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Addressing attitudinal barriers experienced by 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 [46/12](#).

* [A/76/150](#).



Report of the Independent Expert on the enjoyment of human rights by 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, assesses the attitudinal barriers that persons with albinism experience around the world. Research shows that prejudicial and stereotypical attitudes towards persons with albinism are prevalent and ubiquitous and have largely gone unchallenged and unrecognized. The Expert sheds light on some of these attitudinal barriers in different spheres of society and their impact on the enjoyment by persons with albinism of their human rights. She also makes recommendations regarding measures to be taken to tackle these barriers.

I. Introduction

1. The present document is the final report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, to the General Assembly, as her tenure, which began in 2015, will soon come to an end. It is submitted pursuant to Human Rights Council resolutions [28/6](#) and [46/12](#). The present report is based on information and submissions obtained through the Expert's engagement during her tenure with various stakeholders, including representatives of the United Nations, regional organizations, governments, civil society organizations, academics, and persons with albinism and their families. Its focus is the attitudinal barriers that further aggravate the existing challenges experienced by persons with albinism.

2. Attitudinal barriers are pervasive, negative perceptions and value systems that focus on what makes a person different from another, rather than on the inherent dignity of the person, his or her abilities and other valued characteristics. Attitudinal barriers may be present in societies or communities or in specific individuals.¹ Society's attitude, or the way society thinks about, feels about and acts towards persons with albinism, has a tremendous effect not only on the inclusion and participation of persons with albinism, but also on their ability to exercise their rights on an equal basis with others.

3. Deep-rooted sociocultural prejudices and stereotypes about persons with albinism tend to aggravate the human rights violations they experience, and many implicitly or explicitly challenge the essential humanity of persons with albinism. These negative attitudes usually emanate from a lack of knowledge and understanding of what albinism is and its challenges.

4. Albinism is profoundly misunderstood around the world.² The widespread and ongoing ignorance concerning albinism leads to numerous erroneous beliefs in different regions of the world, mostly about what the condition is and what causes it.³ These beliefs have fuelled and perpetuated negative perceptions and harmful practices targeting persons with albinism. The media has played a dual role in perpetuating and entrenching misconceptions about albinism, while at the same time helping to break down these prejudices.

5. There appears to be a positive correlation between the physical visibility of persons with albinism in their community and the depth of the attitudinal discrimination they face.⁴ The more visible they are, the more likely they are to face acute social exclusion and discrimination. Paradoxically, this visibility or hypervisibility of persons with albinism has also been accompanied by an invisibility in all spheres of social discourse. This results in persons with albinism occupying a state of "in-between-ness".⁵ This refers to how persons with albinism are often perceived as not black or melanated enough, not white enough, too white, too blind, not blind enough, having multiple disabilities, having no disabilities or not disabled enough.⁶

¹ Preedy V.R., Watson R.R. (editors), *Handbook of Disease Burdens and Quality of Life Measures* (New York, Springer, 2010).

² [A/74/190](#).

³ [A/71/255](#), para. 4.

⁴ *Ibid.*

⁵ [A/74/190](#), para. 134.

⁶ Ikponwosa Ero and others, "People with albinism worldwide: A human rights perspective", 2021.

II. Role of the media in shaping attitudes on albinism in popular culture

6. The depiction of albinism in popular culture is largely negative. This is concerning, because it reinforces, or even engenders, societal prejudice and discrimination against this group.⁷ The portrayal of persons with albinism in film and fiction is particularly damaging. Characters with albinism are mostly portrayed as deviant, deranged, sadistic, evil or supernatural.⁸ Positive depictions of persons with albinism in popular culture as compassionate and heroic characters are rare.

7. A number of movies, books and other works have been criticized by albinism organizations for perpetuating the “evil albino” stereotype.⁹ These works include *The Da Vinci Code*, which portrayed characters with albinistic features as dangerous, terrifying or criminal. The National Organization for Albinism and Hypopigmentation, a non-profit advocacy group for persons with albinism based in the United States of America, asserts that, since 1960, 68 Hollywood films have been released that feature damaging negative portrayals of persons with albinism.¹⁰ In his research, dermatologist Dr. Vail Reese found 12 motion pictures featuring an “evil albino” that had been released in the 1980s, 20 released in the 1990s and 24 released after 2000.¹¹

8. Even when albinism is portrayed in a positive light, such as in the movie *Powder*, the character is often mystical.¹² The dominant portrayal of persons with albinism as evil or supernatural, in the light of existing negative cultural beliefs, myths and superstitions about albinism, further reinforces pre-existing false notions and harmful stereotypes about this group of people.¹³ This has further detrimental effects on how this group is treated in society. More recently, in the wake of attacks against persons with albinism in some parts of Africa, the media, in a bid to raise awareness about the social issues affecting persons with albinism by focusing on these narratives, has inadvertently portrayed persons with albinism in the region as vulnerable, dependent victims.¹⁴

9. However, in the past few decades, there has been an increasing attempt by the media to depict persons with albinism positively, or at least accurately, highlighting the medical and social implications of the condition as a way to counter the prejudice that persons with albinism experience. In the fashion world, for instance, an increasing number of models with albinism have been cast.¹⁵

⁷ The National Organization for Albinism and Hypopigmentation, “‘Evil Albino’ missing from 2004 movies. Will ‘The Da Vinci Code’ revive the cliché?”, available at <https://web.archive.org/web/20061202081326/http://www.albinism.org/pressRelease/pressRelease2005-01-06.html>.

⁸ Dr. Vail Reese, “Hollywood’s unwritten rules for characters with albinism”, available at www.skinema.com/albinism/.

⁹ Lauren Clark, “Probing question: why are albinos always cast as villains?”, available at <https://phys.org/news/2006-06-probing-albinos-villains.html>.

¹⁰ Edward Schiappa, *Beyond Representational Correctness: Rethinking Criticism of Popular Media* (Illinois, Southern Illinois University, 2008).

¹¹ Findings of this research are available at www.skinema.com/.

¹² Simmons B.J. and others, “The portrayal of albinism in pop culture: a 360° change from previous ideology”, *JAMA Dermatology*, 2015, pp. 151–258.

¹³ Maureen Mswela, “Evil albino stereotype: an impediment to the right to equality”, *Medicine and law*, vol. 32, no. 1 (2013), p. 90.

¹⁴ Jean Burke, “Media framing of violence against Tanzanians with albinism in the Great Lakes region: a matter of culture, crime, poverty and human rights”, *The Australasian Review of African Studies*, 2013, pp. 34 and 57–77.

¹⁵ David Smith, “South African model with albinism challenges prejudices”, *The Guardian*, available at www.theguardian.com/world/2012/nov/02/south-africa-model-albinism-prejudice.

III. Attitudinal barriers experienced by those associated with persons with albinism

10. The negative attitude towards persons with albinism oftentimes extends to those associated with them, particularly their immediate family members. The Independent Expert, in her report on women and children impacted by albinism, noted that mothers of children with albinism were often blamed for “causing” the condition in their children.¹⁶

11. In many parts of the world, women who give birth to children with albinism are accused of infidelity, while in parts of Africa it is believed that they are cursed, are unclean, are witches or are being punished by their ancestors or by god(s) for some wrongdoing. The result is that mothers of children with albinism are commonly stigmatized and ostracized.¹⁷

12. Mothers of children with albinism whose partners do not fully understand how they came to have a child with albinism may end up experiencing domestic violence and, in many cases, abandonment by their partners. This situation may pressure some mothers to abandon their children or commit infanticide.¹⁸ This also partly explains why parents of children with albinism may be involved in their attacks and killings.

