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including the right to development**

Women and children impacted by albinism

Report of the Independent Expert on the enjoyment of human rights by persons with albinism

Summary

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism provides an overview of the situation of women and children impacted by albinism in different regions of the world. She identifies barriers to the enjoyment of human rights in this context, as well as best practices and recommendations.



I. Introduction

1. The present report is submitted pursuant to Human Rights Council resolutions 28/6 and 37/5 on the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism.
2. Section II provides an overview of the activities undertaken by the Independent Expert since her previous report to the Council (A/HRC/40/62). Section III refers to the methodology used in preparing the report, while section IV focuses on women and children impacted by albinism who are from different regions of the world. It should be noted that in 2017, the Independent Expert dedicated a report to the applicable international human rights standards and related obligations addressing the issues faced by persons with albinism, including women and children (A/72/131). The present report should be read with these safeguards in mind.

II. Activities of the Independent Expert

3. Since presenting her previous report to the Human Rights Council at its fortieth session, held in March 2019, the Independent Expert undertook a country visit to South Africa from 16 to 26 September 2019. The report of that visit will be issued as an addendum to the present report. She also visited Brazil, from 28 October to 8 November 2019. The report of that visit will be presented at the forty-sixth session of the Council.
4. During its thirty-fifth ordinary session, the African Union Commission adopted as policy the Regional Action Plan on Albinism in Africa (2017–2021).¹ The Plan was jointly developed by the Independent Expert and various stakeholders in the region, including organizations at the frontline of promoting the enjoyment of human rights by persons with albinism. The African Union also decided that a special envoy would be appointed in 2020 to ensure the implementation of the Plan. Within the framework of the outcome of the 2012 dialogue between the special procedure mandate holders and the African Commission on Human and Peoples' Rights (the road map agreed in Addis Ababa), the Independent Expert engaged African Union mechanisms in the achievement of these important milestones, and intends to continue to provide technical assistance and advisory services in this regard.
5. Throughout 2019, the Independent Expert organized and conducted numerous advocacy activities around the world, including a series of capacity development workshops for civil society organizations across the African region.² She collaborated with academic institutions, United Nations agencies and the private sector in side events and consultations. She also engaged with partners in conducting comprehensive research on the issue of harmful practices relating to so-called witchcraft, a phenomenon that has led to attacks against, ritual killings of and ritual rape of persons with albinism, particularly women and children.
6. In addition, the Independent Expert provided support to various awareness-raising campaigns within the context of International Albinism Awareness Day on 13 June, which included innovative advocacy tools such as the launching of billboards featuring persons with albinism in New York City's Times Square. She also continued to collaborate closely

¹ The Executive Council of the African Union, during its thirty-fifth ordinary session, held in Niamey from 4 to 5 July 2019, adopted and requested the African Union Commission to facilitate the implementation of the Regional Plan of Action on Ending Attacks and Discrimination against People with Albinism. See also A/HRC/37/57/Add.3.

² With the support and collaboration of the Centre for Human Rights at the University of Pretoria, Open Society Initiative for Eastern Africa, for Southern Africa and for West Africa, the Ford Foundation, the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the United Nations country team in Mozambique, and the Office of the United Nations High Commissioner for Human Rights in Uganda.

with the Pan-African Parliament, particularly on the development of regional guidelines on harmful practices relating to abuse of witchcraft.³

7. Summaries of allegation letters sent by the Independent Expert during the reporting period are available in the communications reports of special procedures (A/HRC/41/56 and A/HRC/42/65). The Independent Expert continued to focus on earnest, constructive dialogue with Member States and various stakeholders, through formal and informal channels.

III. Methodology

8. On 29 March 2019, the Independent Expert sent a questionnaire to stakeholders, including Member States, United Nations offices, national human rights institutions, civil society organizations and individuals, including persons with albinism.⁴ The present report is largely based on the compilation of the information received from 97 stakeholders, as well as research⁵ and findings from the Independent Expert's country visits.⁶ The submissions received were primarily from Africa, followed by Latin America and Europe. Some information was also received from Asia and the Pacific, and very little from the Middle East and North Africa.

9. The Independent Expert hopes that the present report will shed light on the situation of women and children impacted by albinism, including women and children with albinism, as well as mothers of children with albinism. She hopes to encourage much-needed discussion, data collection and research on issues affecting this group. The Independent Expert notes that repeated references to particular countries and regions in the present report is due to either the quality or the quantity of inputs received in stakeholders' submissions.

Definition

10. 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. Persons with albinism are highly vulnerable to skin cancer and often have disabilities, mainly as a result of vision impairment and skin impairment. Attitudinal barriers exacerbate discrimination faced by persons with albinism. In addition to disabilities, persons with albinism are recognized as persons who face racial discrimination and stigmatization on the ground of colour (CERD/C/ZAF/CO/4-8, paras. 20–21).

IV. Intersecting and multiple discrimination

11. Among persons with albinism, women and children in particular often face intersecting and multiple forms of discrimination.⁷ Multiple discrimination entails situations or experiences where discrimination intersects on two or more grounds, thus compounding

³ See also the Pan-African Parliament's resolution on persons with albinism in Africa (PAP.4/PLN/RES/05/May.18).

⁴ The list of the submissions received by the Independent Expert is available at www.ohchr.org/EN/Issues/Albinism/Pages/Submissions.aspx. The majority of the submissions were from civil society organizations. She also received submissions from the Governments of the Plurinational State of Bolivia, Colombia, Ecuador, Guatemala, Kenya and Slovenia (as indicated in the relevant footnotes).

⁵ The Independent Expert expresses her appreciation to the International Human Rights Program at the University of Toronto Faculty of Law and to Duncan Dixon, Research Librarian, Trinity Western University, Canada.

⁶ See www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx. The present report also supplements the Independent Expert's report on albinism worldwide (A/74/190).

⁷ See www.ohchr.org/Documents/Issues/Women/WRGS/Report/SpecialProcedures/albinism.docx.

and aggravating the discrimination experienced by a person.⁸ Intersecting discrimination refers to a situation where several grounds for discrimination exist and interact in such a way that they are inseparable.⁹

12. In persons with albinism, disability and colour intersect in a way that is inseparable and often results in prejudices and discrimination that manifest as human rights violations ranging from bullying to violence and attacks. Furthermore, gender and disability are two separate factors which, when combined in the same person, usually reinforce and compound prejudices.¹⁰ Thus, women and girls with disabilities are often at a higher risk of discrimination and exclusion (A/71/314, para. 30). They are also more likely to be subjected to violence, abuse, neglect and multiple human rights violations (A/73/161).

13. In its preliminary report on persons with albinism, the Office of the United Nations High Commissioner for Human Rights (OHCHR) recognized the severity of the human rights violations committed against persons with albinism in many countries, including the multiple and intersecting forms of discrimination that children and women face (A/HRC/24/57, para. 84). It noted that children with albinism are particularly targeted for ritual killings, and women with albinism are sometimes victims of sexual violence (para. 74). The Secretary-General recognized that mothers of children with albinism may face rejection, ostracism and discrimination, which makes them and their child particularly vulnerable to isolation, poverty and attacks (A/72/169, para. 52).

14. Protection against multiple and intersecting discrimination affecting persons with albinism is enshrined in international human rights law and jurisprudence. In this respect, several treaty bodies have applied non-discrimination provisions of human rights treaties to the situation of persons with albinism.¹¹

15. The Committee on the Elimination of Discrimination against Women recognizes intersectionality as a fundamental notion for understanding the scope of the general obligations of States contained in article 2 of the Convention on the Elimination of All Forms of Discrimination against Women (A/HRC/35/10, para. 7). As such, the Committee, in its general recommendation No. 28 (2010) on the core obligations of States parties under article 2 of the Convention, states that the discrimination of women based on sex and gender is inextricably linked with other factors affecting them, such as race, ethnicity, religion or belief, health, status, age, class, caste, and sexual orientation and gender identity. The Committee calls on States parties to legally recognize such intersecting forms of discrimination and their compounded negative impact on the women concerned, and to adopt policies and programmes designed to eliminate such occurrences (para. 18).

