The present report provides guidance to Member States on implementing measures to protect the rights of persons with albinism. It consolidates measures covered in previous reports of the Independent Expert, reports of United Nations entities and other stakeholders, and relevant international policy frameworks and best practices. The report also includes reflections on the first five years of the Regional Action Plan on Albinism in Africa (2017–2021) (see [A/HRC/37/57/Add.3](#)) and provides concrete measures and guidelines on protection and redress at the community level, as well as a template for designing a robust response between now and 2030, in line with the timeline of the 2030 Agenda for Sustainable Development. A majority of the proposed measures are applicable globally. Other measures are tailored toward bringing an end to physical attacks in countries where they occur.

2. The measures in this report are grouped into four clusters: protection, prevention, accountability and non-discrimination. There is considerable overlap among the four clusters which underscores the interdependency of human rights. Best practices for several measures are provided herein, as well as in the supplementary information to the present report.<sup>1</sup>

3. Albinism is a relatively rare, non-contagious, genetically inherited condition resulting in little to no pigmentation in the skin, hair and eyes. The condition affects people worldwide regardless of ethnicity or gender. As a result of a general lack of understanding of the condition and accompanying misinformation, myths, superstitions and beliefs, persons with albinism are vulnerable to human rights violations. These include physical attacks, trafficking, harmful practices related to accusations of witchcraft and ritual attacks and discriminatory practices that have a negative impact on their education, health and employment opportunities.

## II. Protection

4. General comment No. 36 of the Human Rights Committee on the right to life<sup>2</sup> requires States to take special measures to protect “persons in vulnerable situations whose lives have been placed at particular risk because of specific threats or pre-existing patterns of violence.” It identifies persons with albinism and alleged witches as examples of such vulnerable persons. To this end, the Independent Expert has consistently called upon States to develop national plans of action for the protection of persons with albinism. A national plan of action provides the framework for Governments to outline objectives, establish timelines, assign responsibility to particular entities and allocate the necessary resources, financial or otherwise. The Independent Expert has also held numerous consultations with Member States and civil society organizations, to advocate for a Human Rights Council resolution to condemn harmful practices related to accusations of witchcraft and ritual attacks. A resolution would significantly contribute towards strengthening protection measures not only for persons with albinism, but also for other victims of witchcraft accusations and ritual attacks, including women, children, persons with disabilities and older persons. The Independent Expert hopes that such a resolution will mobilize States to urgently take the measures necessary to eliminate harmful practices related to accusations of witchcraft and ritual attacks and address the harm these practices have caused to untold numbers of victims worldwide.

<sup>1</sup> “Protection of human rights of persons with albinism: best practices”, see [www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx](http://www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx).

<sup>2</sup> Human Rights Committee, general comment No. 36 (2018) on the right to life.

5. In this report, protection measures refer to critical steps that are necessary to ensure that rights are protected by law. This includes appropriate legal and policy frameworks and ensuring that State actors have the adequate knowledge and capacity to implement the laws. Protection measures also help to ensure that States provide resources, infrastructure and facilities needed to make such laws effective and accessible to all.

## **A. Legislation and policy**

### **1. Health, education and work**

6. Laws and policies are necessary to ensure adequate access to health services needed by persons with albinism<sup>3</sup> and non-discriminatory treatment in the health sector. In many countries, persons with albinism may fall into the category of persons with disabilities due to visual impairment, which can facilitate access to reasonable accommodation in the education system or at the place of work. Further information on these issues are discussed under the Equality and Non-Discrimination section below.

### **2. Criminalization of trafficking**

7. While existing laws in many countries already criminalize human rights violations and offences against persons with albinism (such as trafficking, abduction, removal of body parts, bodily harm, murder), legislative gaps remain. For example, the removal or taking by force or coercion of hair and nails of a person with albinism are often not criminalized. Although these acts may seem minor, they have a traumatizing effect on persons with albinism, as they often perpetuate the myths that persons with albinism have supernatural powers, as well as violate their physical integrity and create psychological stress and deep fear of further violations and attacks.

8. Under international law, the removal of body parts is not specifically mentioned as a purpose of trafficking in persons, although the removal of organs is.<sup>4</sup> However, the types of exploitation mentioned under article 3 (a) of Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime are not exhaustive and what needs to be shown is that exploitation is the end goal, and can include the recruitment, transportation, transfer, harbouring or receipt of a person. “A common characteristic of all forms of trafficking is that victims are treated as merchandise ‘owned’ by their traffickers, with scant regard for their human rights and dignity.”<sup>5</sup> The removal of body parts for economic or exploitative purpose, such as toes, nails or hair, therefore falls within the meaning of exploitation for trafficking.

9. States can strengthen protection measures regarding trafficking by clearly criminalizing the transfer of a person with albinism from one place to another, either in or outside the country, for the purposes of removing body parts, including, for example, hair and nails. This ensures that trafficking is treated as a serious offence with strict penalties.<sup>6</sup> For example, Kenya and South Africa have trafficking laws that cover trafficking within the country and across borders for any form of exploitation,

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<sup>3</sup> Convention on the Rights of Persons with Disabilities, art. 25 (b).

<sup>4</sup> Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime, art. 3 (a).

<sup>5</sup> Ibid.

<sup>6</sup> United Nations Convention against Transnational Organized Crime, art. 11.

including body parts, not just organs.<sup>7</sup> The law in South Africa further provides strict penalties of fines up to 100 million rand and/or imprisonment for life.<sup>8</sup>

### 3. Harmful practices related to accusations of witchcraft and ritual attacks

10. Persons with albinism, in particular children and their mothers, are susceptible to harmful practices related to accusations of witchcraft and ritual attacks (A/HRC/34/59). They may be accused of witchcraft resulting from beliefs that albinism indicates that a child or the mother has been involved in witchcraft or attacked for ritual killings and practices due to erroneous beliefs about albinism.<sup>9</sup> States thus should enact appropriate legal and policy frameworks in relation to harmful practices related to accusations of witchcraft and ritual attacks.

11. Criminalizing witchcraft tends to reinforce the social stigmatization of those accused of practicing it and legitimize the act of killing persons accused of practicing witchcraft. It is difficult to objectively prove in a court of law that acts of witchcraft have occurred.<sup>10</sup> There is also no agreed definition of witchcraft. For these reasons, witchcraft itself should not be criminalized, but ritual attacks, accusation of witchcraft and related harmful acts should be. Regarding ritual attacks, these should include the criminalization of trafficking and other activities such as the possession or solicitation of body parts, provision of advice or remedy by a healer requiring the use of body parts or stigmatizing acts, disinheritance, plundering of property, and exploitative ritual oaths, often used in trafficking of persons. Appropriately severe sentences should be in place for such crimes. Witchcraft accusations which lead to the above-mentioned violations, or lead to death or bodily injury to the person accused of being a witch, should be proscribed. Ritual or harmful attacks should also receive severe sentences as deterrence.

## B. Strengthening the capacity of the public sector

12. The review and promulgation of good laws will have little impact on the protection of persons with albinism unless those tasked with giving effect to them are aware of them and have the necessary capacity to implement them. This requires public sector agents, including health-care professionals, educators, border control agents and law enforcement officers to receive appropriate sensitization to tackle their own prejudices, and training, resources, coordination and exchange of information to effectively implement the laws and policies.

13. In countries where attacks occur, States should adopt measures to assist persons with albinism to minimize their vulnerability to attacks. The international disability organization, CBM, has developed security guidelines specifically for persons with albinism with concrete measures and steps to prevent and handle attacks.<sup>11</sup> The guidelines are for persons with albinism or organizations working with persons with albinism, however, this does not absolve States from their responsibility to protect.

<sup>7</sup> South Africa, Prevention and Combating of Trafficking in Persons Act, Act No. 7 of 2013, arts. 1 and 4; and Kenya, Counter-Trafficking in Persons Act, Act No. 8 of 2010, arts. 2–3.

<sup>8</sup> South Africa, Prevention and Combating of Trafficking in Persons Act, art. 13.

<sup>9</sup> See [https://violenceagainstchildren.un.org/children\\_with\\_disabilities\\_viewpoint](https://violenceagainstchildren.un.org/children_with_disabilities_viewpoint); and Office of the Special Representative of the Secretary-General on Violence against Children, *Protecting Children from Harmful Practices in Plural Legal Systems with a Special Emphasis on Africa* (New York, 2015).