IV. Effect of attitudinal barriers on the mental well-being of persons with albinism

13. The cumulative effect of negative attitudes on the mental health of persons with albinism was regularly highlighted in information received by the Independent Expert. The stigma, stereotypes, prejudices and social exclusion experienced by persons with albinism within their families, in their immediate community and from society can cumulatively have a detrimental effect on the psychosocial well-being of persons with albinism.¹⁹ This can give rise to mental health issues that include anxiety, panic attacks, depression and suicide ideation.

14. A study conducted in Pakistan found that all persons with albinism who were interviewed faced psychosocial challenges because of the constant humiliation and rejection they experienced in their community. They constantly felt excluded and helpless to change their situations.²⁰

15. Similar results were found in a study conducted in Brazil, in which 70 per cent of persons with albinism were found to have psychosocial issues, presumably due to years of suffering from discrimination.²¹ In Mali, a number of persons with albinism reportedly suffer from depression and alcoholism due to persistent marginalization.²² In South Africa, frequent humiliation and discrimination, along with difficulties in

¹⁶ [A/HRC/43/42](#), para. 19.

¹⁷ Reimer-Kirkham, S. and others, “Mothering, albinism and human rights: the disproportionate impact of health-related stigma in Tanzania”, *Found Sci*, 2020.

¹⁸ [A/HRC/43/42](#).

¹⁹ [A/74/184](#).

²⁰ Samdani, A. J. and Khoso, B. K., “A unique Albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study”, *Iranian Journal of Dermatology*, vol. 12, 2009, pp. 42–46.

²¹ Ikponwosa Ero and others, “People with albinism worldwide: A human rights perspective”, 2021, p. 29.

²² *Ibid.*, p. 85.

having normal, healthy and sustained personal and romantic relationships, resulted in many psychosocial challenges for persons with albinism.²³

16. In some cases, the negative attitudes towards persons with albinism have affected how those persons perceive themselves, their sense of self-worth and their confidence, leading to feelings of shame, self-blame and worthlessness. Studies show that children and adults with albinism have a lower self-image and a higher level of anxiety than their peers.²⁴ In Uganda, children with albinism reportedly have low self-esteem, as they have grown up in households where they were made to feel that they were not wanted and were told to hide when visitors came.²⁵ The Independent Expert also received reports of women with albinism in Brazil enduring abusive relationships owing to very low self-esteem and a related fear that they would not be able to find a new spouse or partner.²⁶

17. In certain countries where there is limited biomedical understanding of albinism among persons with albinism themselves, there is a tendency to internalize and believe some of the prejudices and stereotypes concerning them. In a study conducted in India, respondents with albinism who did not understand their condition believed that they were strange and ugly, and, as a result, they self-isolated.²⁷

18. Some persons with albinism reported a fear of going out in public because of mockery, rejection and discrimination.²⁸ In some countries, this fear is further compounded by ongoing personal safety and security issues. In many countries, persons with albinism often do not have access to State-funded psychosocial support services to help them deal with the mental health effects brought about by the negative attitudes they experience.²⁹

V. Intersectionality and normative framework

19. Persons with albinism commonly experience stigma and prejudice based on their colour, their visual impairment or both, therefore aggravating their experiences. The International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Rights of Persons with Disabilities, taken together, provide a comprehensive framework for tackling the multiple and intersecting attitudinal barriers experienced by persons with albinism.

20. In the International Convention on the Elimination of All Forms of Racial Discrimination, it is recognized that persons with albinism, who are discriminated against on the basis of their colour, notwithstanding that they are oftentimes the same race, descent, national and ethnic origin as those who persecute them, face a manifestation of racial discrimination. The Committee has expressed concern about the discrimination and stigmatization faced by persons with albinism on the basis of their colour.

²³ Ibid., p. 85.

²⁴ Gavron, I., Katz, S. and Galatzer, A., “Self-concept and anxiety among children and adolescents with albinism in Israel as a function of syndrome characteristics, age and sex”, *International Journal of Adolescent Medicine and Health*, vol. 8, 1995, pp. 167–180.

²⁵ Kelly Allen, “Oppression through omission: the human rights case of persons with albinism in Uganda”, Beloit College, Beloit, Wisconsin, United States of America, p. 11.

²⁶ [A/HRC/46/32/Add.1](#), para. 50.

²⁷ White Paper Research and Analysis Pvt. Ltd, “Albinism in India: a situation analysis”, Bihar, India, 2019, p. 11.

²⁸ Mwajabu K. and others, “Perceptions on people with albinism in urban Tanzania: implications for social inclusion”, *Journal of Advocacy, Research and Education*, vol. 2, no. 5 (2018), pp. 81–92.

²⁹ [A/HRC/34/59/Add.2](#), [A/HRC/34/59/Add.1](#), [A/HRC/37/57/Add.1](#), [A/HRC/40/62/Add.3](#), [A/HRC/40/62/Add.1](#) and [A/HRC/43/42/Add.1](#).

21. Both these conventions foster respect for the rights and dignity of persons with albinism. Article 8 of the Convention on the Rights of Persons with Disabilities, when read in conjunction with article 5, sets out States' obligations to:

- (a) Promote positive perceptions and greater social awareness towards persons with albinism;
- (b) Promote awareness of the capabilities and contributions of persons with albinism in society, in particular recognition of their skills, merits and abilities;
- (c) Combat stereotypes and harmful practices impacting persons with albinism;
- (d) Foster at all levels of the education system, from an early age, an attitude of respect for the rights of persons with albinism;
- (e) Encourage all organs of the media to portray persons with albinism in a manner that fosters the dignity and respect of this group;
- (f) Develop awareness-raising training programmes, particularly for government officials, regarding persons with albinism and their rights.

VI. Disaggregation of attitudinal barriers experienced by persons with albinism by region

A. East, South, Central and West Africa³⁰

22. Erroneous beliefs and myths that have taken root in many of the countries in the region of East, South, Central and West Africa have fuelled and perpetuated negative perceptions of persons with albinism.³¹ These misconceptions have resulted in normalized bullying, mockery, name-calling, taunts and jeers targeting persons with albinism in everyday situations, including when just walking down the street. In some cases, they have led to persons with albinism being rejected and abandoned by their families, being subjected to isolation, collective discrimination and customary banishment by their communities, and being vulnerable to physical attacks and infanticide.³²

23. The Committee on the Rights of Persons with Disabilities, in its concluding observations on the initial reports of Ethiopia, Uganda and South Africa, and in *X v. the United Republic of Tanzania*, expressed concerns about the stereotypes and discrimination faced by persons with albinism in these countries.³³

24. In this region, the prevailing view of albinism is influenced by traditional and sociocultural beliefs, despite existing scientific evidence. This leads to an interpretation of albinism as a supernatural phenomenon – a form of evil, a “curse” or “punishment” imposed by supernatural beings. Some view persons with albinism as possessing mystical powers, bringing luck or being subhuman or non-human.³⁴ In Burundi, for instance, persons with albinism are viewed as monsters and ghosts. In

³⁰ The findings discussed are drawn primarily from a total of 62 submissions received from the following countries: Angola, Benin, Burkina Faso, Burundi, Cameroon, Côte d'Ivoire, Democratic Republic of the Congo, Eswatini, Ghana, Guinea, Kenya, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Senegal, Sierra Leone, South Africa, Somalia, Togo, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.