16. The Committee also recognizes the situation of women with albinism under the concept of disadvantaged groups of women, noting the multiple forms of discrimination that they face.¹² Similarly, the Committee on the Rights of Persons with Disabilities has emphasized the need for protective measures against multiple and intersecting forms of discrimination faced by persons with disabilities, including women with albinism.¹³

⁸ Committee on the Elimination of Discrimination against Women, general recommendation No. 25 (2004) on temporary special measures, para. 12, and A/72/131, paras. 8 and 22.

⁹ Committee on the Elimination of Discrimination against Women, general recommendation No. 28, para. 18, and A/72/131, para. 8.

¹⁰ Committee on the Rights of Persons with Disabilities, general comment No. 3 (2016) on women and girls with disabilities.

¹¹ E/C.12/BFA/CO/1, E/C.12/BDI/CO/1, E/C.12/UGA/CO/1, E/C.12/COD/CO/4 and Corr.1, E/C.12/TZA/CO/1-3, CRC/C/CAF/CO/2, CRC/C/COD/CO/3-5, CRC/C/MWI/CO/3-5, CRC/C/TZA/CO/3-5, CRC/C/COG/CO/2-4, CRC/C/KEN/CO/3-5, CCPR/C/GHA/CO/1, CCPR/C/MWI/CO/1/Add.1, CCPR/C/BDI/CO/2 and Corr.1, CCPR/C/TZA/CO/4, CCPR/C/KEN/CO/3, CCPR/C/CIV/CO/1, CEDAW/C/BDI/CO/5-6, CEDAW/C/TZA/CO/7-8, CEDAW/C/SWZ/CO/1-2, CEDAW/C/MWI/CO/7, CRPD/C/ETH/CO/1, CRPD/C/UGA/CO/1 and CRPD/C/KEN/CO/1.

¹² See CEDAW/C/BDI/CO/5-6, CEDAW/C/TZA/CO/7-8, CEDAW/C/SWZ/CO/1-2 and CEDAW/C/MWI/CO/7.

¹³ See CRPD/C/UGA/CO/1.

A. Albinism: related issues disproportionately affecting women

17. Albinism is a condition that can affect individuals and their families medically, socially and psychologically. For some, the social and psychological issues may be more of a burden than the actual medical complaints.¹⁴ Based on available reports and the submissions received, it is safe to conclude that the weight of global suffering surrounding albinism is disproportionately borne by women with albinism and mothers of children with albinism.

18. The elements described below were identified in stakeholder submissions from East, West, South and Central Africa. Submissions from other regions also referred to a number of these issues, even in situations that did not relate to violence or attacks.

19. Blame and abandonment after having a child with albinism: This often entails a significant lack of awareness of how albinism occurs and the fact that it is a genetic condition inherited from both parents. Consequently, the lack of understanding of the condition has a detrimental impact on parents of children with albinism, with a disproportionate impact on the mother. The mother is often blamed for causing the pale colouring of a child with albinism. She is often accused of infidelity or of having a curse that is manifested in the child's appearance. As a result, mothers are often abandoned by their partners or spouses on the grounds that they have been unfaithful, given the child's different skin colour. Isolation and expulsion from the community is also commonplace due to the belief that the child with albinism is a curse on the community. Self-removal from the community by mothers of children with albinism also takes place in some cases to avoid hostility and exclusion from community members.

20. Poverty: Due to abandonment by their spouses or partner upon the birth of the child with albinism, and the ensuing situation of being a single parent, mothers of children with albinism often face abject poverty. This exposes the child with albinism to continuous poverty, especially as the child is generally unable to receive a proper education or, thereafter, opportunities for gainful employment.

21. Health risk: Due to a general lack of education with a view to obtaining adequate work, including indoor employment, women and girls with albinism often take on various types of menial work outdoors. Long-term work outdoors in the sun results in a high risk of contracting skin cancer. Moreover, hypervisibility and constant discrimination in nearly all spheres of their life often mean that women and children with albinism are at a high risk of facing psychosocial challenges that often negatively impact their social relationships and aggravate their social exclusion.

22. Sexual violence: Women with albinism are often targets of sexual violence. This is frequently due to fetishes, myths and misbeliefs that result in rape and sexual assaults. In some countries, it is also due to the prevalent myths that sexual intercourse with women with albinism can cure HIV and can confer good luck. These myths continuously expose these women to violence and increase their vulnerability to unwanted pregnancies and to contracting various sexually transmitted infections.

23. Heightened vulnerability to attacks: In places where attacks against persons with albinism have been reported, poverty, expulsion and isolation often leave the mother and her child with albinism vulnerable to attacks. A significant number of attacks tend to happen against those who have been removed or isolated from the community and against the poorest families of children with albinism. In this context, poverty can also mean that women are unable to afford safe and secure housing, which is a necessary protection against attacks.

24. Victims of impunity: Women have been recognized by both the Committee on the Elimination of Discrimination against Women and the African Committee of Experts on the Rights and Welfare of the Child as being particularly at risk in conflict and disasters and affected by violence more frequently and severely than others, often falling victim to

¹⁴ See, for example, Esther S. Hong, Hajo Zeed and Michael H. Repacholi, "Albinism in Africa as a public health issue", *BMC Public Health*, vol. 6 (2006).

violent acts committed clandestinely and with impunity. In this context, women with albinism are at extreme risk of violence, particularly in regions where attacks abound due to myths and misconceptions about albinism.

25. Reprisals: Women whose spouses, partners and family members were involved in attacks against their child with albinism often face threats of reprisal after testifying against their relatives during investigations and the prosecution process. The threats of reprisal reportedly come from relatives and the community at large.

26. Displacement: Both women with albinism and mothers of children with albinism have been displaced in the wake of physical attacks against persons with albinism in general. Many have gone to shelters set aside for them by governments to provide temporary safety. Some enter the shelters voluntarily and others enter through government and community intervention. Women and children with albinism constitute a significant number of the residents at these shelters, where often, minimal care is provided to them, particularly in the areas of psychosocial support, education, health treatment to prevent skin cancer and low vision support to enable education.

B. Barriers to the enjoyment of human rights

1. Stigma and social exclusion

27. Mothers of children with albinism in parts of Africa, the Caribbean and Latin America are often accused of infidelity, of being solely responsible for their child's albinism or of bringing a curse into the family.¹⁵ There are also instances when women who give birth to children with albinism are expelled from the community because of concerns that they might give birth to more children with albinism, or that they will cause other women in the community to have children with albinism.¹⁶ Some have left the community in order to ensure their own safety or that of their child with albinism.

28. Many have been expelled from their matrimonial homes, are divorced and face persistent ridicule.¹⁷ In one submission from Colombia, it was reported that some people believe that albinism is contagious, leading to social exclusion. The rejection of women with albinism and mothers of children with albinism exposes them to poverty and isolation in many countries, and increases their vulnerability to attacks in others.