<sup>10</sup> Philip Alston, “Of witches and robots: the diverse challenges of responding to unlawful killings in the twenty-first century”, *Macalester International*, vol. 28, No. (2012).

<sup>11</sup> Tom van Herwijnen, Steve Ritchie and Julian Eaton, “Security guideline for people with albinism concrete and specific security measures to prevent and handle attacks on people with albinism”, March 2017.

The capacity of law enforcement officers and border control agents needs to be strengthened, including their knowledge on the types of attacks against persons with albinism and their role in protecting them. This includes situations of harmful practices related to accusations of witchcraft and ritual attacks, trafficking and other criminal offences.

14. A lack of understanding of the laws relating to albinism, and the poor response capacity of the police have been identified in some cases as factors contributing to the ineffective protection of persons with albinism.<sup>12</sup> The role of the police in crime prevention is too often neglected. Inadequate resources, potential corruption, fear (including by police officers too) regarding myths surrounding persons with albinism, can also lead to inadequate protection.<sup>13</sup> The Independent Expert has previously raised concerns about the interaction between the police and persons with albinism, with inadequate information being provided on the progress of cases; limited police patrols in hotspots; and corruption of police personnel (see [A/HRC/40/62](#)). Capacity-building for police officers and immigration officials should address issues related to cross-border cooperation.

15. In some instances, police may be afraid to handle cases of accusation of witchcraft or ritual attacks because they also subscribe to these beliefs and fear its perceived supernatural powers. Due consideration in selecting individuals to take on cases related to albinism and public education campaigns is critical and ought to be extended to criminal justice professionals.

16. Law enforcement in relation to trafficking can only be effective where countries agree to work together. The Independent Expert has called for international cooperation among neighbouring countries, including through shared databases, memorandums of understanding and extradition treaties (see [A/HRC/34/59/Add.1](#)). The “Toolkit to Combat Trafficking in Persons”<sup>14</sup> of the United Nations Office on Drugs and Crime recommends that police enter into multilateral and bilateral cooperation agreements. States may also have to sign extradition treaties (with the relevant human rights protections) to ensure that suspects can be extradited for trials. There are also regional police organizations such as the European Union Agency for Law Enforcement Cooperation and the Southern African Regional Police Chiefs Cooperation Organization which cooperate on transnational organized crime matters.

### C. Human rights defenders

17. Human rights defenders working on issues related to albinism are often persons with albinism themselves. The organizations they represent are often small, with limited resources and capacity. Some carry out activities with great personal financial costs and need to balance income-generating work with their work as human rights defenders, further putting pressure on their time and resources. In countries where attacks against persons with albinism occur, their work puts them at personal risk and because it reportedly threatens the interests of powerful groups, their chances of effective support from the criminal justice system can be jeopardized. The protection that these human rights defenders require is not only physical, but includes economic, political, environmental and digital security, as well as support for their psychosocial well-being (see [A/HRC/31/55](#)).

<sup>12</sup> Redson E. Kapindu, Study on Challenges and Best Practices in Investigation, Prosecutions and Sentencing in Offences against Person with Albinism in Malawi, report submitted to the United Nations Children’s Fund (UNICEF), March 2018.

<sup>13</sup> *Ibid.*, sects. 8.2, 8.3 and 8.5.

<sup>14</sup> *Toolkit to Combat Trafficking in Persons: Global Programme against Trafficking in Human Beings* (United Nations publication, Sales No. E.06.V.11).

18. The organization Front Line Defenders produced a protection manual for human rights defenders<sup>15</sup> which was updated by Protection International.<sup>16</sup> The purpose of the manual is to provide human rights defenders with the knowledge and tools for understanding and assessing risk and threats in order to develop effective security and protection strategies. The manual is supplemented by the “Workbook on security: practical steps for human rights defenders at risk”, also published by Front Line Defenders. Other organizations have developed similar manuals specific to certain professions,<sup>17</sup> and on digital and online protection.<sup>18</sup> There are also regional networks of human rights defenders that provide resources and support.<sup>19</sup> While many of these give special focus to different groups of human rights defenders, none appear to have a special focus on defenders with albinism or working on albinism.

19. States are primarily responsible for the protection of human rights defenders. The Declaration on Human Rights Defenders<sup>20</sup> requires States to take all necessary measures to ensure the protection of human rights defenders “against any violence, threats, retaliation, de facto or de jure adverse discrimination, pressure or any other arbitrary action as a consequence of... [their work as human rights defenders].”<sup>21</sup> Various reports of the Special Rapporteur on the situation of human rights defenders provide measures States should follow in protecting human rights defenders.<sup>22</sup> These reports require States to protect human rights defenders by (a) creating an enabling environment for their work, (b) ensuring accountability for violations against human rights defenders, and (c) cooperating with regional and international bodies in the protection of human rights defenders in their own and other countries. All such interventions should take into account, address and include the specific challenges of persons with albinism as human rights defenders. Strategies to protect persons with albinism as human rights defenders should involve them in the development process to ensure understanding of their specific challenges.

#### D. Refugee status and asylum seekers

20. Persons with albinism may seek protection outside their home country, either because they have been trafficked to such countries or have fled attacks in their own and are unable or unwilling to seek protection from their own States. As such, third States may have a legal obligation under international refugee law to provide asylum or refugee status to non-national persons with albinism within their territory. Under the Convention relating to the Status of Refugees, a State should grant asylum to anyone who has a well-founded fear of being persecuted due to, inter alia, their

<sup>15</sup> Enrique Eguren, *Protection Manual for Human Rights Defenders* (Dublin, Front Line, 2005).

<sup>16</sup> Enrique Eguren and Marie Caraj, *New Protection Manual for Human Rights Defenders*, 3rd ed. (Brussels, Protection International, 2009).

<sup>17</sup> Office for Democratic Institutions and Human Rights, Organization for Security and Cooperation in Europe, *Guidelines on the Protection of Human Rights Defenders* (Warsaw, 2014); and International Bar Association, “Toolkit for lawyers at risk”, modules 1–3, 2020.

<sup>18</sup> See [www.digitaldefenders.org/](http://www.digitaldefenders.org/); Pavle Petrovic, *Security Guidelines for Human Rights Defenders* (Civil Rights Defenders, 2019); and Amnesty International, “Digital surveillance threats for 2020”, 15 January 2020.

<sup>19</sup> Pan-African Human Rights Defenders Network, with membership of subregional networks (<https://africandefenders.org/about/>); EU-LAT Network ([https://eulatnetwork.org/about-eu-lat-network/#who\\_we\\_are](https://eulatnetwork.org/about-eu-lat-network/#who_we_are)); Euro-Mediterranean Foundation of Support to Human Rights Defenders (<http://emhrf.org/>); and Asian Forum for Human Rights and Development (Forum Asia) ([www.forum-asia.org/](http://www.forum-asia.org/)).

<sup>20</sup> See [www.ohchr.org/EN/Issues/SRHRDefenders/Pages/Declaration.aspx](http://www.ohchr.org/EN/Issues/SRHRDefenders/Pages/Declaration.aspx); see also General Assembly resolution 53/144.

<sup>21</sup> Declaration on Human Rights Defenders, art. 12 (2).

<sup>22</sup> See [A/HRC/13/22 A/HRC/22/L.13, A/HRC/25/55 and A/HRC/31/55](http://www.ohchr.org/EN/Issues/SRHRDefenders/Pages/AnnualReports.aspx), available at [www.ohchr.org/EN/Issues/SRHRDefenders/Pages/AnnualReports.aspx](http://www.ohchr.org/EN/Issues/SRHRDefenders/Pages/AnnualReports.aspx).

membership of a particular social group; is outside their country of nationality, and is unable, afraid, or, unwilling to seek protection in that country or the country of their habitual residence if they are stateless.<sup>23</sup>

21. States should recognize persons with albinism as constituting a particular social group within the definition of article 1 (A) (2).<sup>24</sup> A number of countries have already done this.<sup>25</sup> In a 2007 case involving a man with albinism from Indonesia seeking refugee status in the United States of America,<sup>26</sup> the judge held that the man was a member of a particular social group because of his albinism. According to the judge, “[a]lbinism is an immutable characteristic that [one] is incapable of changing. It clearly identifies [one] on sight.”