³¹ A/74/190, paras. 6–30.

³² Ibid., para. 13.

³³ CRPD/C/UGA/CO/1, CRPD/C/ZAF/CO/1 and CRPD/C/ETH/CO/1; and *X v. the United Republic of Tanzania* (CRPD/C/18/D/22/2014).

³⁴ A/74/190, paras. 6–30.

addition, albinism is also considered to be contagious, and anything a person with albinism touches is seen as contaminated. Persons with albinism are also seen as foreigners.

1. Impact of attitudinal barriers on social inclusion

25. The impact of these erroneous beliefs on societal attitudes towards persons with albinism has been immense. In societies where these beliefs exist, there is a formidable barrier to the inclusion and effective participation of persons with albinism, because these attitudes question the humanity of this group from the outset.

26. This negative view of persons with albinism is evident from the pejorative names used to refer to them in this region. In Malawi, they are called “*napwere*” (yellow tomatoes), in Kenya “*zeruzeru*” (ghost), in Ghana “*gesoshi*” (strange being), in Nigeria “*jambiri*” (white monkey), in Côte d’Ivoire “*gombêlê*” (fake white man) and in the United Republic of Tanzania “*mbilimelo*” (white goat). In South Africa, names such as “*isishawa*” meaning “*curse*” and “*inkawu*” meaning “*monkey*” are commonly used to refer to persons with albinism.³⁵ In Zambia, it has become common for persons with albinism to be referred to as “*ndalama*”, meaning “*money*”. This is a reference to the money that can be paid for body parts of persons with albinism.

27. The fact that many people use these names without a second thought and take them for granted is telling. A study in Sierra Leone found that 80 per cent of persons with albinism were called by derogatory names.³⁶ These names, which describe persons with albinism as plants, animals, supernatural beings and objects, pave the way for the social exclusion of and attacks against persons with albinism.

28. These misconceptions about albinism have also resulted in a deeply entrenched sociocultural “othering” of persons with albinism. According to the theory of othering, this is a process by which some individuals or groups are defined and labelled as not fitting within the norms of a social group and are therefore perceived as “others”.³⁷

29. In many societies in the region, persons with albinism continue to be perceived and treated as outsiders by their communities. The distancing, alienation and marginalization from the rest of society that ensues has meant that the opinions, views and needs of persons with albinism are not considered during decision-making at the community level. With the exception of a few countries, including Kenya and the United Republic of Tanzania, and more recently Malawi and Guinea, persons with albinism are visibly absent in key governmental positions, and many are not involved in civic or political life or representation.³⁸ Persons with albinism are considered to be inferior to the rest of society and to be second-class citizens.

30. Social stigma regarding persons with albinism shapes people’s perceptions about marrying them. In many countries in the region, persons with albinism are viewed as undesirable marriage and life partners and are often rejected by the families of their partners.³⁹ The inability to marry can compound social exclusion, particularly in countries where social standing and privileges are inherently tied to the institution of marriage. This is especially common in patriarchal societies, where the

³⁵ [A/HRC/43/42/Add.1](#).

³⁶ [A/74/190](#), paras. 6–30.

³⁷ Deacon, H., Prosalendis, S. and Stephney, I., *Understanding HIV/AIDS Stigma: A Theoretical and Methodological Analysis* (Pretoria, HSRC Press, 2005).

³⁸ [A/74/190](#), para. 14.

³⁹ Kelly Allen, “Oppression through omission: the human rights case of persons with albinism in Uganda”, Beloit College, Beloit, Wisconsin, United States of America, p. 12.

socioeconomic well-being of women is often improved by marriage or by the status of the person they marry.

31. In a study conducted in the United Republic of Tanzania, respondents said that they would not want to marry someone with albinism because they would be stigmatized, segregated and mocked. They also didn't want children with albinism, as they saw this as quite negative.⁴⁰ Other respondents said they would only marry a person with albinism as a last resort. This social exclusion based on albinism can also affect the marital prospects of persons without albinism who are related to a person with albinism.

32. A study conducted in the Democratic Republic of the Congo found that 22 per cent of persons with albinism faced discrimination within their families. Children with albinism are sometimes seen as a source of shame, which can lead to the children being abandoned or killed and to spouses divorcing as a result of the birth of children with albinism. Having a family member with albinism can negatively impact the whole family. In Uganda, tribe members encourage men to abandon their wives who give birth to children with albinism, based on myths that their union will bring bad luck upon the community.⁴¹ In Ghana, whole communities have in place a standing order or a ban against the entry of persons with albinism, even though the Constitution of Ghana guarantees the freedom of movement of all Ghanaians without exception.⁴²

2. Impact of attitudinal barriers on access to employment and income opportunities

33. Access to employment is a challenge for persons with albinism in the region because of the attitude of employers. Employers or potential employers in the region often discriminate against persons with albinism, stigmatizing them as inferior or incompetent.⁴³ Employers often underestimate the capacities and abilities of persons with albinism. Some view them as incapable of many of the mental and physical tasks carried out by persons without albinism. This results in low employment rates among persons with albinism, and those who are able to procure employment often face unjust and unfavourable conditions at work, ending up in low-paid and minimum-wage employment. In some cases where employers do hire someone with albinism, they see this as a benevolent act of charity and may exploit the person.

34. Many employers fear that hiring a person with albinism is bad for business. They fear that the person's physical presence, especially in cases where the person has skin lesions, may scare potential customers away.⁴⁴ In other instances, particularly in private enterprises, female employees – and males to a lesser extent – with albinism are vulnerable to sexual harassment and ritual rape by employers, due to the belief that such acts bring wealth and good luck in business.⁴⁵ Research conducted in Uganda showed that it was not uncommon to hear professional females with albinism complain about sexual harassment and exploitation by their superiors and colleagues in the workplace.⁴⁶

35. Most of the myths and superstitions surrounding albinism typically foster fear and avoidance of colleagues with albinism in the workplace. Forty-five per cent of

⁴⁰ Mwajabu K. and others, "Perceptions on people with albinism in urban Tanzania: implications for social inclusion", *Journal of Advocacy, Research and Education*, vol. 2, no. 5 (2018), p. 85.

⁴¹ Bradbury-Jones C. and others, "Beliefs about people with albinism in Uganda: a qualitative study using the Common-Sense Model", *PLoS One*, vol. 13, October 2018.

⁴² Art. 21(g) of the Constitution of Ghana (1992).

⁴³ [A/74/190](#), para. 26.

⁴⁴ *Ibid.*, para. 68.

⁴⁵ [A/HRC/40/62/Add.3](#) and [A/74/190](#), para. 70.

⁴⁶ Kelly Allen, "Oppression through omission: the human rights case of persons with albinism in Uganda", Beloit College, Beloit, Wisconsin, United States of America, p. 12.

research participants in the United Republic of Tanzania reported that their reactions when meeting persons with albinism were a mixture of pity and fear.⁴⁷

36. Persons with albinism who have their own businesses also face discrimination, because potential clients do not wish to buy from someone with albinism for fear that the condition is contagious. The goods they sell are seen as contaminated. Persons with albinism have reportedly been forced to close their business enterprises for this reason.⁴⁸

37. These attitudinal barriers result in persons with albinism being impoverished and depending on public social security, thus reinforcing assumptions that persons with albinism are economically less productive and socially helpless, and further compounding existing attitudes that fundamentally call into question their personal capacity and human value.