29. Government-induced displacement is not particularly common, but the Government of the United Republic of Tanzania did set up temporary holding shelters for children with albinism and their guardians in order to ensure their safety from attacks. Unfortunately, the shelters became a medium to long-term solution and they are no longer considered to be in the best interest of the child. During an on-site visit to such shelters in the United Republic of Tanzania, the African Committee of Experts on the Rights and Welfare of the Child noted that although the shelters had been established by the Government with the intention of protecting children with albinism, they did not meet the minimum standards to house children.¹⁸ In 2016, the Independent Expert visited the shelters and noted some improvement in the living conditions. She made recommendations for further improvement and for the immediate and safe reintegration of the children into the community (A/HRC/37/57/Add.1, para. 107 (b) and (c)). Information on progress on the reintegration process was not available at the time of writing of the present report.

30. Both quantitative and qualitative data on specific vulnerabilities faced by children with albinism, including stigma and social isolation, are largely unavailable. Disaggregated data on children with albinism, including by sex, are also unavailable. However, some submissions received stated that girls with albinism often face a heightened risk of sexual

¹⁵ Submissions from Colombia, Haiti (Fondation ALBHA) and Zimbabwe.

¹⁶ Submissions from Côte d'Ivoire, Eswatini and Zimbabwe.

¹⁷ Submissions from Kenya and Zimbabwe.

¹⁸ 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" (Addis Ababa, 2016).

harassment and violence, particularly in parts of Africa and Latin America, for reasons including superstitions, fetishes and curiosity due to their colouring and appearance. Girls with albinism are often insulted for not conforming to, or for attempting to conform to, the prevailing standard of “beauty”. Boys with albinism who are disowned by their fathers reportedly suffer from low self-esteem and psychological trauma linked to the lack of a father figure, particularly in patriarchal societies. This is also due to the multiple and intersecting discrimination they experience because of albinism.¹⁹

31. Bullying of children with albinism was reported in all regions. The problem was particularly dire in schools in rural areas. For instance, in some parts of Africa, due to systemic overcrowding and poor learning conditions, particularly in rural public schools, teachers rarely had the time to address the bullying and social isolation faced by children with albinism, or any interest in doing so.²⁰ Furthermore, many teachers are simply unaware of or insensitive to the educational needs of learners with albinism or lack any knowledge of how to provide reasonable accommodation for them.²¹

32. Bullying incidents are not limited to school settings.²² In several regions, children with albinism are bullied in various spheres of society. A non-governmental organization in Japan stated that bullying is still notable in some local schools, largely due to the hair colour of children with albinism. Given the lack of an effective response from school authorities to end the bullying, many parents change their children’s hair colour to black so that they are accepted by their peers and school authorities. In some cases, children have been instructed by school authorities to dye their hair black.

33. Within various communities across Africa, the Caribbean and Latin America, children with albinism also face stigma instigated by adults. For instance, submissions received indicate that adults fuel the exclusion of children with albinism by warning their own children against playing with children with albinism.²³ In Africa, because the rate of abductions and killings of persons with albinism is particularly high for children, parents of children with albinism often keep them hidden and prevent them from taking part in social interactions. Hiding may also occur in order to reduce stigma on the family.²⁴ Hiding, for whatever reason, deprives children with albinism from having healthy social relationships, unlike their peers without albinism. This has an adverse effect on their mental and social development.

34. To avoid bullying and discrimination and enhance safety, some children have been taken to, or have chosen to attend, special schools such as schools for children with visual impairment. Social inclusion in special schools is sometimes problematic, and learners with albinism can continue to face bullying even in these schools. Moreover, these schools often promote segregation and not integration, especially when they provide a curriculum that is limited in comparison to that offered in mainstream schools.

35. As a result of incessant bullying, insults, rejection, isolation, exclusion and overall discrimination, both in and out of school, children with albinism across the world tend to develop low self-esteem and mental health and psychosocial challenges,²⁵ including anxiety, depression²⁶ and suicidal ideation. Others succumb to alcohol and drug abuse as an antidote against discrimination and stigma.²⁷

¹⁹ Submission from Kenya.

²⁰ Submission from Zimbabwe.

²¹ Submissions from Burundi, Cameroon, Côte d’Ivoire, Kenya, Mali, Mozambique, Niger, Nigeria, Senegal, Uganda and Zimbabwe.

²² Submissions from Argentina, Colombia, Haiti and Venezuela (Bolivarian Republic of).

²³ Submissions from Burundi, Cote d’Ivoire and Turkey.

²⁴ Submissions from Colombia and Uganda.

²⁵ Submissions from Colombia and Haiti (Fondation ALBHA).

²⁶ Submissions from Argentina, Colombia and Ecuador. See also A.J. Samdani and B.K. Khoso, “A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study”, *Iranian Journal of Dermatology*, vol. 12, No. 2 (2009).

²⁷ Submissions from Colombia, Kenya, Mali and Senegal.

36. Psychosocial support is rarely available to address these challenges, either in schools or at the community level.²⁸ Mothers of children with albinism also often suffer from depression and lack a support system, which sometimes has drastic consequences. For instance, a woman in Gboko, Nigeria, killed her baby with albinism after her husband's family threatened to expel her if she failed to do so.²⁹

2. Access to education

37. Although children with albinism are generally guaranteed access to education as any other child, there are significant challenges in ensuring the provision of sufficient support for them in school.³⁰ Teachers often do not have sufficient knowledge on how to provide reasonable accommodation or a generally supportive learning environment for children with albinism.³¹ In some cases, teachers are trained to support children with visual impairments only, as opposed to the whole spectrum of what albinism entails.³²

38. Some public schools provide a certain level of reasonable accommodation, such as seats in the front row during class sessions, copies of teachers' notes, and adjusted uniforms for sun protection, among other measures.³³ However, more systematic attempts at ensuring such accommodation are rarely made in developing countries, which is often attributed to limited resources. In a survey conducted in Sierra Leone, 57 per cent of school-age respondents with albinism said that their schools did not provide them with the necessary support and accommodation to enable them to access education on equal terms with others.³⁴ In Zimbabwe, large print materials are sometimes available upon request, but students with albinism are not aware that they can access these resources and teachers often do not request them.³⁵

39. Similar situations were noted in Latin American countries, where the lack of accommodation for students with low vision is often the main barrier to education.³⁶ For instance, in a submission from Colombia, it was noted that adaptive devices are expensive and inaccessible to learners with albinism.³⁷ Even where visual aids and devices are available, students with albinism and their schools may be unaware of their availability.

40. In other submissions, it was noted that government assistance is available only if children meet certain criteria. For instance, a submission from Japan indicates that, as children with albinism are not recognized as being disabled, approximately 60 per cent of them fail to obtain a disability certificate from the Government,³⁸ which would otherwise facilitate access to the necessary services and resources. In some cases where resources are available, provision of supportive devices to children with albinism are neither taken into account nor prioritized. This is in spite of the existence of legislative provisions for reasonable accommodation for persons with disabilities.³⁹ Submissions from Europe listed several commendable measures. Children with albinism generally have easier access than elsewhere to adaptive devices, such as large-print books and specialized glasses. However, this was not always guaranteed throughout the education system. An organization working on albinism in Norway notes that assistive devices are generally available throughout childhood education, but not necessarily in higher education.

41. Due to attacks against persons with albinism in some parts of Africa, many parents have stopped sending their children with albinism to school, while others send them to

²⁸ Submission from Kenya.

²⁹ Submission from Nigeria.

³⁰ Submission from Japan.

³¹ Submissions from Colombia and Japan.

³² Submission from Burkina Faso.

³³ Submissions from Malawi and United Republic of Tanzania.

³⁴ Submission from Sierra Leone.

³⁵ Submission from Zimbabwe.

³⁶ Submissions from Argentina, Chile, Colombia, Ecuador, Haiti and Venezuela (Bolivarian Republic of).

³⁷ Submissions from Argentina and Paraguay.