22. States should further recognize that persecution within the definition of article 1 (A) (2) encompasses non-State persecutors. The Office of the United Nations High Commissioner for Refugees (UNHCR) makes it clear that there is no requirement that the persecutor be a State actor.<sup>27</sup> This principle was applied in the United Kingdom of Great Britain and Northern Ireland in relation to albinism where the judges noted, “if there is a failure to provide necessary protection against persecution ... then there is a proper basis for finding that [persons with albinism] are refugees.”<sup>28</sup> The continued physical attacks against persons with albinism and lack of accountability for such attacks in some countries make it evident that authorities are either unwilling or unable to effectively protect persons with albinism. Consequently, persons with albinism fleeing such contexts, can be said to be fearing persecution.

23. In relation to children, the UNHCR Handbook and Guidelines on Procedures and Criteria for Determining Refugee Status<sup>29</sup> calls upon States to adopt a child-sensitive approach that takes into account the particular forms and manifestations of persecution experienced by children. States should recognize that while children may face similar or identical forms of harm as adults, they may experience them differently. For example, in a 2016 case involving a 7-year-old boy with albinism in the United Kingdom facing deportation to Nigeria, the judge held that the societal discrimination and ill-treatment might amount to real persecution in relation to a child in circumstances where it would not amount to such in respect of an adult.<sup>30</sup> The court also used a subjective analysis stating that the ill-treatment was more likely to amount to persecution in respect of the child because he had not been brought up in Nigeria and was not accustomed to the negative perception towards his albinism.<sup>31</sup>

<sup>23</sup> Convention relating to the Status of Refugees, art. 1 (A) (2); and Protocol Relating to the Status of Refugees, art. 1.

<sup>24</sup> See HCR/GIP/02/02.

<sup>25</sup> AC (Egypt), [2011] NZIPT 800015, New Zealand: Immigration and Protection Tribunal, 25 November 2011; Commission des recours des réfugiés (French Refugees Appeal Board), 10 June 2005; M.T. n° 04041269/514926 R; Cour nationale du droit d’asile (French National Court of Asylum), n°629447, 28 April 2009.

<sup>26</sup> United States Court of Appeals, Eighth Circuit, *Makatengkeng v. Alberto R. Gonzales, Attorney General*, case No. 06-1630, 3 August 2007.

<sup>27</sup> Office of the United Nations High Commissioner for Refugees (UNHCR), *Handbook and Guidelines on Procedures and Criteria for Determining Refugee Status under the 1951 Convention and the 1967 Protocol Relating to the Status of Refugees*, HCR/1P/4/ENG/REV.3 (Geneva, 2011).

<sup>28</sup> United Kingdom, Upper Tribunal, Immigration and Asylum Chamber, *JA (child – risk of persecution) Nigeria v. The Secretary of State for the Home Department*, case No. 00560 [2016], decision of 24 November 2016, para. 8.

<sup>29</sup> UNHCR, *Handbook and Guidelines on Procedures and Criteria for Determining Refugee Status*.

<sup>30</sup> United Kingdom, Upper Tribunal, Immigration and Asylum Chamber, *JA (child – risk of persecution) Nigeria v. The Secretary of State for the Home Department*, decision of 24 November 2016, para. 8.

<sup>31</sup> *Ibid.*

24. Even when the discrimination itself does not amount to persecution, if it is combined with other adverse factors (e.g. a general atmosphere of insecurity in the country of origin), then the discrimination and the other ground can reasonably justify a claim to well-founded fear of persecution on “cumulative grounds.”<sup>32</sup> This is the case if the adverse factors cause the individual concerned to be fearful regarding their future. The UNHCR Handbook further calls upon States to take a gender-sensitive approach taking into account how multiple forms of discrimination disproportionately impact on women, including how harmful practices could amount to persecution. France for example, granted refugee status to a Nigerian woman with albinism who had fled Nigeria after her albinism was blamed for the death of men in her clan. The court considered the strong beliefs, traditions and customs relating to albinism in Nigeria, and the dearth of protective measures, in deciding that there was a real risk of persecution if she were to return to Nigeria.<sup>33</sup>

25. It is essential that those making refugee status determinations are aware of the multiple layers of discrimination and other human rights violations persons with albinism are often exposed to and the impact of these on the lives of persons with albinism. Lawyers and charities representing asylum seekers, as well as judges and other relevant officials responsible for refugee status determination, are not always aware of harmful practices against women and children with albinism (including ritual sexual intercourse, ostracism and abandonment), which would warrant the application of relevant guidelines such as those on discrimination, persecution, child asylum, gender and potentially trafficking.<sup>34</sup> Further, tribunals determining refugee status should be aware of the severity of attacks and the lack of accountability in relation to attacks in some countries.

26. The human rights principle of non-refoulement also prohibits the removal of anyone, whether a refugee or not, if they are at risk of torture, or cruel, inhuman or degrading treatment or punishment. The Committee against Torture and the Committee on the Rights of the Child have stated that attacks against persons with albinism can, in certain circumstances, amount to torture.<sup>35</sup>

### III. Prevention

27. Prevention measures seek to address conditions in a State which might give rise to unnecessary and foreseeable human rights violations. Such threats could emanate from physical and violent attacks or little to no access to appropriate health care, education or work opportunities. Best practices typically comprise the elements listed below.<sup>36</sup>

#### A. Data collection and situational analysis

28. Research and data are essential for developing action plans and strategies (see [A/HRC/34/59](#), [A/HRC/43/42](#) and [A/73/181](#)) and to ensure that appropriate policies

<sup>32</sup> UNHCR, *Handbook and Guidelines on Procedures and Criteria for Determining Refugee Status*.

<sup>33</sup> Commission des Recours des Réfugiés (French Refugees Appeal Board), decision of 29 August 2006, Melle, AO, n°545655.

<sup>34</sup> See HCR/GIP/06/07.

<sup>35</sup> [CAT/C/BDI/CO/2](#); [CRC/C/CAF/CO/2](#). See also [A/72/131](#), paras. 33–36.

<sup>36</sup> Several organizations have developed strategies that include these elements including, for example, see UNICEF, “Preventing and responding to violence against children: UNICEF’s approach”, November 2017; World Health Organization, *Violence Prevention: The Evidence* (Geneva, 2010); and Inter-Agency Standing Committee Task Team on Inclusion of Persons with Disabilities in Humanitarian Action, *Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action* (2019).

and procedures are put in place. Increasingly, data suggests that there are significant underestimates in previously reported prevalence rates of albinism globally, specifically in parts of Europe and Africa. Accurate statistical and research data on people with albinism are critical. These include: the number of people for which protection measures are required; the types of threats they face; root causes of such threats; availability and accessibility of laws and policies to mitigate risks, as well as available health-care and education services, among other human rights, in a specific country.<sup>37</sup> The vulnerability and protection needs of persons with albinism will differ depending on age, gender, economic status, health status, geographic location (urban versus rural) and whether or not there is a prevailing pattern of violence against persons with albinism. The data collected, both qualitative and quantitative, should be disaggregated (see A/74/190, para. 137 (c)) to enable targeted interventions and adaptation to geographical location and demographic groups.

29. The United Nations has carried out situational analyses of persons with albinism in different countries. The Equal Opportunities Commission and the Office of the United Nations High Commissioner for Human Rights assessed the discrimination against persons with albinism in Uganda.<sup>38</sup> Similarly, in Mozambique the International Organization for Migration carried out a situational analysis in relation to trafficking of persons with albinism.<sup>39</sup> Organizations of persons with albinism, where they exist, play an important role in providing information, but they often cannot reach all persons with albinism, in particular in rural and remote areas. The most important and comprehensive information therefore must come from the State, which has a much wider reach.

30. The Washington Group on Disability Statistics has developed a short set of questions and an extended set on functional issues which can be added to a census or survey to identify people with a disability and challenges they face.<sup>40</sup> These questions can be adapted for collecting census data on albinism.

## B. Social protection measures

31. For persons with albinism living in poverty, discrimination results in fewer opportunities to escape the cycle of poverty and increases their vulnerability to human rights violations. International norms and standards<sup>41</sup> and Sustainable Development Goal 1 require States to reduce poverty, including through the implementation of social protection measures. Social protection and poverty reduction programmes are available for persons with disabilities in a number of countries. However, persons with albinism are unlikely to benefit from them unless they have severe visual impairment or other disabilities. Many social protection programmes also fail to take into account multidimensional poverty, such as lower educational attainment, fewer employment opportunities for persons with albinism in countries with high levels of stigmatization and low levels of knowledge surrounding the condition. Consequently, these measures fail to promote the social, economic and political inclusion of persons with albinism as required by target 10.2 of the Sustainable Development Goals.