3. Impact of attitudinal barriers on access to health

38. The attitudes of health-care providers tend to limit access to health for persons with albinism in the region. In some cases, health-care providers exhibit hostile attitudes towards persons with albinism seeking health-care services, because of deep-rooted prejudices and stereotypes about persons with albinism and limited biomedical knowledge of this condition.

39. In some countries, persons with albinism have reported that health-care providers treat them inhumanely, ignore them or are afraid to attend to them.⁴⁹ In certain instances, health-care professionals go so far as to refuse to provide services to persons with albinism. Health-care professionals sometimes turn persons with albinism away because of fear of contagion or bad luck, or because they find persons with albinism repugnant or undeserving of treatment.⁵⁰

40. The sexual and reproductive health of persons with albinism is an issue of particular concern. The rights to sexual and reproductive health of women with albinism are often neglected, due to beliefs that women with albinism should be celibate to avoid the procreation of more persons with albinism. In some instances, doctors refuse to prescribe contraceptive pills to women with albinism because of their skin colour. Further, women with albinism who go against this prescribed celibacy and become pregnant are often mistreated when they go to hospital for prenatal care.

41. In addition, the belief in a number of countries in the region that an HIV-positive male can be cured by having sexual relations with a female with albinism puts females with albinism at higher risk of sexual violence and sexually transmitted infections. In a study conducted at a tertiary hospital in Abuja, Nigeria, 20.2 per cent of patients with albinism tested positive for HIV.⁵¹ This was unusually high, given that the highest national prevalence calculated during the study was 4.6 per cent.⁵² Based on the study, it was concluded that society had turned this group into a “virus

⁴⁷ Mwajabu K. and others, “Perceptions on people with albinism in urban Tanzania: implications for social inclusion”, *Journal of Advocacy, Research and Education*, vol. 2, no. 5 (2018), p. 86.

⁴⁸ A/74/190, para. 69.

⁴⁹ Ikponwosa Ero and others, “People with albinism worldwide: A human rights perspective”, 2021, p. 78.

⁵⁰ Ibid.

⁵¹ Bayo Aluko-Olokun and others, “Is there an association between African national HIV prevalence values and socio-economic status of their albino populations?” *HIV & AIDS Review*, vol. 15, no. 2 (2016), pp. 73–79.

⁵² Ibid., p. 73.

reservoir”.⁵³ Persons with albinism reportedly struggle to access free antiretroviral treatment because of the stigma attached to their condition.

42. There is a dangerous casual attitude about skin lesions in many parts of this region. The common belief among persons with albinism, which is often deeply rooted in ignorance about the condition, particularly in rural areas where there is a dearth of specialists and health-care practitioners, is that precancerous lesions are a normal part of albinism or the result of food allergies. This has resulted in many persons with albinism refraining from seeking medical attention until they are in the advanced stages of skin cancer.

43. During the coronavirus disease (COVID-19) pandemic, reports emerged of persons with albinism being branded as “corona” and “COVID-19” in some countries, effectively labelling them as scapegoats of the pandemic. Because of their colour, they are seen as carriers of a “white” man’s disease, further ostracizing them in their communities.⁵⁴

B. Asia and the Pacific⁵⁵

44. There are limited data available concerning the attitudinal barriers experienced by persons with albinism in the Asia and the Pacific region. However, the Independent Expert’s report on her visit to Fiji in 2017,⁵⁶ research and existing literature (though limited), suggest that discrimination against persons with albinism in this region has a strong attitudinal dimension. This ranges from being treated as invisible to being unwelcome and can emanate from a lack of knowledge and widespread misconceptions about albinism and the issues faced by persons with albinism, including the belief that it is a communicable disease.⁵⁷

45. In China, albinism is seen by some as a curse, and families feel extremely unlucky to have a child with albinism, resulting in children with albinism being abandoned by their families or locked away. Chinese model Xueli Abbing’s story highlights such an example,⁵⁸ where her parents left her outside an orphanage in China when she was born. In Japan, persons with albinism are often viewed as punks and foreigners, making many feel compelled to dye their hair black to fit in with popular notions of what a Japanese person ought to look like. In India, albinism is seen as a strange infectious disease and a curse that can be passed on to those who come into contact with persons with albinism. Persons with albinism are in many cases viewed as untouchables and are therefore ostracized.⁵⁹ In Malaysia, persons with albinism are often seen as harbingers of bad luck, aliens or foreigners. In general, there tends to be a cycle of shame, blame and guilt associated with the diagnosis of albinism.

⁵³ Ibid., p. 77.

⁵⁴ Office of the United Nations High Commissioner for Human Rights, “The COVID-19 pandemic and harmful practices impacting persons with albinism: accusations of witchcraft and ritual attacks (“HPAWR”)”, July 2020, available at www.ohchr.org/Documents/Issues/Albinism/COVID-19_and_Harmful_Practices.pdf.

⁵⁵ The findings discussed are drawn from submissions received from the following countries: Australia, Fiji, India, Japan, Malaysia, Nepal, New Zealand and Pakistan.

⁵⁶ A/HRC/40/62/Add.1.

⁵⁷ Ibid., para. 33.

⁵⁸ Jennifer Meierhans, “Xueli Abbing: the abandoned baby who became a Vogue model”, BBC News, available at www.bbc.com/news/world-asia-china-56464881.

⁵⁹ White Paper Research and Analysis Pvt. Ltd, “Albinism in India: a situation analysis”, Bihar, India, 2019.

1. Social inclusion

46. During the Independent Expert's visit to Fiji, she noted that persons with albinism were not fully embraced by society. She observed that basic acts such as walking around the community and participating in social activities were particularly difficult, due to frequent and commonly accepted taunts and teasing. For some living in rural areas and villages, the act of wearing hats and sunglasses as sun protection was seen as inappropriate social behaviour. Consequently, persons with albinism often isolated themselves, further entrenching their invisibility and creating a false impression that they intentionally distanced themselves from the rest of society.⁶⁰

47. In India, persons with albinism, irrespective of class, reportedly faced exclusionary attitudes from their own families and also from society because of their different appearance. In a situational analysis conducted in India in 2019, 59 per cent of respondents with albinism said that, when in public, people tended to mistreat them or avoid them, were emotionally abusive or did not want to touch or be touched by them.⁶¹ These repeated bad experiences have created a sense of shame, fear and anxiety among persons with albinism when they have to go out in public.⁶²

48. In Pakistan, adults with albinism are often seen as undesirable marriage partners, evidenced by the fact that none of the adult males with albinism in the study were married.⁶³ In Japan, persons with albinism have to make additional efforts to be accepted and to succeed, including by changing their appearance.⁶⁴ In Australia, albinism is viewed in a relatively positive light, as people tend to be curious and want to know more about the condition.⁶⁵

2. Access to inclusive education

49. The unfounded perception that the visual impairments of persons with albinism can evolve into blindness has led to learners with albinism in Fiji being predominantly placed in special schools where they are taught Braille,⁶⁶ even when these impairments can be easily resolved through proper optical devices.

50. In India, although in a recent study few respondents with albinism reported dropping out of school due to their condition, close to half of those who had attended school faced minor to serious problems resulting from the attitudes of teachers and peers alike.⁶⁷ Sitting arrangements isolating them from other students were imposed in the classroom. This was attributed to a mistaken fear of contracting albinism. Rude behaviour by both the teachers and peers, including unkind comments about their low vision and appearance, were reported. Many of the respondents said that the parents of other students had objected to their admission, due to worries that albinism could be contagious.⁶⁸ Some teachers had also objected to their admission, due to the same belief. Admission processes were often delayed as a result.