³⁸ Submissions from Colombia and Japan.

³⁹ Submission from United Republic of Tanzania.

school before the normal age of school entry because of fear of attacks, prejudice or concerns about their children's learning ability.⁴⁰ In some instances, children with albinism have also been rejected by school authorities on the misconception that they are unable to learn in mainstream schools.⁴¹

42. While the school attendance rate for children with albinism in Australia and Japan is almost 100 per cent, the dropout rate in parts of Latin America is quite high, particularly among children with albinism from poor families, who leave school to seek work to support their families.⁴² The dropout rate is also reportedly high in Burkina Faso, where 30 per cent of girls with albinism do not finish primary school.⁴³ In Burundi, 56 per cent of persons with albinism have not completed their schooling and 20 per cent of girls with albinism do not finish primary school.⁴⁴ A Zambian civil society organization estimates that only 3 out of 3,000 children with albinism finish primary school.

43. Reasons for dropping out include: (a) incessant bullying by both students and teachers; (b) poverty and an inability to pay tuition fees;⁴⁵ (c) challenges in obtaining or a lack of support for using adaptive devices;⁴⁶ and (d) a lack of sun protection supplies to use during sporting or outdoor activities. All of these factors adversely affect learning.⁴⁷ Children with albinism who have to travel long distances to school often drop out because of high risks of long-term sun exposure while walking to and from school, and due to fear of being attacked on the way to school.⁴⁸

3. Access to health

44. The majority of submissions indicated that access to health care, especially for those residing in rural areas, is a significant challenge for many women and children impacted by albinism.⁴⁹ For example, in the United Republic of Tanzania, reportedly only 42.7 per cent of persons with albinism living in the Buhangija and Mitindo temporary holding shelters have access to health services.⁵⁰

45. Barriers faced by women and children impacted by albinism in health care include: (a) the poor quality of general health services in public hospitals; (b) the high cost of health services, especially with regard to skin cancer prevention and treatment; (c) insufficient health information on albinism; and (d) negative and discriminatory attitudes from health professionals regarding albinism.⁵¹ Even in instances where public hospitals provide free health services, there is a lack of support for eye-care services and skin cancer prevention.⁵² There are very few specialists available to respond to the particular issues faced by persons with albinism. For instance, in Colombia it can reportedly take up to two years to see a dermatologist.

46. Health care is further restricted for women with albinism and mothers of children with albinism when they have been expelled from their community. In Guinea, women with albinism are expelled from their families due to the odour associated with festering and

⁴⁰ Submissions from Kenya, Malawi, Mozambique and Uganda.

⁴¹ Submissions from Burundi, Côte d'Ivoire, Kenya and Nigeria.

⁴² Submission from Colombia.

⁴³ Submission from Burkina Faso.

⁴⁴ Submission from Burundi.

⁴⁵ Submissions from Burundi, Cameroon, Kenya and Uganda.

⁴⁶ Submissions from Burundi, Cameroon, Côte d'Ivoire and Eswatini.

⁴⁷ Submissions from Burundi and Uganda.

⁴⁸ Submissions from Cameroon, Eswatini, Guinea and Uganda.

⁴⁹ Submissions from Angola, Burkina Faso, Burundi, Cameroon, Colombia, Côte d'Ivoire, Guinea, Kenya, Malawi, Mozambique, Niger, Nigeria, Sierra Leone, Somalia, South Africa, Uganda, United Republic of Tanzania and Zimbabwe.

⁵⁰ Submission from United Republic of Tanzania.

⁵¹ Submissions from Burundi, Colombia, Kenya, Mozambique, Nigeria, South Africa and Uganda.

⁵² Submissions from Côte d'Ivoire, Democratic Republic of the Congo, Ghana, Mali, Niger and Uganda.

untreated skin cancer.⁵³ Their resulting isolation further restricts their access to health treatment for the cancer.

47. In other countries, the lack of availability of health insurance coverage for albinism-related health conditions or products, or the cost of such insurance, pose additional barriers.⁵⁴ Submissions from Argentina and Paraguay highlighted the high costs of adaptive devices and sunscreen, which makes them unaffordable for a significant number of mothers of children with albinism.

48. Many mothers around the world who have children with albinism rarely have access to specialists who have information on the condition. Therefore, the early health intervention crucial to their child's development is rarely available to them.⁵⁵ Thus, mothers of babies and young children do not often have the necessary information on how to take care of their child with albinism, including information on vision impairment and measures to protect them from skin cancer.⁵⁶ This can lead to the development of skin cancer that could have been easily prevented. Moreover, the lack of adequate health information on albinism has also led to distress, depression and self-blame among mothers of children with albinism. Mothers reportedly suffer from postnatal depression after giving birth to a child with albinism and are not adequately informed about their rights to available services for the child and the necessary psychosocial care and support.⁵⁷

49. Sometimes, owing to their limited understanding of albinism, health professionals give parents of children with albinism incorrect information.⁵⁸ A submission received from Turkey indicates that some health professionals have erroneously told parents that their baby with albinism would never be able to see and that they cannot leave the house because of potential sun damage.⁵⁹ A submission from Mexico, among others, also noted that some mothers of babies with albinism have been told that the condition would result in total blindness, which is not usually the case.

50. To compensate for the lack of support in national health systems, several non-governmental organizations around the world⁶⁰ provide support to new parents of children with albinism. Such work should be increasingly supported by States and development partners.

4. Sexual and reproductive health

51. Civil society organizations in several countries reported that women and girls with albinism have limited or no access to sexual and reproductive health services. Reasons provided include stigma and discrimination from health-care providers.⁶¹

52. Access to maternal health care is another challenge in some countries. Midwives, who are often the first contact with babies with albinism when they are born, often lack the knowledge to give sound advice to concerned parents.⁶² In some cases, health professionals repeat prevailing myths about albinism or give parents erroneous information. This discourages mothers of children with albinism from seeking services, including for their sexual and reproductive health.

⁵³ Submission from Guinea.

⁵⁴ Submissions from Burkina Faso, Cameroon, Eswatini, Ghana, Kenya, Mali, Mozambique, Nigeria, South Africa, United Republic of Tanzania, Uganda and Zimbabwe.

⁵⁵ Submissions from Angola, Burkina Faso, Ghana, Japan, Kenya, Mozambique, Uganda and Zimbabwe.

⁵⁶ Submissions from Eswatini, Kenya, Mozambique, Nigeria, Somalia and United Republic of Tanzania.

⁵⁷ Submission from Eswatini.

⁵⁸ Submissions from Argentina, Colombia and Paraguay.

⁵⁹ Submission from Turkey.

⁶⁰ Submission from New Zealand (Albinism Trust). See also www.albinism.org/information-for-parents-grandparents-and-caregivers/.

⁶¹ Submissions from Ghana, Kenya, Japan, Jordan, Mali, Slovenia (Government), Uganda and United Republic of Tanzania.

⁶² Submission from Kenya.

53. In some cases, health professionals will not attend to persons with albinism, believing that they are foreigners who cannot speak the local language and preferring to address a family member or a companion instead.⁶³ For women, this sometimes means that the presence of a companion is mandatory or makes things easier, even during personal appointments, such as gynaecological check-ups. This lack of privacy and dignity deters women from accessing sexual and reproductive health services, which are highly sensitive in nature.