<sup>37</sup> Convention on the Rights of Persons with Disabilities, art. 31 (1).

<sup>38</sup> Office of the United Nations High Commissioner for Human Rights (OHCHR), *Enhancing Equality and Countering Discrimination against Persons with Albinism in Uganda* (2019).

<sup>39</sup> International Organization for Migration (IOM) and others, *Situation Analysis on the Human Rights and Protection of Persons with Albinism in Mozambique with a Special Focus on Human Trafficking* (Maputo, 2019).

<sup>40</sup> See [www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/](http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/).

<sup>41</sup> Convention on the Rights of Persons with Disabilities, art. 28.

32. Effective social protection measures require levelling the playing field in relation to health care, education and work opportunities for persons with albinism, in order to assist in reducing poverty and providing education and employment opportunities. Additionally, attacks against persons with albinism must be mitigated. Factors such as the lack of adequate shelter, safe transport or financial resources for public transport, distance from police or other protective services, and the need for a child with albinism to be constantly accompanied due to security concerns, increases living costs for parents and guardians. Necessary social protection measures could be, inter alia, subsidized housing, childcare, the provision of mobile phones, toll-free hotlines, or cash transfers. In Malawi, for example, persons with albinism are provided housing subsidies<sup>42</sup> and personal alarms<sup>43</sup> by the Government.

### C. Addressing root causes

33. The root causes of human rights violations, which include cultural norms, values, superstitions that perpetuate said violations, must be addressed in a plan of action. Strategies should eliminate discrimination and violence against persons with albinism and promote bystander intervention to prevent human rights violations.<sup>44</sup> This can be done through public education and awareness-raising campaigns.

34. Human rights violations against persons with albinism are aggravated in countries where there are erroneous beliefs that persons with albinism have supernatural powers that bring bad or good luck. Such beliefs make them susceptible to accusations of witchcraft and ritual attacks. The media in some countries have also reinforced this by portraying persons with albinism as supernatural beings possessing extraordinary qualities. Examples of plans that specifically tackle belief in witchcraft and make recommendations for awareness-raising programmes include the draft Pan-African Parliament regional guidelines on witchcraft, the national action plan against sorcery and witchcraft-related violence in Papua New Guinea,<sup>45</sup> and the national action plan to tackle child abuse in the United Kingdom.<sup>46</sup>

35. The international non-governmental organization, Stop Child Witch Accusations has outlined a particular model of training, The Heart of the Matter, which uses religious teachings to educate communities about the harm of accusing children of witchcraft, emphasizing the importance of children's rights. When this message is disseminated by reputable religious leaders or religious organizations, it bolsters the argument that the prohibition of harmful practices is in harmony with the majority of religious or cultural beliefs.<sup>47</sup> In Mozambique, the Ministry of Health has a traditional medicine department which works with medical practitioners and traditional healers to ensure they are aware of the needs of persons with albinism and to demystify harmful myths associated with them.<sup>48</sup>

<sup>42</sup> Alfred Chauwa, "Ministry ready to build 600 secure houses for persons with albinism", *Nyasa Times*, 9 January 2020.

<sup>43</sup> Peter Kanjere, "Malawi gives personal 'emergency alarms' to albino citizens", *Independent Online*, 3 May 2019.

<sup>44</sup> WHO, "Inspire: seven strategies for ending violence against children – executive summary, document WHO/NMH/NVI/16.7.

<sup>45</sup> See [www.stopsorceryviolence.org/snap-sarv-nap/](http://www.stopsorceryviolence.org/snap-sarv-nap/).

<sup>46</sup> United Kingdom, Department of Education, "National action plan to tackle child abuse linked to faith or belief", 2012.

<sup>47</sup> See <https://www.stop-cwa.org/>.

<sup>48</sup> See <https://actiononalbinism.org/page/i4dszdwe0fq4ii34m2lyaxlrx>.

## D. Inclusion and active participation

36. Action plans for persons with albinism should be developed with their participation and inclusion. Article 4 (3) of the Convention on the Rights of Persons with Disabilities requires States to closely consult with and actively involve persons with albinism in decision-making processes concerning issues that concern them. This entails partnerships with persons with albinism, putting them at the centre of the decision-making process, awareness-raising and public education campaigns, and supporting their capacities and efforts as agents of change in their families and communities.<sup>49</sup>

37. There is also a need to target and empower persons with albinism, providing them with information on their rights, including in relation to health care, education and work and access to protection from attacks. They should also be given information on their rights and how to take recourse when violations occur. Empowerment can be enhanced through training programmes; reports, pamphlets and posters; and community, online, radio and television campaigns. These should be in accessible language and format. Campaigns and programmes should also include families, in particular parents and guardians of children with albinism.

38. Attacks are often accompanied by trafficking in persons, in particular for the purposes of removal of body parts. The Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime requires States to work with civil society to establish measures to prevent trafficking targeted at vulnerable groups.<sup>50</sup> Some States have prevention strategies specifically for women, children and ethnic minorities. States should ensure that persons with albinism and their relatives receive information on what trafficking is, the methods employed by traffickers to traffic persons with albinism and available support services.

## IV. Accountability

### A. Ensuring accountability

39. Concerning attacks against persons with albinism, police, prosecutors, lawyers and judges must have sufficient capacity to investigate, prosecute and represent persons with albinism and appropriately sentence offences related to attacks against persons with albinism. Detailed concerns regarding the lack of capacity in relation to accountability for attacks against persons with albinism are set out in the report of the Independent Expert on the right to access to justice for persons with albinism (see [A/HRC/40/62](#)). Further concerns are outlined below.

#### 1. Investigations

40. Insufficient capacity to carry out investigations, in particular forensic investigations, in relation to albinism, and to draft criminal charges that ensure all

<sup>49</sup> UNCHR, “Need to know guidance: working with persons with disabilities in forced displacement”, 2019.

<sup>50</sup> Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime, art. 9; and Council of Europe, “Compendium of good practices on the implementation of the Council of Europe Convention on Action against Trafficking in Human Beings”, 2017.

potential charges are included, were concerns that were highlighted in the study on Malawi published by the United Nations Children's Fund.<sup>51</sup>

41. The study recommends that police have appropriate knowledge and expertise in relation to the specific crimes related to albinism, methods of investigation (including forensic investigation techniques), skills for interviewing witnesses, knowledge on available victim assistance and witness protection measures, and skills in drafting comprehensive charges.<sup>52</sup> Where there is an insufficient number of experts, States should invest in capacity-building programmes for senior police officers and ensure wide dissemination of capacity-building handbooks and information on changes to laws.<sup>53</sup>

42. To facilitate investigations related to trafficking, police should enter into cooperation agreements. States may also have to sign extradition treaties to ensure suspects can be extradited for trials. The police in Malawi and Mozambique have signed a memorandum of understanding to this effect.

43. In many cases, police have received information about attacks from associations of persons with albinism and have worked with them to track down family members of victims. Formal memorandums of understanding between the police and the associations can help ensure cooperation as well as ensure that associations are able to obtain follow-up information on cases, in particular when a victim is not identified. The police in Zambia<sup>54</sup> and South Africa (see [A/HRC/43/42/Add.1](#), para. 30), for example, have signed such memorandums of understanding with organizations working with persons with albinism.

## 2. Legal assistance

44. In some countries, persons with albinism may not have the financial capacity to retain an adequately qualified lawyer and may not be able to obtain legal aid to address violations in a court of law. Even when legal aid is available, lawyers are often overworked or underqualified and are not able to provide the best services. They are often not present in remote areas where victims live. Furthermore, lawyers do not always speak the same language as the victims or use overly technical language, including in written documents.<sup>55</sup> States should ensure that affordable legal aid services are accessible to persons with albinism, offer language support and be geographically accessible. Bar associations and law societies providing legal assistance should also provide assistance to vulnerable victims and witnesses.

## 3. Trial and sentencing

45. Concerns have also been raised concerning judges that do not appropriately apply laws to cases related to albinism. In some cases, magistrates have acquitted and released individuals where all the elements of a crime were not proven, instead of convicting them of a lesser crime when all the elements of that lesser crime were present.<sup>56</sup> Some courts have found that they have the discretion to do this when the crime was not included by the prosecutor in the charges. Courts have also given lenient sentences not commensurate with the crime, despite laws providing for more

<sup>51</sup> Kapindu, Study on Challenges and Best Practices in Investigation, Prosecutions and Sentencing in Offences against Person with Albinism in Malawi.