⁶⁰ [A/HRC/40/62/Add.1](#), para. 34.

⁶¹ White Paper Research and Analysis Pvt. Ltd, "Albinism in India: a situation analysis", Bihar, India, 2019, p. 16.

⁶² *Ibid.*, p. 20.

⁶³ Samdani, A. J. and Khoso, B. K., "A unique Albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study", *Iranian Journal of Dermatology*, vol. 12, 2009, p. 44.

⁶⁴ Ikponwosa Ero and others, "People with albinism worldwide: A human rights perspective", 2021.

⁶⁵ [A/74/190](#), para. 46.

⁶⁶ [A/HRC/40/62/Add.1](#), para. 43.

⁶⁷ White Paper Research and Analysis Pvt. Ltd, "Albinism in India: a situation analysis", Bihar, India, 2019, p. 14.

⁶⁸ *Ibid.*

51. A study conducted among members of the Bhatti tribe in Pakistan showed low school attendance among persons with albinism.⁶⁹ Only 10 out of the 40 persons interviewed were either attending or had attended school. This study showed that students with albinism were often discouraged by school authorities from attending schools. School authorities experienced immense pressure from parents of children without albinism to not admit children with albinism, for fear that their condition was contagious or that it was God's curse.⁷⁰ In parts of Asia, some families choose not to send their children with albinism to school because they see them as a burden.⁷¹

52. Even in Australia, where attitudes towards persons with albinism are relatively positive, children with albinism endure bullying owing to their physical appearance and are excluded from social activities, including sports, because of their low vision.⁷²

53. In Japanese public schools, the requirement that all students must have black hair means that schools often pressure students with albinism to dye their white-to-blond hair black.

3. Access to employment and income opportunities

54. Most of the information received by the Independent Expert indicated that persons with albinism faced employment discrimination in the workplace. Persons with albinism in Japan have reportedly failed job interviews because of their colouring and are often forced by the employer to dye their hair black.⁷³

55. In Fiji, persons with albinism face discrimination in gaining access to and maintaining employment due to existing prejudices. In India, unemployment is higher among persons with albinism in comparison with persons without the condition. In cases where persons with albinism are employed, they often do not have long-term employment.⁷⁴ They are employed part-time, as daily wage labourers, contractually or seasonally. Employees with albinism experience a lack of cooperation and isolation at work.

4. Access to health-care services

56. Little is documented about attitudinal barriers experienced by persons with albinism in the region while accessing health-care services. It appears that persons with albinism in countries that have a good health-care system, such as Australia and New Zealand, have generally positive experiences compared with those using health-care systems that are under financial constraints. For example, during her visit to Fiji, the Independent Expert noted that the health-care needs of persons with albinism were underprioritized. Information about the availability of services offered by the skin clinic at PJ Twomey Hospital in Tamavua had not reached a large number of persons with albinism in the various regions of Fiji.

57. Most of the persons with albinism who the Independent Expert met in Nadi and Rakiraki were not aware of the skin clinic and were often left with no choice but to purchase the necessary health-care products themselves, which was particularly expensive. Those who knew about the clinic had found out about it through referrals

⁶⁹ Samdani, A. J. and Khoso, B. K., "A unique Albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study", *Iranian Journal of Dermatology*, vol. 12, 2009.

⁷⁰ Ibid.

⁷¹ [A/74/190](#), para. 55.

⁷² [A/74/190](#).

⁷³ Ibid.

⁷⁴ White Paper Research and Analysis Pvt. Ltd, "Albinism in India: a situation analysis", Bihar, India, 2019, p. 11.

from their doctors or by chance, either by listening to a radio programme or through community outreach activities undertaken by the Fiji Albinism Project.

58. In India, when visiting health-care facilities, some persons with albinism experienced negative treatment by support staff and rude behaviour by doctors and other patients. The shame and stigma associated with albinism also deter persons with the condition and their families from seeking medical attention or rehabilitation.

C. Latin America, North America and the Caribbean⁷⁵

59. The Independent Expert obtained information through submissions received from 22 stakeholders in 13 countries in the Latin American, North American and Caribbean region. This information was supplemented by follow-up interviews with organizations working on albinism in the region.

60. The lack of knowledge about albinism in this region often leads to discrimination fuelled by myths and misconceptions. Persons with albinism face discrimination as a result of their physical appearance in Argentina, Chile, Colombia, Ecuador, Guatemala, Haiti, Mexico, Panama and Paraguay. Reactions to persons with albinism vary from admiration and curiosity to rejection and bullying. Some have experienced discrimination on the basis of a belief that albinism is contagious.

61. In Colombia, some persons with albinism have reportedly been insulted for not conforming to the prevailing standards of “beauty”, and others have been harassed due to their fair skin, or because they appear to conform to an idea of “beauty” that is foreign. Women with albinism in Mexico are subject to sexual harassment because of a perception that blonde, white women are reportedly considered more attractive. The link made between albinism and consanguineous relationships has made albinism something shameful in some parts of the region.

1. Social inclusion

62. The exclusion of persons with albinism is a common reality in Latin America and parts of the Caribbean, especially for women, and for those living in rural areas in particular.

63. Persons with albinism are sometimes rejected by their parents and relatives at birth because they do not resemble their family members. A civil society organization in Argentina reported that nurses sometimes did not recognize that a newborn baby had albinism at birth and misinformed the parents that the child was blonde. This has led to conflicts among couples, centred around accusations of infidelity and the father rejecting the child. The information obtained indicates that the success of persons with albinism often depends on the level of family support they receive at home and in the community, as well as the level of accurate public information about albinism. Frequent humiliation and discrimination within the family, the immediate community, society at large and particularly in schools were cited.

64. In Brazil, stigma against persons with albinism has reportedly decreased in recent decades. Nevertheless, name-calling using terms such as “gringo”, “white rat”, “monkey”, “shrimp”, “panda” and “peeled cockroach” reportedly still occurs, particularly in the more rural parts of the country.⁷⁶ People fear the colouring and appearance of persons with albinism, particularly when they have visible sun damage,

⁷⁵ The findings discussed are drawn from nine submissions received from the following countries: Argentina, Bolivia (Plurinational State of), Brazil, Chile, Colombia, Ecuador, Guatemala, Haiti, Mexico, Panama, Paraguay, United States of America (the) and Venezuela (Bolivarian Republic of).

⁷⁶ [A/HRC/46/32/Add.1](#), para. 47.

such as skin lesions.⁷⁷ The Independent Expert, during her visit to Brazil, received reports of women with albinism enduring abusive relationships owing to their very low self-esteem and a related fear of the inability to find a new spouse or partner.⁷⁸

65. In Argentina, even though some negative attitudes towards persons with albinism still exist, they are less overt.

2. Access to inclusive education

66. Some parents in the region withhold their children with albinism from school, owing to the belief that their low vision and condition render them incapable of learning. In Haiti, some parents do not send their children with albinism to school at all, given the shorter life span associated with the condition and a belief that education is not a worthwhile investment. In Colombia, some children with albinism are withdrawn from school at a young age, confined at home or forced to support the family.⁷⁹ In Guatemala, some children reportedly suffer physical violence at school.