54. In some instances, women with albinism who get pregnant are encouraged to abort the baby on the grounds that their baby will be born with albinism.⁶⁴ Some health providers reportedly find it strange, when dealing with women with albinism who are seeking maternity services, family planning or other consultations relating to sexual and reproductive health, that a woman with albinism has had sexual relationships.⁶⁵

5. Access to information and meaningful participation in decisions that affect women and children impacted by albinism

55. Lack of education is one of the main obstacles that women with albinism face in obtaining information, including about their rights. The inaccessible format of pertinent information is also a critical challenge, for instance, information that is not compatible with adaptive or assistive devices.⁶⁶ Language barriers are also a challenge, including the use of technical and complex terminology that many persons with albinism cannot understand due to their level of education.⁶⁷ The fact that women impacted by albinism are at a heightened risk of social isolation and ostracism also results in inadequate access to information on an equal basis with others. This results in a lack of participation in the spheres of life where such information is essential, including health, education, employment and family life.

56. Several submissions indicate that women with albinism are largely absent from decision-making forums that concern them.⁶⁸ Moreover, platforms to ensure meaningful engagement of women with albinism, particularly in decisions that affect them, are generally non-existent. Meaningful participation enables the advancement of all human rights. It plays a crucial role in the promotion of democracy, the rule of law, social inclusion and economic development and is essential for reducing inequalities and social conflict.⁶⁹ As such, the meaningful participation of women and children impacted by albinism is crucial to the realization of their rights.

57. While the number of civil society organizations representing persons with albinism is growing, these organizations often do not know about or use a human rights-based approach. That said, these groups are considered critical platforms in which persons with albinism can advocate for their interests, including their rights. However, the extent to which issues affecting women and children impacted by albinism are adequately captured in such settings is not clear. There is also little to no information on whether women hold decision-making positions in those platforms or whether there are deliberate mechanisms to allow for their participation in decision-making.

58. In Eswatini, persons with albinism are sometimes unable to participate in public and political engagements at the community level because of health risks. The prevailing culture dictates that wearing a hat is disrespectful when going to community meetings, which are usually conducted outdoors in the sun.⁷⁰ A similar situation was reported to the

⁶³ Submission from Colombia. This is due to the distinct appearance of a person with albinism – a pale complexion is associated with foreigners.

⁶⁴ Ibid.

⁶⁵ Submission from Venezuela (Bolivarian Republic of).

⁶⁶ Submissions from Colombia, Malawi, United Republic of Tanzania, Zambia and Zimbabwe.

⁶⁷ Submission from Eswatini.

⁶⁸ Submissions from Eswatini, Malawi, Mozambique, Nigeria, Somalia and United Republic of Tanzania.

⁶⁹ See the guidelines for States on the effective implementation of the right to participate in public affairs.

⁷⁰ Submission from Eswatini.

Independent Expert during her visit to Fiji, where in some rural areas, wearing hats and sunglasses in certain contexts, even for sun protection, is seen as socially inappropriate behaviour (A/HRC/40/62/Add.1, para. 34).

59. There are rare instances in which women with albinism have created their own platforms to advance their interests. They include women who have established organizations focused on public education on albinism, women who are using the media to advocate for persons with albinism, and women who are using cultural platforms such as pageants and sporting events to raise awareness and advocate for the rights of persons with albinism.⁷¹ Some women with albinism have also become renowned models and public figures, using their public status to raise awareness and advocate for issues relating to albinism. In addition to these examples, there are less targeted efforts to ensure inclusion and meaningful participation of women with albinism in decision-making spaces.

6. Access to an adequate standard of living

60. There is general consensus, particularly among organizations working on the rights of persons with albinism in parts of Africa, Asia and Latin America, that many women and children impacted by albinism live in dire poverty.⁷² This reflects the general correlation between disability and poverty.⁷³ It is also linked to single motherhood and situations where women have been subjected to stigma, isolation and ostracism.⁷⁴ Such isolation limits their meaningful participation in income-generating activities, subjecting them to a perpetual cycle of poverty. In addition, dropping out of school early often results in limited economic opportunities.

61. In countries where persons with albinism are reportedly victims of attacks, mothers of children with albinism constantly factor their children's safety into their daily lives. Others stay at home to care for their child part-time or full-time, given the difficulty in finding a caregiver who is willing or able to look after a child with albinism. For instance, some mothers of children with albinism take their children to and from school, and sometimes wait at the school premises until their child finishes school in order to ensure their safety.⁷⁵

62. The fact that many women with albinism have not received a proper education hampers their ability to obtain gainful employment opportunities, including indoors.⁷⁶ Many therefore work in the informal sector, pursuing work in agriculture or street peddling.⁷⁷ This exposes them to skin cancer, which further limits their capacity to work. In addition, women with albinism in Africa often cannot work night shifts due to the threat or fear of attacks.⁷⁸ Many alter their working hours to ensure that they work only during daylight, which in turn limits their employment opportunities. In addition, employers generally do not have security measures in place to ensure the protection of women with albinism from sexual harassment and exploitation, which may be instigated by harmful myths and misconceptions.

63. In nearly every region, many women with albinism who have access to employment are unable to work effectively as some employers are unwilling to incur the costs of reasonable accommodation for women with albinism.⁷⁹ This is the case even when there are legislative provisions in place prohibiting discrimination based on disability. Moreover,

⁷¹ Submission from Kenya.

⁷² Submissions from Africa and from Colombia and Ecuador. See also Samdani and Khoso, "A unique albino village of Bhatti tribe in rural Sindh, Pakistan".

⁷³ Gerard Quinn and Theresia Degener, "Human rights and disability: the current use and future potential of United Nations human rights instruments in the context of disability" (Geneva, OHCHR, 2002). See also A/73/181.

⁷⁴ Submission from Japan.

⁷⁵ Submission from Eswatini.

⁷⁶ Submissions from Eswatini and Uganda.

⁷⁷ Submissions from Ghana and Uganda.

⁷⁸ Submissions from Colombia and Eswatini.

⁷⁹ Submissions from Cameroon, Kenya, Mozambique and United Republic of Tanzania.

some employers discriminate against women with albinism based on the prejudice that persons with albinism cannot work effectively or are less capable of working than their peers.⁸⁰ Some employers reportedly do not want to hire women with albinism because they are concerned that they might scare away potential customers due to their colouring and appearance.⁸¹ In some cases, both employers and employees express resistance to working with someone with albinism due to prejudices about albinism.⁸²

64. Many women with albinism who pursue their own businesses as entrepreneurs face discrimination, as potential customers refuse to enter into transactions with a person with albinism.⁸³ This is particularly the case in regions where albinism is hypervisible. Pursuing business interests is problematic for women with albinism living in poverty as they often have difficulty accessing loans because many are uneducated and lack the necessary capital or assets to serve as the collateral security required for loan applications.⁸⁴ Women with albinism also face difficulties in accessing community initiatives on financial savings and loans due to prevailing stigma and discrimination, as well as myths that persons with albinism disappear and will not therefore pay money back to the community lender.⁸⁵

65. Economic empowerment initiatives supporting women with albinism and mothers of children with albinism are particularly limited. Initiatives supporting persons with albinism continue to be modelled on acts of charity and not designed from a human rights-based perspective. This perception limits strategic interventions from women with albinism and mothers of children with albinism that could positively transform these initiatives into true access, enabling those women to benefit from available economic opportunities. Thus, women with albinism rarely exercise autonomous decisions in programmes designed to support them and do not have co-ownership of the process in a meaningful way.

66. Women with albinism reportedly do not benefit from or are unaware of economic initiatives designed to support women with disabilities in general. For example, the Uwezo Fund in Kenya is an initiative aimed at enabling women with disabilities to access finances to promote business ventures and enterprises at the community level.⁸⁶ However, one submission from Kenya indicated that it was unclear whether women with albinism were fully benefiting from the fund.