<sup>52</sup> Ibid.

<sup>53</sup> Ibid.

<sup>54</sup> Interviewee from Zambia.

<sup>55</sup> Julinda Beqiraj, Lawrence McNamara and Victoria Wicks, *Access to Justice for Persons with Disabilities: from International Principles to Practice* (International Bar Association, 2017).

<sup>56</sup> Kapindu, Study on Challenges and Best Practices in Investigation, Prosecutions and Sentencing in Offences against Person with Albinism in Malawi.

serious sentences. The UNICEF study on Malawi recommends to upskill members of the judiciary to respond to cases appropriately, provide sentencing guidelines, and that only experienced and well-qualified members of the judiciary take on these cases. More magistrates should be upskilled to adjudicate such cases in places where there are not enough qualified members of the judiciary. The study recommends adequate resources for courts and the use of ad hoc and mobile tribunals to ensure speedy resolution of cases as well as accessibility of courts to victims and witnesses.<sup>57</sup>

## B. Capacity-building

46. Capacity-building programmes need to be put in place for lawyers, prosecutors, immigration personnel and border police in relation to trafficking in persons, including persons with albinism. To facilitate investigations and prosecutions into such cases, mutual legal assistance agreements or memorandums of understanding should be established.

47. The complicity of public officials in trafficking in persons also needs to be addressed.<sup>58</sup> This requires policies and laws to identify public sector involvement or complicity in trafficking, to identify steps to prevent this and to hold perpetrators accountable regardless of their rank (see [E/2002/68/Add.1](#)). In their report on public corruption and trafficking in persons, the International Bar Association provides recommendations on combating corruption of public officials related to trafficking.<sup>59</sup>

## C. Witness protection

48. Effective prosecution of trafficking, harmful practices related to accusations of witchcraft and ritual attacks and other attacks against persons with albinism are often hindered by a lack of cooperation from witnesses who fear the possibility of reprisals or as a result of their belief in witchcraft.<sup>60</sup> The establishment and effective implementation of witness protection laws and policies have been shown to increase cooperation of witnesses, to increase access to justice and to reduce the incidence of crime.<sup>61</sup> Witnesses include those who have given or agreed to give a statement in relation to a crime, as well as their families or persons associated with them.<sup>62</sup> Victims, who are also witnesses, qualify for protection.<sup>63</sup> A number of tools exist to help States to put measures in place for the protection of witnesses, including two model laws.<sup>64</sup>

<sup>57</sup> Ibid.

<sup>58</sup> International Bar Association, *Human Trafficking and Public Corruption. A Report by the IBA's Presidential Task Force against Human Trafficking* (2016); and Sofia Jonsson, "The complex relationship between police corruption and sex trafficking in origin countries", *Journal of Human Trafficking*, vol. 5, No. 2 (2019).

<sup>59</sup> International Bar Association, *Human Trafficking and Public Corruption*.

<sup>60</sup> [A/HRC/40/62](#) and the draft Pan-African Parliament regional guidelines on witchcraft.

<sup>61</sup> United Nations Office on Drugs and Crime (UNODC), *Good Practices for the Protection of Witnesses in Criminal Proceedings Involving Organized Crime* (Vienna, 2008); Jasmina Mujkanović, *Development of a Witness and Victim Support System Croatian Experience: Good Practices and Lessons Learned* (United Nations Development Programme, 2014); and UNODC, "Cross-cutting issues: victims and witnesses – criminal justice assessment toolkit", 2006.

<sup>62</sup> United Nations International Drug Control Programme, "Model witness protection bill", 2000, part 2.

<sup>63</sup> United Nations Convention against Corruption, art. 32 (4); and United Nations Convention against Transnational Organized Crime, art. 24 (4).

<sup>64</sup> United Nations International Drug Control Programme, "Model witness protection bill"; and UNODC and UNICEF, *Justice in Matters Involving Child Victims and Witnesses of Crime: Model Law and Related Commentary* (Vienna, UNODC, 2009).

49. States should also carry out an evaluation, review and continuous enhancement of the legal framework for the protection of witnesses and how it addresses the rights of witnesses. Witnesses must be treated with appropriate sensitivity, dignity and respect, and in the case of children, with the best interest of the child in mind.<sup>65</sup> This includes ensuring that all witnesses receive access to information at the earliest possible opportunity, on expected steps and stages of the case, as well as their rights, available support, where to make complaints if needed and on the outcome of the police investigation.<sup>66</sup> Such information must be in an accessible format, for example in large print in a language they understand and also provided verbally, especially for those with low literacy.

#### **D. Victim assistance**

50. Article 25 of the United Nations Convention against Transnational Organized Crime contains a number of provisions dealing specifically with the protection of victims of trafficking in persons. Likewise, article 6 of the Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime includes the following provisions for the physical, psychological and social recovery of victims of trafficking in persons: “(a) appropriate housing; (b) counselling and information, in particular as regards their legal rights, in a language that [they] can understand; (c) medical, psychological and material assistance; and (d) employment, educational and training opportunities.”<sup>67</sup>

51. The Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power calls for the provision of necessary material, medical, psychological and social assistance for victims.<sup>68</sup> It defines victims to include the immediate family or dependent of the direct victim where appropriate.<sup>69</sup>

52. Victims of harmful practices related to accusations of witchcraft and ritual attacks may find themselves victims of eviction, physical injuries and sexual assault. In addition to medical and psychological assistance, they may be in need of shelter and other material assistance to reduce their vulnerability to further attacks. States should therefore extend these measures to them.

53. International human rights standards call for States to work with civil society for the provision of such assistance, which is often done in practice. Trainings for those coming into contact with victims of attacks must include information on available victim assistance programmes and their duty to direct victims to places where they can get such assistance.

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<sup>65</sup> UNODC and UNICEF, *Justice in Matters Involving Child Victims and Witnesses of Crime*.

<sup>66</sup> Directive 2012/29/EU of the European Parliament and of the Council of 25 October 2012 on establishing minimum standards on the rights, support and protection of victims of crime, art. 4.

<sup>67</sup> Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime, art. 6.

<sup>68</sup> General Assembly resolution 40/34, annex.

<sup>69</sup> *Ibid.*, art. A (2).

## V. Equality and non-discrimination

### A. Health

54. The right to the highest attainable standard of health is one that needs to be protected in of itself, but also as part of the protection of the right to life.<sup>70</sup> The failure of a State to prevent any “intentional or otherwise foreseeable and preventable life-terminating harm or injury” can constitute a violation of the right to life. In her report on the enjoyment of human rights by persons with albinism (see [A/HRC/37/57](#)), the Independent Expert provides information on the impact and challenges related to persons with albinism having access to the highest attainable standard of health. Plans of action and protection measures for persons with albinism should therefore address health. This is in line with Sustainable Development Goal 3 which calls for States to ensure healthy lives and promote well-being for all at all ages.

#### 1. Research and data collection

55. The Committee on Economic, Social and Cultural Rights has called upon States to develop national health policies and to continually monitor and evaluate their implementation to ensure the promotion, protection and fulfilment of the right to health.<sup>71</sup> The Independent Expert and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health have urged States to assess the needs of persons with albinism to increase their life chances and ensure their enjoyment of the right to health.<sup>72</sup> Research and data collection should identify the health needs of persons with albinism, the number of persons affected, availability of relevant services and support as well as obstacles to accessing the services, including developing capacity of health professionals. Plans implemented without appropriate research may prove insufficient for the number of persons affected or unimplementable due to a lack of required human resources or other barriers. In Kenya, the national albinism sunscreen and support programme provides services to 3,182 persons with albinism in the country. The census of August 2019 indicated that there was a need to reach an additional 6,547 individuals.

56. Research assists in the development of new treatments, innovation and improvement of health services for persons with albinism. To this end, in France the National Plan for Rare Diseases (2018–2022)<sup>73</sup> aims to improve scientific research in the area of rare diseases, including in relation to identification and detection. Albinism is covered under this plan.<sup>74</sup>

57. Genetic testing is an important aspect of research. Many countries rely on the appearance of the child or examination of their eyes to determine if a child has albinism. Where albinism is not apparent at birth, it is usually diagnosed by an ophthalmologist or paediatrician when the child is three months old or later when

<sup>70</sup> International Covenant on Economic, Social and Cultural Rights, art. 12; Convention on the Rights of Persons with Disabilities, art. 25; International Convention on the Elimination of All Forms of Racial Discrimination, art. 5 (d)(iv); Convention on the Elimination of All Forms of Discrimination against Women, arts. 11 (1)(f) and 12; and Convention on the Rights of the Child, art. 24.