67. A number of responses called for education professionals to be trained to respond to learners with albinism, including protecting them from bullying. Some teachers in Brazil were seen as uninformed about the condition, signalling a need to provide them with information and training.

3. Access to employment and income opportunities

68. A lack of or incomplete formal education becomes a barrier to employment for persons with albinism in the region. Stigma is an additional barrier that prevents them from accessing the labour market. Employers often underestimate the capacities and abilities of persons with albinism. Some employers are unwilling to hire persons with albinism because they do not want to be liable if the person suffers burns or other injuries at work due to low vision.⁸⁰ They are also reluctant to incur additional expenses to accommodate the person.

69. During her visit to Brazil, the Independent Expert was informed that, due to prevailing stigma and prejudice, only 10 per cent of persons with albinism were reportedly employed in the formal sector and 18 per cent in the informal sector. The situation for those living in rural areas and *quilombos* (historical communities founded by freed slaves) is even worse. When persons with disabilities, including persons with albinism, are hired, there is a tendency to relegate them to low-ranking jobs, sometimes outdoors.⁸¹

70. Financial loans to start businesses are often inaccessible to persons with albinism, owing to a lack of sufficient collateral – given that they are often from an economically disadvantaged background – and prejudicial assumptions about their ability to repay the loans. In Paraguay, 20 per cent of the total population with albinism lives in poverty.

4. Access to health

71. A lack of knowledge about and expertise on albinism often leads to misdiagnosis, incorrect treatment and also misinformation about albinism, with far-reaching consequences. In Brazil, some doctors misinform parents that their child will inevitably die of skin cancer and turn blind. Some doctors refuse to treat persons with albinism due to stereotypes. In Colombia, health-care professionals sometimes refuse

⁷⁷ Ibid., para. 48.

⁷⁸ Ibid., para. 50.

⁷⁹ A/74/190, para. 110.

⁸⁰ A/74/190, para. 114.

⁸¹ A/HRC/46/32/Add.1, para. 95.

to communicate with a person with albinism directly and instead address only the person's companion, based on the belief that the person with albinism is a foreigner, due to their skin colour.⁸²

D. Europe

72. The attitudinal barriers experienced by persons with albinism differ across Europe. Submissions to the Independent Expert from Finland, Belgium, Norway and France give the impression that albinism is not as noticeable in certain European countries, in particular in Northern European countries, because the population generally has very fair or pale skin, light hair and light eye colouring. In Finland, it is very common to be diagnosed with albinism only at an adult age. Many people with ocular albinism, or albinism affecting the eyes alone, are never diagnosed. In Denmark, the traits of albinism are often not clearly distinguishable from the skin or hair colour of the majority of the population. Therefore, many individuals with albinism do not physically stand out in everyday life. As a result, the stigma experienced by persons with albinism in these countries is often related to their visual impairment rather than to their colouring. However, this is not to suggest that stigma based on skin colour is completely absent.

73. In Southern European countries, where the population's pigmentation is generally a bit darker than their northern counterparts, the appearance of a person with albinism might be more distinguishable, and stigma is likely to be based on both visual impairment and colour. It is not uncommon for persons with albinism in these countries to be mistaken for foreigners. International awareness-raising campaigns in these regions have reinforced the idea that albinism is an African issue and affects black people only.

1. Social inclusion

74. According to submissions received, stigmatization exists partly as a result of myths, such as the myth that albinism causes mental illness. In the Netherlands, many people assume that persons with albinism have red eyes and white hair. These images fit into the stereotype of the "evil albino" perpetuated in popular culture.

75. In Norway and Spain, adults and children with albinism face stigma and exclusion in the community owing to low vision. In Turkey, some people think that albinism is an infectious disease. As a result, some parents do not let their children play with children with albinism. In a few countries, it was reported that women and girls dyed their hair to avoid discrimination or social exclusion.⁸³

76. In a few cases in France, children with albinism were reportedly abandoned during their first months of life and subsequently placed in foster homes.⁸⁴ In Germany, the use of derogatory terms about albinism is not uncommon. In the United Kingdom of Great Britain and Northern Ireland, there are incidences of bullying. In Norway, persons with albinism experience distancing by other members of the community because of their appearance. In Spain, social exclusion is said to be one of the main barriers encountered by persons with albinism, as the condition tends to draw excessive attention and taunts aimed at the person.

77. Some submissions suggest that there is greater acceptance and inclusion of persons with albinism in European countries in which the human rights-based approach

⁸² Ikponwosa Ero and others, "People with albinism worldwide: A human rights perspective", 2021, p. 78.

⁸³ A/74/190, para. 71.

⁸⁴ Ibid., para. 46.

to disability has been embedded into national norms and practices and the level of public awareness of and accurate information on the condition is relatively high.

2. Inclusive education

78. Bullying has been highlighted as an ongoing challenge by young Europeans with albinism from various European associations during their biannual meetings, which take place alongside the European Days of Albinism international event. Several submissions including reports of bullying of children with albinism in school. In Germany, bullying is reportedly such a common phenomenon that most adults with albinism testify to experiencing it from multiple sources in their childhood. According to a civil society group in the Netherlands, bullying is the most frequently discussed topic among parents of children with albinism.

79. Bullying ranged from sporadic incidences to common occurrences and took the form of insults, harassment, mockery, intimidation and, in some cases, physical assault. Bullying is mainly attributed to a lack of knowledge or understanding of the condition among teachers, classmates and parents alike.

80. In some cases, children face social isolation in schools. Children with albinism are often left out of sporting events because they are perceived as not being good at sports due to their eyesight. They are also left out of group activities. Name-calling was a particular challenge.

3. Access to employment and income opportunities

81. As in other regions, employers in Europe are often hesitant to hire a person with albinism, owing to the perception that they will have difficulty performing their tasks because of their visual impairment, the cost of providing reasonable accommodation and the fear of the potential negative impact of their physical appearance in some customer service positions.⁸⁵ In Germany, persons with albinism tended to have a more limited choice of professions. Although disability quotas are in place in Belgium to encourage the employment of persons with disabilities, including persons with albinism, these are not always respected.

82. In Denmark, some employers have a negative predisposition towards hiring a person with albinism because they believe they are difficult to work with due to their visual impairment. Inclusion and reasonable accommodation policies in some countries in the region have helped to counter some of these issues.

4. Access to health

83. In Europe, where health-care services are, for the most part, readily accessible to persons with albinism, experiences are largely positive. In some countries, there is little knowledge about albinism among medical professionals, leaving them unable to effectively assist persons with albinism in better understanding their condition. This often leads to a late diagnosis of albinism, particularly among persons with relatively high visual acuity and those whose colouring is not so distinct in comparison with others in their society.⁸⁶

84. Respondents from Italy have indicated that the information provided on albinism is oftentimes very scientific and does not include information on the condition's impact on and implications for the social life and well-being of the person with albinism.

⁸⁵ A/74/190, para. 79.

⁸⁶ Ibid., para. 72.

E. Middle East and North Africa

85. The Independent Expert noted a significant lack of data on persons with albinism in the Middle East and North Africa region.⁸⁷ The limited information available suggests that persons with albinism experience stigmatization, including public humiliation, and social obstacles to marriage (which have a negative impact on their socioeconomic rights and privileges).⁸⁸

86. Furthermore, persons with albinism experience social exclusion, stigmatization and discrimination based on colour, to the extent that name-calling and taunting are normal occurrences. There appears to be a lack of acceptance in society with regard to social relationships and marriage in particular, which affects persons with albinism regardless of gender.⁸⁹ For mothers of children with albinism, there is a lack of social support provided at the time of the birth.