67. Several countries have adopted affirmative action measures in order to specifically provide persons with disabilities with economic empowerment opportunities, but such measures are not fully implemented and often do not include persons with albinism or women with albinism. For example, in Argentina, public agencies at the municipal, provincial and national levels have a 4 per cent employment quota for persons with disabilities.⁸⁷ However, that quota is not strictly adhered to. Similarly, in Chile, a law exists which obliges all companies to ensure that 1 per cent of their employees are persons with disabilities.⁸⁸ However, employers reportedly do not consider albinism a disability, and hence women with albinism are often excluded from this benefit.

7. Sexual violence and harmful practices

68. Data on sexual violence that specifically targets women and girls with albinism are not available globally. However, some of the submissions received refer to cases in which fetishization of albinism has resulted in sexual violence against women and children.⁸⁹ In addition, rape of women and girls with albinism based on the myth that having sex with a

⁸⁰ Submissions from Burundi, Cameroon, Côte d' Ivoire, Ghana, Kenya, Mali, Mozambique, Nigeria, South Africa, United Republic of Tanzania, Uganda and Zimbabwe.

⁸¹ Submissions from Ghana, Spain and Uganda.

⁸² Submission from Zimbabwe.

⁸³ Submissions from Nigeria and Uganda.

⁸⁴ Submissions from Eswatini and Kenya.

⁸⁵ Submission from Eswatini.

⁸⁶ Submission from Kenya (Government).

⁸⁷ Submission from Argentina.

⁸⁸ Submission from Chile.

⁸⁹ Submissions from Eswatini, United Republic of Tanzania and Zimbabwe.

woman with albinism can heal HIV was reported. In 2016, in its concluding observations on the combined seventh and eighth periodic reports of the United Republic of Tanzania, the Committee on the Elimination of Discrimination against Women raised concerns about harmful practices against women with albinism, noting the practice of prescribing sex with girls or women with albinism as a cure for HIV, ritual killings and attacks on persons with albinism, including women and girls, the use of their body parts for purposes of witchcraft, and the stigma and social exclusion suffered by mothers of children with albinism (CEDAW/C/TZA/CO/7-8, para. 18 (b)).

69. In some cases, women with albinism are perceived to be of less value than other women, and are thus subjected to sexual humiliation and sexual assault by their partner.⁹⁰ Such instances are often not reported, particularly in marital contexts. In addition, women and girls with albinism are frequently sexually exploited by men, but rejected for relationships or marriage, especially if they become pregnant.⁹¹ Thus, they become destitute with limited opportunities to fend for themselves and the new baby.

70. In extreme cases, especially in South, East, West and Central Africa, women and children impacted by albinism are kidnapped or sacrificed for ritual purposes. Their organs and body parts are harvested for preparing “charms for magic and spiritual powers”. In other cases, they are simply murdered to ensure that they do not procreate.⁹² The majority of the victims of these crimes are children.

71. Cases have also been reported in which mothers of babies with albinism have been accused of witchcraft and subjected to physical harm on ill-founded claims that such babies are a curse or a bad omen to the community in which they reside.⁹³ Giving birth to a child with albinism is considered a curse in certain societies, which leads to the ostracization of mothers of babies with albinism in their communities in the misbelief that they have “bad spirits”.⁹⁴

8. Data for decision-making

72. Nearly all submissions received indicated that there are limited data (including surveys and censuses) on persons with albinism, particularly women and children impacted by the condition.⁹⁵ Most data that are available have merely captured the number of females and males with disabilities in general.⁹⁶

73. Consequently, there are limited data available to strategically support initiatives for women and children with albinism. However, progress is being made. Namibia, Sierra Leone, the United Republic of Tanzania and most recently, Kenya and Malawi, have conducted national censuses that included specific questions in order to collect data on the number of persons with albinism. They used a modified version of the Washington Group short set of questions on disability. These initial data give impetus to in-depth situational analyses that could address and provide comprehensive data on the specific issues faced by women and children impacted by albinism, beyond the collection of data disaggregated by sex.

⁹⁰ Submissions from Eswatini, Kenya, Nigeria and Senegal.

⁹¹ Submissions from Togo, Uganda and Zimbabwe.

⁹² Aloy Ojilere and Musa Saleh, “Violation of dignity and life: challenges and prospects for women and girls with albinism in sub-Saharan Africa”, *Journal of Human Rights and Social Work*, vol. 4, No. 2 (September 2019).

⁹³ Ibid. The Independent Expert has also received anecdotal reports of similar situations in China, India and other parts of Asia and the Caribbean.

⁹⁴ Submissions from Burundi, Democratic Republic of the Congo, Eswatini, Ghana, Kenya, Mozambique, Senegal and Uganda.

⁹⁵ Submissions from Angola, Argentina, Australia, Azerbaijan, Belgium, Burkina Faso, Burundi, Cameroon, Chile, Colombia, Democratic Republic of the Congo, Ecuador, Eswatini, France, Germany, Ghana, Guatemala (Government), Guinea, Haiti, Jordan, Kenya, Mali, Mexico (census being developed), Mozambique, Nigeria, Niger, Panama, Senegal, Slovenia (Government), Somalia, United Republic of Tanzania (although Lund and Roberts use Tanzanian census data collected in 2012), Turkey, Uganda, Venezuela (Bolivarian Republic of), Zambia and Zimbabwe.

⁹⁶ See, for example, a submission from a stakeholder in the United Republic of Tanzania.

74. In some countries, particularly where there have been no reports of attacks against persons with albinism, there has been a presumption that it is not necessary to collect data specifically in relation to persons with albinism.⁹⁷ This presumption is problematic because insufficient data, or a total absence of data, constitute a barrier to understanding the condition and the situation of those impacted by it. For instance, emerging data are challenging the previously reported prevalence of albinism across Europe. Previously, this was reported as 1 person in 17,000, whereas new data indicate a significantly higher prevalence in the region, for instance in parts of Northern Ireland and the Netherlands (A/74/190, para. 65).

9. Access to justice, redress and rehabilitation

75. The relatively high incidence of attacks against children with albinism has been attributed to the fact that attackers often find it easier to manipulate or entice children away from a secure environment. Children rarely have the physical ability to defend themselves against such attacks. Therefore, it is important to ensure that access to justice is available and accessible. However, a child-sensitive approach has not been adopted in the justice system in many countries.⁹⁸

76. In addition, since targeted attacks against women and girls with albinism often involve sexual violence, it is imperative that the justice system be gender sensitive in the handling of the victim throughout the entire court process. However, this is often a challenge. One stakeholder notes that the bureaucratic nature of the justice system remains a barrier to access to justice. The long process is exhausting, emotionally draining and embarrassing to the victim, leading to a lack of willingness by victims to report violations against them.

77. There are also concerns about the safety of the women with albinism who choose to report their ordeal to the authorities, because many fear reprisals from the perpetrators.⁹⁹ For instance, in Kenya and the United Republic of Tanzania, women with albinism whose conjugal partner, family member or friend was involved in attacks against them or their child with albinism reportedly face threats of reprisals after testifying against such perpetrators. Reprisals often come from both family members and the community at large.¹⁰⁰ Other women complain of the lack of privacy and confidentiality in the justice system, particularly in sexual assault cases. A submission received from Mozambique indicates that when a crime is reported to the police, the complainant's personal information is usually disclosed to the accused.¹⁰¹ Moreover, women with albinism are sometimes deterred from seeking redress through the justice system because of the discriminatory attitudes of agents or personnel of the justice system.¹⁰²

78. As stated above, women with albinism and mothers of children with albinism often face banishment from their community. However, when this is reported to the police, the authorities rarely consider banishment to be a crime or do not prioritize the matter for investigation.¹⁰³

79. In several regions, the poverty faced by women with albinism often means that they are unable to pay the high cost of legal fees and therefore have to rely on the public legal aid system, which is usually overburdened with other cases.¹⁰⁴ Moreover, lawyers often do

⁹⁷ Submission from Azerbaijan.