<sup>71</sup> Committee on Economic, Social and Cultural Rights, general comment No. 3 (1990) on the nature of States parties’ obligations.

<sup>72</sup> United Nations News, “Persons with albinism must not be treated as ‘ghosts’, United Nations experts stress”, 4 May 2013.

<sup>73</sup> France, Ministry for Solidarity and Health and the Ministry for Higher Education, Research and Innovation, *French National Plan For Rare Diseases 2018–2022: Sharing Innovation, a Diagnosis and a Treatment for All* (2018).

<sup>74</sup> Interviewee from France.

nystagmus or poor vision become apparent.<sup>75</sup> In some cases, especially where there is little to no visual impairment, individuals may not know that they have albinism until well into adulthood. Genetic testing is required to identify the specific type of albinism and is especially important in respect of rarer forms such as Hermansky-Pudlak syndrome,<sup>76</sup> Chediak Higashi syndrome<sup>77</sup> and Griscelli syndrome.<sup>78</sup>

## 2. Capacity-building

58. It is critical that health-care professionals understand albinism. Midwives and doctors who are unaware of albinism have provided wrong information to families of persons with albinism, including perpetuating the misbelief that a child with albinism is the result of adultery, or is simply very fair and blonde. Health-care professionals therefore need the skills to identify potential cases of albinism, provide support and advice, as well as refer families to places where they can receive appropriate testing, counselling, information on albinism and other relevant services.

59. Many countries have insufficient qualified professionals to carry out skin cancer screening, detection and treatment, and provide optometric and ophthalmological examinations. Where these are available, they are mainly found in the cities, with no access for those in rural or remote areas. Further, hospitals may not have the right facilities for testing. States need to ensure adequate resources, facilities and training of medical professionals. Stigma and discrimination from health-care professionals may further prevent persons with albinism from accessing services. Sensitization of health-care professionals is required to tackle such stigma. Capacity-building and training programmes are needed for doctors, nurses, midwives, optometrists, ophthalmologists and other health-care professionals. Training can be offered through stand-alone modules on albinism or incorporated into larger modules including on disability, rare conditions, low vision, dermatology, genetics and midwifery

## 3. Barriers to accessing health care

60. A national plan of action on albinism should address barriers to accessing health care for persons with albinism. These barriers include a lack of understanding by persons with albinism of their own health needs and how to access health-care services, physical accessibility of health-care services, and stigma and discrimination from the health-care service environment and service providers. Awareness-raising campaigns and training sessions for persons with albinism should include information related to health care. Public education campaigns should also target health-care professionals to demystify albinism and counter stigma.

61. Many persons with albinism, particularly in developing countries, live in remote areas with limited access to health-care services. They may need to travel significant distances to get to hospitals or health posts, may not be able to afford the cost of public transportation and may have to walk in harsh conditions. This affects their ability to access health-care services, including free suncare products. To alleviate this, distribution of health goods is sometimes done through associations of persons with albinism. Some States have also reduced the number of times persons have to travel to collect suncare products by providing more products at once to last for extended periods.

62. States should further take steps to ensure health services and professionals are available in more remote areas, including through the use of mobile clinics and through social protection measures. The World Health Organization has developed

<sup>75</sup> Interviewees from Argentina, France, Spain and Turkey.

<sup>76</sup> See <https://ghr.nlm.nih.gov/condition/hermansky-pudlak-syndrome>.

<sup>77</sup> See <https://rarediseases.org/rare-diseases/chediak-higashi-syndrome/>.

<sup>78</sup> See <https://ghr.nlm.nih.gov/condition/griscelli-syndrome>.

recommendations on increasing the number of qualified health-care workers in rural and remote areas through improving retention.<sup>79</sup>

#### 4. Social protection measures

63. Social protection programmes for persons with disabilities are often designed in such a way that persons with albinism are only likely to benefit from them in relation to their visual impairment. In many European countries, for example, persons with disabilities may qualify for a number of subsidies, tax exemptions and rebates, access to free services or products, or cash transfers, depending on the extent of their impairment; however, the procedures for applying for these can be confusing and are often dependent on a medical assessment. Medical professionals often only understand albinism in terms of visual impairment, which hinders their access to other social protection measures which could benefit them.

64. Many countries have social protection measures in place to help with visual impairment. It is possible for persons with albinism to get free assistive devices in Argentina, Brazil, France and Spain as part of social protection measures. However, social protection measures need to extend beyond recognizing visual impairment to include barriers to interaction, such as susceptibility to skin cancer and other complications. The Committee on the Convention on the Rights of Persons with Disabilities has called for States to, “adopt specific measures on persons with albinism in policies on health and disabilities, ensuring the availability, accessibility, affordability and quality of prevention and treatment for skin cancer” (see [CRPD/C/RWA/CO/1](#)).

65. Measures specifically for persons with albinism include the provision of free sunscreen, lip care, after-sun products, protective clothing, screening, detection and treatment of cancer, optometric and ophthalmological tests, and access to visual aids and other forms of adaptive devices, such as monocular, glasses and magnifying glasses. Measures should also consider related costs, such as travel costs to collect products and cost of treatments and the increased susceptibility to skin cancer as a result of walking long distances in the sun. In many countries, particularly in North America, Europe and Latin America, persons with disabilities, including persons with albinism, qualify for free or subsidized public transport. This is in line with target 11.2 of the Sustainable Development Goals which calls upon States to ensure that transportation is “safe, affordable, accessible and sustainable” for all, “notably by expanding public transport, with special attention to the needs of those in vulnerable situations ... and persons with disabilities”. Further, cash transfers, tax exemptions and rebates and subsidies exist in States with social welfare systems. However, the challenge is showing that an individual qualifies for these as a result of to their albinism. Organizations of persons with albinism in countries such as Argentina, France and Spain have assisted persons with albinism in obtaining such benefits, but they do not always reach everyone in the country. Social protection measures should ensure increased social and economic participation, to reduce poverty.<sup>80</sup>

#### 5. Legislation and policies

66. Laws and policies are critical to guaranteeing the rights of persons with albinism to relevant social protection measures and non-discriminatory treatment in public and

<sup>79</sup> WHO, *Increasing Access to Health Workers in Remote and Rural Areas through Improved Retention: Global Policy Recommendations* (Geneva, 2010).

<sup>80</sup> Convention on the Rights of Persons with Disabilities, art. 28; [A/70/297](#); and International Disability Alliance, “Ensuring that the social protection floor works for persons with disabilities”, position paper presented at the Governing Body Meeting of the International Labour Organization, Geneva, November 2011.

private health-care services. In many countries, persons with albinism are not recognized as persons with disabilities, unless they have a visual impairment. Most countries do not recognize sun-care products as essential drugs for persons with albinism. In Turkey, for example, individuals with vitiligo receive free sun-care products, but persons with albinism do not, and they are not recognised as an essential drug.<sup>81</sup> National laws and policies should recognize hyper-sensitivity to the sun as an impairment which substantially impacts health, that sunscreen is an essential drug for persons with albinism, and set out the social protection measures to which they are entitled.<sup>82</sup>

67. In Panama and the Argentine Province of Misiones, there are specific laws on albinism, including declaring 13 June as National Albinism Awareness Day and adopting preventive and other measures for persons with albinism, including in the area of health and education. In Argentina and Brazil, bills on albinism have been proposed which, among other things, would provide for regular skin examination, skin cancer treatment, sun-care products and assistive devices for persons with albinism, while encouraging scientific research and training for health professionals on the care of persons with albinism. Uganda, Nigeria and Puerto Rico have also proposed bills relating to albinism.

## **B. Education**

68. In the report of the Independent Expert report on the applicable international human rights standards and related obligations addressing the issues faced by persons with albinism (see [A/72/131](#)), she notes that a lack of education confines persons with albinism to poverty and outdoor jobs thus exposing them to skin cancer, early death and vulnerability to attacks. Some States and organizations have strategies for improving access to education for persons with albinism,<sup>83</sup> while others have strategies for persons with disabilities which can be tailored for persons with albinism.