87. A study investigating the impact of albinism on the self-perception and level of anxiety among children and adolescents with albinism in Israel, and the extent to which age and sex impacted this, found anxiety to be highest among young males with albinism, due to the stigmatizing attitudes they experienced.⁹⁰

VII. Challenges in addressing attitudinal barriers

A. Attitudinal barriers linked to harmful practices

88. Some attitudinal barriers appear to be particularly difficult to counter, as they stem from traditional beliefs and practices, particularly in socio-culturally entrenched systems where ignorance and deprivation exist. Such a situation fosters attitudinal barriers, justifying them by means of the supernatural and other metaphysical belief systems, which leads to human rights violations that include the exploitation, torture and murder of persons with albinism, and other harmful practices.

89. A recent ethnographic study conducted in the United Republic of Tanzania and South Africa⁹¹ confirmed that the attitudinal barriers faced by persons with albinism and their family members were often considered legitimate based on age-old beliefs and practices. For instance, it was believed that children were born with albinism as a result of the mother's wrongdoing or that it was a spiritual punishment divinely imposed on the mother. These were more than mere myths, they were the culturally sanctioned rationale which often justified the abandonment of the mother by her spouse and justified violence against her, especially when she had more than one child with albinism.

90. The Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa, although yet to come into force, addresses some of these complex harmful practices. It broadly defines harmful practices as including behaviour, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the human rights and fundamental freedoms of persons with disabilities or perpetuate discrimination (art. 1). The Protocol also

⁸⁷ A total of three responses were received, from Jordan, Iran (Islamic Republic of) and Israel.

⁸⁸ *Ibid.*, para. 132.

⁸⁹ *Ibid.*, para. 127.

⁹⁰ Gavron, I., Katz, S. and Galatzer, A., "Self-concept and anxiety among children and adolescents with albinism in Israel as a function of syndrome characteristics, age and sex", *International Journal of Adolescent Medicine and Health*, vol. 8, 1995, pp. 167–180.

⁹¹ Reimer-Kirkham, S. and others, "Mothering, albinism and human rights: the disproportionate impact of health-related stigma in Tanzania", *Found Sci*, 2020.

addresses the issue in several other provisions, including a preambular section that refers to persons with albinism. Article 11 qualifies the use of derogatory language as a harmful practice, and article 9(2)(c) prohibits exploitation, violence and abuse within and outside the home.

91. The open-ended approach to harmful practices throughout the Protocol is indicative of the intent to include both contemporary and emerging forms of these practices. It is of utmost importance that States members of the African Union sign and ratify the Protocol as soon as possible, so as to put protection measures in place against these attitudinal barriers that both stem from and lead to practices that are harmful for people with disabilities, including persons with albinism.

92. Similarly, the requirement that students and employees dye their hair in parts of Asia is highly discriminatory and, coupled with bullying and taunts, can be considered as a harmful practice. These can be tackled through awareness-raising efforts targeted at the education sector, the public sector as a whole and the private sector.

B. Lack of political will and engagement

93. There is often a reluctance on the part of some Member States to engage on the issue of persons with albinism. This is due to several factors, including population size. Persons with albinism constitute a relatively small segment of the population. Moreover, because some governments may have addressed issues affecting persons with albinism in a general way or may have invested in matters relating to disabilities generally, their preference is that persons with albinism benefit from these existing programmes.

94. In several countries, there are efforts to integrate persons with albinism into existing funding and other support programmes for constituents with disabilities.⁹² In other countries, this process is slower for various reasons, including a lack of coordination between albinism groups or a lack of coordination between the disability agency and albinism groups.

95. Moreover, there is often also a lack of knowledge about persons with albinism as a subset of persons with disabilities. Regarding the size of this subset and the lack of political will to act in cases where such action may not have an obvious impact on the aggregate outcome, it is crucial that Member States remember that the focus on aggregates was one of the issues addressed by the adoption of the Sustainable Development Goals.

96. The Sustainable Development Goals support the need for specific measures to improve the enjoyment of human rights by groups on the margins, regardless of the groups' size. This was one of the lessons learned through the implementation of the Millennium Development Goals. Many of those Goals targeted only a percentage of the mainstream population, and progress was measured with averages instead of disaggregated indicators. Consequently, inequalities affecting specific groups and subgroups were neither measured nor addressed, even though the situation of many of the groups was deteriorating according to the General Assembly. The Sustainable Development Goals, which are intended to be a continuation of the Millennium Development Goals, contain a central pledge "to leave no one behind". Thus, in countries with records of attacks, it is important that Member States recognize that

⁹² [A/HRC/40/62/Add.1](#) and [A/HRC/40/62/Add.3](#).

there is indeed a “small-scale humanitarian crisis”⁹³ made up of “hate crimes”⁹⁴ affecting this group of people. To put this matter in perspective, where one person with albinism is killed or attacked in a village with three persons with albinism, one can surmise that 30 per cent of the population with albinism has been attacked or wiped out. Given the hypervisibility of persons with albinism, the insecurity that befalls the surviving members of the victim’s family and other persons with albinism should not be underestimated or dismissed.

97. There is a need to combat attitudinal barriers with an intense investment in awareness-raising programmes that focus on positive stories highlighting the capabilities of persons with albinism. These campaigns cannot be merely ad hoc; rather, they must be set out for the medium to long term. They can include programmes for mass consumption by the general public and targeted programmes for particular sectors, such as the health and education sectors.

98. Reports received by the Independent Expert suggest that awareness-raising that is sustained for a minimum of two years⁹⁵ can replicate the frequency of albinism and thereby normalize the condition relatively quickly in the social consciousness.⁹⁶ When supporting awareness-raising efforts, there should be consultation with and involvement of organizations representing persons with albinism on the design, implementation and evaluation of such activities.

C. Prevailing medical approach to disability

99. In some parts of the world, there is limited knowledge about the human rights approach in general and as it relates to disability in particular. One study by the United Nations Children’s Fund (UNICEF) in Malawi found that government officials were unable to articulate the human rights model of disability.⁹⁷ In developing countries, there is also a prevailing view of disability as a medical issue or a cause for pity or charity. The medical approach to disability often excludes persons with albinism, finding their overall level of functioning to be satisfactory. The problem with the persistence of the medical approach is that, without knowledge of albinism, not only does it become a barrier to accessing social services for persons with disabilities, but it also provides a basis for mystifying albinism as “otherworldly”. In other words, if persons with albinism are not found to be persons with disabilities, they become highly vulnerable to ridicule. The “in-between-ness” of albinism leads to situations in which the approach taken towards the condition is haphazard, as opposed to the human rights approach, which ensures that all the human rights issues faced by those with albinism are addressed.⁹⁸

⁹³ International Federation of Red Cross and Red Crescent Societies, “Through albino eyes: the plight of albino people in Africa’s Great Lakes region and a Red Cross response”, p. 6, available at https://reliefweb.int/sites/reliefweb.int/files/resources/E492621871523879C12576730045A2F4-Full_Report.pdf.

⁹⁴ A/HRC/46/32, para. 75.

⁹⁵ A/HRC/37/57/Add.3.