⁹⁸ The Guidelines on Justice in Matters involving Child Victims and Witnesses of Crime indicates that the term "child-sensitive" denotes an approach that balances the child's right to protection and that takes into account the child's individual needs and views.

⁹⁹ Submissions from Burundi, Democratic Republic of the Congo, Kenya, Mozambique and Senegal.

¹⁰⁰ Submission from Kenya.

¹⁰¹ Submission from Mozambique.

¹⁰² Submissions from Colombia and Venezuela (Bolivarian Republic of).

¹⁰³ Submissions from Cameroon, Democratic Republic of the Congo, Eswatini, Ghana, Kenya, Malawi, Mali, Mozambique, Senegal, United Republic of Tanzania and Uganda.

¹⁰⁴ Submissions from Burundi, Cameroon, Eswatini, Guinea, Kenya, Malawi, Nigeria, Senegal and Uganda.

not have the contextual knowledge to adequately handle albinism-specific cases.¹⁰⁵ Other cost-related barriers also exist. For instance, in Uganda, it was reported that the police charge a fee for making inquiries into an allegation, which is unaffordable for most persons with albinism,¹⁰⁶ particularly women who are often the most economically disadvantaged. Furthermore, the corruption that can occur in police departments is costly to the complainants and effectively delays investigations.¹⁰⁷

80. Rehabilitative support for women and children with albinism who are victims of attacks and discrimination is largely unavailable, although sporadic support is often provided by civil society organizations.¹⁰⁸ This lack of support adversely affects the sustainability of such initiatives.

V. Best practices: law, policy, concrete measures and development initiatives

A. Meaningful participation

81. Programmes are currently being rolled out by civil society organizations in Kenya and the United Republic of Tanzania to develop forums and structures that enable women with albinism and mothers of children with albinism to share information, access to social and psychosocial support, and carry out joint economic activities.¹⁰⁹ There are also civic spaces for enhancing autonomy and agency by developing both self-advocacy and group-advocacy skills to enable women and girls impacted by albinism to participate in public decision-making that concerns them.¹¹⁰

82. In the United Republic of Tanzania, a mothers' group for women impacted by albinism, called Upendo wa Mama ("mothers' love" in Swahili), empowers its members by giving them a physical space to carry out income-generating activities, nurture solidarity and provide emotional support, especially for women whose children have been attacked or rejected and for mothers experiencing domestic problems. It is a platform for individuals to assert their strength, and helps leaders in the fight to build a better society for persons with albinism in the United Republic of Tanzania, particularly mothers and children impacted by the condition.¹¹¹ In 2019, the organization Positive Exposure-Kenya launched a mobile application called "Albinism and I" to demystify albinism and connect people to helpful resources in their area. The organization also provides a skills training programme for women impacted by albinism.

83. Article 6 of the 2017 Constitution of the Junior Council of the United Republic of Tanzania provides for special measures for the inclusion of children with albinism (among other vulnerable groups) in its processes. The Junior Council currently has two children with albinism on its executive committee.¹¹² Similarly, article 54 (2) of the 2010 Constitution of Kenya provides that at least 5 per cent of the members of elected and appointed public bodies must be persons with disabilities.¹¹³ Consequently, several persons with albinism now hold high positions in the Government and other institutions, including the Senate and the High Court.¹¹⁴

¹⁰⁵ Submission from Kenya.

¹⁰⁶ Submission from Uganda.

¹⁰⁷ Submission from Malawi.

¹⁰⁸ Submission from Colombia.

¹⁰⁹ See <https://allafrica.com/stories/201910250107.html> and <https://positiveexposure.org/our-amazing-jayne-waithera-positive-exposure-kenya/>.

¹¹⁰ Submission from Kenya.

¹¹¹ See <https://standingvoice.exposure.co/upendo-wa-mama>.

¹¹² Submission from United Republic of Tanzania.

¹¹³ Submission from Kenya (Government).

¹¹⁴ Ibid.

B. Access to health

84. The National Disability Insurance Scheme in Australia supports mothers of babies with albinism to access early interventions for their children. This includes information on and services for sun protection and low vision services to assist the child to make the most of his or her vision and to be mobile in a manner that is safe and independent.¹¹⁵

85. The Uganda Revenue Authority provides tax exemptions on imported products to support the health of persons with albinism, such as sunscreen.¹¹⁶ The non-governmental organization Source of the Nile Union of Persons with Albinism has thus been able to import thousands of bottles of donated sunscreen duty-free for many persons with albinism, including women and children.¹¹⁷ In the United Republic of Tanzania, with the support of the Government, the United Nations Children's Fund (UNICEF) and non-governmental organizations such as KiliSun and Standing Voice, sunscreen is produced locally and distributed to persons with albinism, especially children, across the country.

C. Rehabilitation and psychosocial support

86. The non-governmental organizations Under the Same Sun and Standing Voice, both of which are based in the United Republic of Tanzania, have established rehabilitation facilities and services for survivors of violence, particularly women and children impacted by albinism. The facilities and services include counselling and socioeconomic programmes aiming to heal the survivors of violence and assist them to again become productive members of their communities.¹¹⁸

D. Employment and an adequate standard of living

87. The Upendo wa Mama group in the United Republic of Tanzania empowers its members to support themselves and their families through jewellery-making, soap-making, making beeswax products, sewing and baking. Under the Same Sun also invests in the education of children with albinism, particularly those from the poorest families, and victims of attack and displacement. Their entire education, from primary to tertiary, is paid for by Under the Same Sun and its partners. A partnership with Standing Voice ensures that their health and well-being are checked and that they are provided with the necessary adaptive devices. Furthermore, after they graduate, Under the Same Sun provides them with training in employment integration and support in job placement. To date, hundreds of children with albinism have received this support and have successfully graduated. This programme is transformative for their standard of living and in terms of changing the perception of society vis-à-vis the capacity of children with albinism and persons with albinism more broadly.¹¹⁹

88. Additionally, some Member States have adopted legislation and affirmative action policies in public offices as described above or in employment in general. These laws and policies also mandate reasonable accommodation at the workplace for persons with disabilities. For instance, Denmark, Slovenia and Spain, among others, provide grants to employers that need to provide reasonable accommodation for their employees with disabilities.¹²⁰

89. Denmark also provides financial aid to families with a child with albinism until the child is 18 years old. In Fiji, the Government is implementing a policy of providing 10,000 Fiji dollars of financial support to all households with an annual income of 50,000 Fiji dollars or less for the purchase of a house or an apartment. This is important for the

¹¹⁵ Submission from Australia.

¹¹⁶ Submissions from Uganda and Zimbabwe.

¹¹⁷ Submission from Uganda.

¹¹⁸ Submissions from Malawi and United Republic of Tanzania.

¹¹⁹ See www.underthesamesun.com/content/education-support.

¹²⁰ Submissions from Denmark, Slovenia (Government) and Spain.

independence of persons with albinism living in poverty or those dependent on relatives who reportedly, in some cases, abuse and mistreat them.

90. Furthermore, under a tax deduction programme, the Government has encouraged Fijian businesses to support the employment of school leavers, tertiary students and persons with disabilities. In Kenya, persons with disabilities are also granted duty and tax exemptions. There is also a social protection fund in place to minimize the socioeconomic disparities experienced by persons with disabilities.¹²¹

E. Access to sexual and reproductive health services

91. Population Services Zimbabwe provides free sexual and reproductive health services for women and girls with albinism on a biweekly basis, and discussions are under way to provide the services on a daily basis. This eases the burden in terms of cost and distance in accessing these services.