### **1. Attitudinal barriers**

69. Students with albinism may not attend school due to stigmatization and bullying by other students, and even teachers at times. Some believe students with albinism cannot learn and that sending them to school is a waste of money. Awareness-raising programmes targeting schools, parents and the community to counter such attitudes could increase the likelihood of parents sending children to school and the community being a positive influence on parents to send them to school. This could reduce incidents of bullying and harassment at places of learning and encourage vigilant responses to such cases.

### **2. Legislation, policies and practice**

70. The Convention on the Rights of Persons with Disabilities calls upon States to ensure inclusive education and reasonable accommodation for persons with disabilities. In addition, the Sustainable Development Goals require States to, “ensure equal access to all levels of education ... for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations” and “provide

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<sup>81</sup> Interviewee from Turkey.

<sup>82</sup> Panama and the Argentine Province of Misiones have specific laws. Argentina, Brazil, Nigeria, Uganda and Puerto Rico have bills relating to albinism.

<sup>83</sup> Federal Republic of Nigeria, Nigerian Educational Research and Development Council, “Core messages on albinism education”, 2017; and see [www.albinism.org/information-bulletin-assisting-students-with-albinism/](http://www.albinism.org/information-bulletin-assisting-students-with-albinism/).

safe, non-violent, inclusive and effective learning environments for all.”<sup>84</sup> To ensure this applies to persons with albinism, elements such as hyper-sensitivity to the sun, and other potentially associated conditions,<sup>85</sup> need to be recognized as impairments affecting the capacity of students with albinism to learn on a level playing field with others. In some countries, children with albinism are placed in schools for visually impaired students. Such schools are not inclusive and do not often provide reasonable accommodation for all the specific needs of children with albinism. Specific measures should be included in legislation and relevant national education policy. This includes sensitizing all teachers and students about the condition of albinism in a way that addresses myths and superstitions, and making reasonable accommodations such as the provision of printed material with large print, assistive devices (magnifying glasses and monoculars); allowing students to sit near the front and away from direct sunlight so they can see the board; using black on whiteboards or white on blackboards, writing in large letters; exempting students from outdoor activities in very hot weather; and permitting them to wear appropriate clothing to protect them from the sun, even when this is not part of the school uniform.

### 3. Physical security

71. In some countries, the distance children need to walk to get to school prevents many from attending. The situation is worsened where children with albinism have to walk in the harsh sunrays to get to school and where there is a risk of physical attack on the way. In Malawi, the national action plan on albinism calls for the placement of learners with albinism in schools with boarding facilities with the police providing security.<sup>86</sup> Boarding schools have also been adopted as a strategy in Tanzania. However, concerns have been raised about the institutionalization of children, overcrowding, unhygienic conditions, the inability of parents to visit their children in the schools due to financial constraints and reports of abuse of children in such places.<sup>87</sup>

72. States need to implement measures to protect children travelling to school. Measures that have been adopted in relation to other vulnerable groups have included school mapping aimed at ensuring that schools are within a reasonable distance to communities, and the provision of transport or transport allowance for those living beyond a certain distance from schools. Increasing police patrols on routes to schools, streetlights where children have to walk home in the dark, for example in winter, and flexible school times to prevent students walking home in the dark have also been used.

### 4. Financial barriers

73. Financial obstacles not only consist of the cost of education, but may include loss of immediate income or human resources through child labour; and miscellaneous costs associated with education, such as transport, uniforms, books, school meals, assistive and adaptive devices, sunscreen, appropriate clothing for protection from the sun and keeping children with albinism safe from attacks. Poverty also affects the health and nutrition of children and those with a poor diet may not be able to concentrate in class even if able to attend. Some States have introduced

<sup>84</sup> Sustainable Development Goal 4, targets 4.5 and 4.a.

<sup>85</sup> Rarer forms of albinism, Hermansky-Pudlak syndrome, Chediak Higashi syndrome and Griscelli syndrome.

<sup>86</sup> Malawi, “National action plan on persons with albinism in Malawi: 2018–2022”, June 2018.

<sup>87</sup> African Committee of Experts on the Rights and Welfare of the Child, “Report on investigative mission on the situation of children with albinism in temporary holding shelters: Tanzania”, March 2016; and [CRC/C/TZA/3-5](#), paras. 29–31.

programmes such as free education, school meals, transport and cash transfers to families to encourage them to send their children to school.

## 5. Policies beyond formal education

74. What happens to individuals before they start formal education impacts their ability to learn and compete effectively in school. Sustainable Development Goal 4 calls for all States to ensure access to quality early childhood development, childcare and pre-primary education for all. States should thus seek to ensure that children with albinism are able to access childcare facilities from an early age. This includes requiring nursery schools to accept children with albinism and extending social protection measures to pre-primary school children.

75. Strategies are needed to assist students with albinism in the transition from school to the workforce. These include offering technical and vocational training targeting skills in high demand and to instil confidence.

## C. Employment

76. Target 8.5 of the Sustainable Development Goals require States to achieve full and productive employment and decent work for all including for persons with disabilities by 2030. A lack of education impacts on access to work opportunities for persons with albinism. However, it is not the only factor. Other barriers include stigma and discrimination which excludes them from being hired, being successful at entrepreneurship, risk of attack and exposure to the sun while commuting, increased risk of attack for children with albinism left at home or with others, and lack of reasonable accommodation being made at workplaces. Some employers believe that persons with albinism are incapable of working productively. Some refuse to employ persons with albinism because of their colouring or appearance, particularly where individuals have developed skin lesions.<sup>88</sup> There have also been cases of persons having job offers withdrawn due to their albinism.<sup>89</sup> States should ensure there is research and data collection in order to fully understand the barriers to work for persons with albinism and put in place measures to counter these barriers, or review relevant policies on disability or minorities to include measures for persons with albinism.

77. In addition to national laws protecting persons with disabilities and minorities, national action plans on albinism will need to tackle attitudinal barriers to accessing work and provide an appropriate legal and policy framework, including requiring workplaces to make reasonable accommodations for persons with albinism and affirmative action programmes for persons with albinism. Social protection measures such as the provision of free transportation, vocational and skills training will further assist in increasing opportunities for work.

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<sup>88</sup> Interviewees from Brazil, China and Malaysia.

<sup>89</sup> Interviewee from Malaysia referred to a case where a woman with albinism had her job offer at a nursery school withdrawn due to prospective employer's belief that her appearance might frighten the children.

## **VI. Guiding principles for implementing national plans of action**

### **A. Multisectoral approach**

78. The participation of multiple State agencies and sectors is required for the prevention, detection and appropriate implementation of health, education and security measures for persons with albinism. Schools, for example, can assist in raising awareness of health needs for students and their parents, minimizing exposure to sun, referring cases to health professionals for early detection of skin cancer, and identifying and minimising security risks for learners with albinism.

79. The prevention of physical attacks, including harmful practices related to accusations of witchcraft and ritual attacks, requires the participation of educators, medical professionals, police, prosecutors, judges, social services and statisticians. If it involves the movement of persons across borders, immigration and border officials will be involved. Effective coordination is essential in developing and implementing the work of all relevant agencies and sectors to ensure adequate exchange of information and that all critical services and responsibilities are carried out efficiently and effectively. Coordination of training sessions and capacity-building of the various agencies can also help in raising awareness of their roles of responsibilities. Another best practice is the coordination centralized at the National Council of Persons with Disabilities in Kenya. Setting up an inter-agency coordination mechanism is a good practice worth replicating.<sup>90</sup>

### **B. International cooperation**

80. Sustainable Development Goal 17 calls for global partnerships in implementing the Goals, including capacity-building for developing States. States should provide technical and financial assistance to other States seeking to strengthen their health services. International cooperation in research, information-sharing, capacity-building, technical and economic assistance is essential in increasing the knowledge base and capacity of States to provide effective healthcare, understand scientific and technological advances in prevention and treatments and in assistive and adaptive devices, and other advances relevant for persons with albinism.

81. International cooperation can enhance resource mobilization, technology, capacity-building, data, monitoring and accountability.<sup>91</sup> The Independent Expert has encouraged and supported the development of action plans and working groups to facilitate regional coordination and collaboration in relation to albinism. Regional coordination can further ensure harmonized messaging around awareness-raising campaigns and trainings, sharing of best practices, and provision of technical or financial assistance for trainings and campaigns.