⁹⁶ Kelly Allen, a researcher who conducted a comparative analysis on the situation of persons with albinism in Panama compared with those in Uganda, found that the reason those in Panama faced less discrimination was due in part to the higher number of persons with albinism in that country.

⁹⁷ UNICEF, “A situation analysis of children with disabilities in Malawi”, July 2020.

⁹⁸ Emily Urquhart, “The meaning of white”, *The Walrus*, March 20, 2013, available at <https://thewalrus.ca/the-meaning-of-white/>.

D. Good practices and positive developments⁹⁹

1. International

100. Since 2014, the Office of the United Nations High Commissioner for Human Rights (OHCHR) has hosted and updated a successful campaign website for persons with albinism at albinism.ohchr.org. The website highlights positive stories of persons with albinism around the world using various media. It includes storytelling, photos, best practices and resources such as a quiz on albinism awareness to demystify the condition. Moreover, having the platform as a subdomain of the OHCHR website has greatly contributed to the dignified responses that persons with albinism have been receiving in various international forums.

101. In 2019, an international symposium featuring persons with albinism from Asia and Africa took place in Japan. The symposium, which was organized by the Nippon Foundation in collaboration with the Independent Expert, featured governmental and non-governmental actors as well as civil society organizations and media outlets. The event raised awareness not only about persons with albinism from the African region but also about persons with albinism from Japan, who, until then, had reportedly been unknown to many of the participants of the symposium.

102. In 2020, seizing the opportunity presented by the lockdown due to the COVID-19 pandemic, the Independent Expert, together with the Global Albinism Alliance, OHCHR and other partners,¹⁰⁰ organized an online concert to commemorate International Albinism Awareness Day. The concert featured persons with albinism and their family members from six continents as well as musicians with albinism, family members of persons with albinism, researchers and other stakeholders. The concert, which has been viewed more than 20,000 times, was part of a larger campaign on International Albinism Awareness Day that reached more than 1 million people. This type of multi-stakeholder approach to the celebration of the Day should be replicated so as to increase reach and impact.

2. Regional

103. In the European region, European Days of Albinism is celebrated. This is a biennial conference on albinism at which professionals from various sectors, particularly health-care professionals, exchange knowledge on albinism to improve the quality of and access to health and education services for persons with albinism and their family members. In North America, a similar biennial conference, and one of the largest globally, is organized by the National Organization for Albinism and Hypopigmentation.

104. Regional and subregional bodies and coalitions are also starting to take shape, centring on albinism awareness. This includes a regional group in South America that publishes a regional magazine, as well as the burgeoning Africa Albinism Alliance.

105. The Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa includes attitudinal barriers in its protection framework under the theme of harmful practices. In addition, in 2019 the African Union adopted a plan of action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031), which includes measures to prevent human rights violations, such as awareness-raising and public education measures.

⁹⁹ Ikponwosa Ero, "Best practices in the protection of human rights of persons with albinism", available at www.ohchr.org/Documents/Issues/Albinism/A-75-170-Addendum.pdf.

¹⁰⁰ Open Society Foundations and the Disability Rights Fund.

106. The Pan-African Parliament is currently drafting guidelines to eliminate harmful practices and other human rights violations against persons with albinism. The draft, which was elaborated with the support of the Independent Expert and the Centre for Human Rights at the University of Pretoria, is in its final stage. Once adopted, it would be the first of its kind in the region and a crucial indicator of a collective will to implement the Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa.

3. National

107. The appointment of persons with albinism to senior government positions, including to the House of Representatives in Kenya and the United Republic of Tanzania and to the national human rights institutions in Guinea and Malawi, has also helped to counter negative stereotypes of persons with albinism. A similar effect has been achieved by the positive portrayal of persons with albinism in the media in South Africa.

108. New pieces of legislation focusing specifically on the rights of persons with albinism have been passed in Guinea and Panama. In July 2019, the Executive Council of the African Union adopted the Plan of Action on Ending Attacks and Discrimination against People with Albinism 2021–2031 as a continent-wide strategy.

109. In Fiji, Kenya, Malawi and Nigeria, for example, associations of persons with albinism have worked with the authorities in the development of national action plans and policies on albinism and have been empowered to provide services to communities, including through the implementation of awareness-raising programmes.

110. In some countries, national human rights institutions and parliamentary human rights committees respond to cases of intimidation and attacks against human rights defenders, including through inquiries and by making recommendations to relevant institutions for appropriate steps to be taken.

VIII. Conclusions and recommendations

111. Attitudinal barriers significantly impede the achievement of equality and the realization of human rights for persons with albinism. These barriers result in intersecting forms of discrimination that are exacerbated by a lack of understanding and awareness about the condition of albinism. The 2030 Agenda for Sustainable Development and its central pledge to leave no one behind warrants both an integrated approach to the issue, ensuring that persons with albinism benefit from relevant rights such as disability, health and education rights, but also to ensure that specific measures are put in place to target particular attitudinal barriers that general integration into large sectors may not reach.

112. As such, the Independent Expert calls on all Member States, particularly where persons with albinism face significant attitudinal barriers, to conceptualize and carry out the following recommendations, with meaningful consultation with persons with albinism and their representatives, and with the support of relevant national and international partners:

(a) **Invest significantly in awareness-raising targeted at particular sectors such as the health sector, the education sector, and custodians of traditions such as traditional chiefs in parts of Africa;**

(b) Demystify and tackle erroneous beliefs on an ongoing rather than ad hoc basis for a minimum of two years, using various campaigns and strategies, including relevant international days such as International Albinism Awareness Day, International Women's Day, International Day of Persons with Disabilities and International Day for the Elimination of Racial Discrimination, among others;

(c) Combat hate speech against persons with albinism through collaboration with multiple stakeholders (civil society organizations, faith-based organizations and the media);

(d) Combat general harmful practices targeting persons with albinism;

(e) Ensure that access to health is prioritized for persons with albinism and their family members, particularly women impacted by albinism, in specific laws, policy or action plans, including early intervention measures upon the birth of a child with albinism;

(f) Ensure access to reasonable accommodation, including low vision devices and support in the education and employment sectors, sun protection goods such as sunscreen lotions, and access to therapies and social frameworks to address psychological and psychosocial issues triggered by the condition;

(g) Combat negative stereotyping and representation of persons with albinism via specific measures as well as by integrating their situation in broader efforts to combat gender stereotypes, including by engaging in deeper consultations with women in the process;

(h) Make concerted efforts to ensure genuine consultation with and the effective participation of persons with albinism in relation to decisions that affect them;

(i) Replicate good practices such as those provided herein and in the Independent Expert's compilation of best practices.¹⁰¹

113. In the African region, Member States of the African Union should:

(a) Adopt the Protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa, which integrates norms, standards and obligations to address various harmful practices, including attitudinal ones peculiar to the region such as ritual attacks;

(b) Adopt and implement the Guidelines for Parliamentarians on Accusations of Witchcraft and Ritual Attacks: Eliminating Harmful Practices and other Human Rights Violations, once these have been adopted by the Pan-African Parliament;

(c) Adopt and implement national action plans, policies or other specific measures to address the challenges in the sectors of health, employment and education and to enhance the social inclusion of persons with albinism;

(d) Prioritize multi-year budgetary allocations towards the implementation of such action plans and policy measures and fund local organizations representing persons with albinism.

¹⁰¹ Ikponwosa Ero, "Best practices in the protection of human rights of persons with albinism", available at www.ohchr.org/Documents/Issues/Albinism/A-75-170-Addendum.pdf.