92. In Ecuador, the Ministry of Public Health has prepared a handbook on comprehensive sexual and reproductive health care for persons with disabilities.¹²² It aims to fill the knowledge gap experienced by service providers in the provision of proper information and care, including for women and girls with albinism, and addresses issues around stigma.

F. Access to education

93. In Burkina Faso, school examinations are reproduced in large print and a civil society organization working on the rights of persons with albinism is currently enlarging the print of primary school textbooks.¹²³ In other countries, civil society organizations, namely, Engage Now Africa and the Ghana Association of Persons with Albinism, are also working with the West African Examination Council to provide large-print books for students with albinism.¹²⁴

94. In Senegal, a programme known as Jang Pekki was designed to help meet the learning needs of children with albinism by providing medical consultations, school equipment, clothing and free transportation to and from school.¹²⁵

95. In France, once a child has been recognized as having a disability under the disability legislation, he or she is given the necessary adaptive resources. This includes computer software to enlarge documents, cameras to read information remotely, and personalized programmes to ensure that students have sunscreen when necessary.¹²⁶

96. In Burundi, organizations working on albinism, namely Albinos Sans Frontières and Femmes Albinos, and in Côte d'Ivoire, Bien-Etre des Albinos de Côte d'Ivoire, regularly disseminate information about the needs of children with albinism to teachers and fellow students.¹²⁷ Similarly, the Albino Foundation in Nigeria updates its documentation on core messages on albinism and on frequently asked questions about albinism for distribution to schools to facilitate understanding of albinism among learners and teachers.¹²⁸

97. As in a significant number of countries, Malawi¹²⁹ and the United Republic of Tanzania¹³⁰ have developed national inclusive education strategies, and Nigeria has

¹²¹ Submission from Kenya.

¹²² Submission from Ecuador (Government).

¹²³ Submission from Burkina Faso. Similar initiatives were also reported in submissions from Cameroon, Kenya and Uganda.

¹²⁴ Submission from Ghana.

¹²⁵ Submission from Senegal.

¹²⁶ Submission from France.

¹²⁷ Submissions from Burundi and Côte d'Ivoire.

¹²⁸ Submission from Nigeria.

¹²⁹ Submission from Malawi.

¹³⁰ Submission from United Republic of Tanzania.

introduced a national inclusive education policy.¹³¹ All efforts are aimed at ensuring that a policy framework is in place to enable all children, especially those who are the most vulnerable, to have equal access to quality education in inclusive settings. The respective strategies include training teachers on how to provide support for students with disabilities, including albinism.

G. Access to justice

98. In Malawi, the Penal Code was revised to increase penalties for crimes against persons with albinism, which has reportedly reduced the frequency of such crimes.¹³² Additionally, in the United Republic of Tanzania, cases involving crimes against persons with albinism are expedited as a matter of policy. Similar efforts can also be made to expedite crimes of sexual violence against women with albinism, and to recognize attacks against children with albinism as an aggravating factor during sentencing.

99. Legal practitioners in Malawi have been trained, with the support of the United Nations country team, on the contextual elements pertinent to prosecuting the types of crimes relating to persons with albinism. Thus, efforts can also be made to develop the capacity of legal practitioners on gender sensitivity and child-centred approaches when dealing with women and children with albinism in the justice system.

VI. Conclusions and recommendations

100. Women and children impacted by albinism, that is, women with albinism, children with albinism and mothers of children with albinism, disproportionately bear the stigma, discrimination and human rights violations resulting from the social exclusion of persons with albinism as a whole. It could reasonably be extrapolated that other family members of persons with albinism bear similar burdens. The situation of other family members, although beyond the scope of the present report, warrants further study.

101. Judging from the submissions received by the Independent Expert, it is clear that the situation of women and children impacted by albinism is directly linked to the ranking on the human development index of the State where they reside; countries with higher poverty rates are those in which the situation is most dire for such women and children. It is known that persons with disabilities are among the poorest globally, and persons with albinism are no exception in this regard. Furthermore, the level of ignorance and lack of awareness about albinism, the lack of education on albinism and the pre-existing and stigmatizing myths on the condition, as well as the relative visibility (hypervisibility) of persons with albinism vis-à-vis the rest of their community, seem to be aggravating factors in terms of discrimination on the ground of “colour”.

102. The situation for women and children impacted by albinism is further exacerbated in communities where harmful practices prevail, including sexual violence based on fetishization of the condition and attacks and killings that are based on mystification of the body of persons with albinism. These forms of violence have particularly targeted women and children with albinism.

103. It is therefore imperative that States, with the support of development partners, take into account the following gender- and child-sensitive recommendations. They are provided in the context of a twin-track approach, involving measures that require integration of the issues raised in the present report into the relevant sectors, and measures that call for targeted and specific focus on women and children impacted by albinism. While all the recommendations apply to countries with records of attacks against persons with albinism, a significant number is also applicable to other countries where attacks may not have been reported, but where various levels of discrimination were reported.

¹³¹ Submission from Nigeria.

¹³² Submission from Malawi.

104. **The Independent Expert recommends that Member States take the following measures, which require integration of the issues raised in the present report into the relevant sectors.**

105. **Incorporate albinism into public health initiatives, including through:**

- (a) **Maternal and family support policies;**
- (b) **Cancer prevention policies;**
- (c) **Rare condition policies;**
- (d) **Genetic counselling policies, particularly in communities with consanguineous marriage practices.**

106. **Implement albinism development initiatives, including through:**

- (a) **National development plans and strategies aimed at the protection of vulnerable groups, which give life and true meaning to the pledge in the 2030 Agenda for Sustainable Development to leave no one behind;**
- (b) **The elimination of harmful practices;**
- (c) **Policies relating to disability, education and access to justice;**
- (d) **Policies relating to ending colour and racial discrimination.**

107. **The Independent Expert recommends that Member States ensure provision of the following to women and children with albinism:**

- (a) **Access to education and socioeconomic development;**
- (b) **Income-generating activities;**
- (c) **Adaptive devices, among other measures of reasonable accommodation, to improve access to employment and education;**
- (d) **Human rights training and capacity development for organizations representing women and children impacted by albinism;**
- (e) **Access to justice, redress and rehabilitation;**
- (f) **Remedial support for women and children who have been victims of attacks, including rehabilitation services, in the form of medical, psychological and socioeconomic support in regaining their livelihood;**
- (g) **Adequate witness protection for women and children impacted by albinism who wish to testify against family or community members who have perpetrated attacks against them;**
- (h) **Quality legal counsel at no cost to witnesses of attacks, particularly for survivors who testify during trial to ensure substantive and procedural fairness in accessing judicial remedies.**

108. **The Independent Expert recommends that Member States empower civil society organizations representing persons with albinism to:**

- (a) **Raise awareness about albinism among health and medical professionals, particularly in the maternity, oncology and cancer prevention sectors, by integrating albinism into existing training modules;**
- (b) **Adopt awareness-raising measures to educate men about the genetic origins of albinism.**

109. **The Independent Expert recommends that Member States include persons with albinism in national censuses, pursuant to best practices and the recommendation of the Washington Group on Disability Statistics, and in national health surveys in order to gather data disaggregated at a minimum by sex and age.**

110. **The Independent Expert recommends that civil society and international development partners:**

(a) **Ensure that measures that involve specific activities for women and children impacted by albinism are implemented only after meaningful consultation with them;**

(b) **Ensure that in all albinism programming, a gender perspective forms an integral part of the design, implementation, monitoring and evaluation of all interventions.**