### **C. Budgeting for rights**

#### **1. Prioritizing persons with albinism**

82. Under international law, States are required to prioritize the implementation of certain minimum core obligations. These include the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable

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<sup>90</sup> See national action plans for Malawi and Mozambique.

<sup>91</sup> Sustainable Development Goal 17.

or marginalized groups; access to freedom from hunger for everyone; and access to free and compulsory primary education.<sup>92</sup> States are also required to ensure revenue is raised, allocated and spent in a manner which addresses inequalities in society (see [A/HRC/29/31](#) and [A/HRC/31/60](#)). In her various official visits and research, the Independent Expert has found that persons with albinism constitute a marginalized group who are among the furthest left behind in many countries. States should therefore ensure that protection measures for persons with albinism are prioritized in the budgeting process, particularly in countries with high ultraviolet radiation, high social ignorance about albinism and with reported attacks.

## 2. Mobilization of resources

83. Lack of sufficient funds is often used as a reason for the failure to implement protection measures. While many States recognize measures requiring funding will only be fully achieved over a period of time owing to resource constraints (progressive realization), (see [E/2007/82](#)) they are still obligated to undertake deliberate, concrete and targeted measures, such as legislative reform, which can be implemented without specific funding. States are also required to use the maximum of their available resources to move expeditiously towards the full realization of rights of concerned groups.<sup>93</sup>

84. This requirement is reinforced by Sustainable Development Goal 17 which calls for economic and technological resource mobilization, including through internal taxation, natural resources, debt and deficit financing, foreign direct investment, Overseas Development Assistance, South-South cooperation, institutional investors, such as pension funds, funds raised by philanthropic foundations, funds raised by non-governmental organizations and remittances sent home by migrants working overseas.<sup>94</sup> The Organization for Economic Cooperation and Development further recommends that States diversify development resources and makes suggestions for more innovative ways of mobilizing resources for the Sustainable Development Goals.<sup>95</sup>

## 3. Ensure non-retrogression

85. States should continue towards the full realization of rights for all. Resources allocated should continue to increase and any economic reforms put in place should not have a retrogressive effect. This is particularly important during this time, when funds are being reallocated to respond to the global pandemic caused by the coronavirus disease (COVID-19) which occurred at the time of preparing the present report. In January 2019, the Independent Expert on the effects of foreign debt and other related international financial obligations of States on the full enjoyment of all human rights, particularly economic, social and cultural rights issued guiding principles on human rights impact assessments of economic reforms. These principles highlight the need for human rights to be at the centre of good policymaking to ensure economic reforms “help advance societies, rather than hinder people’s lives” (see [A/HRC/40/57](#)).

<sup>92</sup> Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) on the right to the highest attainable standard of health; International Covenant on Economic, Social and Cultural Rights, arts. 11 and 13.

<sup>93</sup> International Covenant on Economic, Social and Cultural Rights, art. 2 (1); Convention on the Rights of the Child, art. 4; and Convention on the Rights of Persons with Disabilities, art. 4 (2).

<sup>94</sup> Human Rights, Institute, International Bar Association, *The Obligation to Mobilise Resources: Bridging Human Rights, Sustainable Development Goals, and Economic and Fiscal Policies* (2017); and Organization for Economic Cooperation and Development (OECD), *Development Cooperation Report 2014: Mobilizing Resources for Sustainable Development* (OECD Publishing, 2014).

<sup>95</sup> For example, crowdfunding, advance market commitments and international levies; carbon tax, green bonds and redirection of fossil fuel subsidies.

#### 4. Active participation and transparency

86. States should ensure that the public is able to actively participate in the budgeting process. Specifically, a diversity of persons with disabilities and minorities including persons with albinism, should be consulted and included in the process of allocating funds for different protection measures and in relation to the expenditure of such funds (see [A/HRC/17/34](#)).

87. Participation can only be effective where the State provides comprehensive, clear, reliable, timely and relevant public reporting on the public finances.<sup>96</sup> Appropriate disclosure of information about public finances can be assessed with reference to the International Monetary Fund Fiscal Transparency Code<sup>97</sup> and the Fiscal Transparency Handbook.<sup>98</sup> States should further ensure that there are procedures in place, including judicial and administrative procedures, to provide effective remedies where things go wrong.<sup>99</sup> Such transparency helps strengthen a State's fiscal management, provides an accurate picture of the costs and impact of policies and helps to ensure that budget spending is indeed having the desired impact.

## VII. Conclusions and recommendations

88. **Violations of the rights of persons with albinism continue to be a concern worldwide. While physical attacks predominantly occur in the African context, concerns related to the full enjoyment of the rights to health, education and work are visible globally. Some positive steps have been taken by States to put in place protection measures. Most notable in relation to attacks are the measures taken by countries such as Malawi and South Africa. In relation to visual impairments and reasonable accommodation in schools and workplaces, many of the countries of the European Union and some countries in Latin America and Asia have implemented best practices. However, not enough is being done in these regions in relation to impairments caused by hypersensitivity to the sun and increased vulnerability to skin cancer. The Independent Expert notes that it is mainly countries in Africa, such as Kenya, Malawi and the United Republic of Tanzania, where authorities have put in place specific measures for the provision of free sunscreen products and protective clothing. She notes with concern the paucity of legislative and policy framework specifically providing protections for persons with albinism in the areas of health, education and work. She welcomes the legislation in this regard, in Panama and the Argentine Province of Misiones, and proposed national legislation in Latin America and Africa, including Argentina, Brazil, Nigeria, Uganda and Puerto Rico.**

89. **The Independent Expert once again encourages States to adopt a national plan of action on albinism with specific protection measures in relation to attacks, health, education and work. To this end, countries in Africa should consider domesticating the Regional Action Plan, while other regions can consider adopting relevant measures identified in the supplemental information<sup>100</sup> to the present report.**

<sup>96</sup> See [www.imf.org/external/np/fad/trans/](http://www.imf.org/external/np/fad/trans/).

<sup>97</sup> International Monetary Fund (IMF), "The fiscal transparency code", 2019.

<sup>98</sup> IMF, *Fiscal Transparency Handbook* (Washington, D.C., 2018).

<sup>99</sup> Scottish Human Rights Commission, "Human rights budget work: what, why and how?", 3 September 2019. See also IBAHRI, Footnote 200, pg. 46.

<sup>100</sup> "Protection of human rights of persons with albinism: best practices", see [www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx](http://www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx).

90. In developing action plans in response to the situation of persons with albinism, the Independent Expert recommends that all Member States:

(a) Closely consult with, and actively involve persons with albinism in the development of the national action plans and all decision-making processes related to them;

(b) Consider entering into formal memorandums of understanding with organizations working on albinism on information exchange and cooperation;

(c) Consider and incorporate guidance from the best practices published by the Independent Expert in the supplemental information to the present report;<sup>101</sup>

(d) Carry out a situational analysis, including through research, legislative and policy review, and data collection disaggregated at a minimum by gender, age, health status and rural/urban prevalence, by the numbers of persons with albinism in the country, their specific challenges and needs, the availability of services and the gaps in the provision of such services, laws and policies;

(e) Incorporate a method of ensuring multisectoral coordination and cooperation in the development, implementation and evaluation of the national plan of action, such as setting up an inter-agency coordination mechanism or designating an efficacious focal point or focal entities within a relevant State agency, such as one working with health and disabilities, to facilitate cooperation;

(f) Address root causes of violations through, among other things, putting in place public education and awareness-raising campaigns which seek to demystify the beliefs and superstitions that dehumanize persons with albinism;

(g) Increase the understanding of albinism and the rights of persons with albinism, including what is required to provide them with a level playing field with others in the enjoyment of their rights;

(h) Cooperate with other States, including through research, capacity-building, information exchange, sharing of best practices, technical and financial assistance, for the purposes of increasing the knowledge base and capacity to carry out and improve protection measures;

(i) Continually move towards the full realization of all rights for persons with albinism and ensure transparency and active participation of persons with albinism in resource mobilization, allocation and expenditure;

(j) Prioritize marginalized groups, such as persons with albinism in national budgetary allocations, in accordance with international human rights standards;

(k) Continually monitor and evaluate the impact of measures adopted and adapt such measures as required.

91. The Independent Expert calls on Member States to adopt a resolution condemning harmful practices related to accusations of witchcraft and ritual killings and to bring to justice perpetrators of these violations. She stands ready to provide any necessary support towards this process.

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<sup>101</sup> Ibid.