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Tenth anniversary report of the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism

Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka Miti-Drummond*

Summary

The year 2025 marks the tenth anniversary of the establishment of the mandate on the enjoyment of human rights by persons with albinism. In commemoration of this milestone, in the present report the Independent Expert provides an overview of progress made in the implementation of rights of persons with albinism worldwide over the last decade. The Independent Expert also outlines persisting challenges and makes recommendations for the continued advancement of the rights of persons with albinism.

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

I. Introduction

1. By its resolution 28/6, the Human Rights Council established the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism. The mandate was created in response to a global increase in reports of severe human rights abuses against persons with albinism. Of great concern was the widespread and systemic discrimination and violence against persons with albinism in many parts of Africa. The Council has extended the mandate three times since its inception through the adoption of resolutions 37/5 , 46/12 and 55/18. The extension of the mandate reflects the commitment of the United Nations to addressing the specific human rights challenges and needs of persons with albinism and the continued need for international attention and action on issues faced by them.

2. On 3 July 2015, the Human Rights Council appointed Ikponwosa Ero of Nigeria as the first Independent Expert on the enjoyment of human rights by persons with albinism.[1] Ms. Ero was succeeded by the current mandate holder Muluka-Anne Miti-Drummond, who assumed her duties in August 2021.[2] The scope of the mandate of the Independent Expert, which includes promoting good practices in the realization of the rights of persons with albinism, raising awareness and combating stereotypes and prejudices against persons with albinism, working with States and other actors to promote and safeguard the rights of persons with albinism and identifying obstacles to the enjoyment of their rights, has remained largely the same since 2015. The guiding principles of the work of the mandate have been participation, inclusiveness and diversity, gender sensitivity and a collaborative approach. The Independent Expert wishes to express her deepest gratitude to the many States and non-State actors that have supported the creation and continuance of the mandate and have collaborated with the mandate holders in the execution of their duties, and to acknowledge, in particular, the groundbreaking work and contribution made by her predecessor, Ikponwosa Ero, during her tenure.

3. In compiling the present report, the Independent Expert distributed a questionnaire to gather inputs from a wide range of stakeholders.[3] Four written submissions were received from the Governments of Colombia,[4] Lebanon,[5] Mauritius[6] and South Africa[7] as well as two from civil society organizations. Virtual regional consultations were held with organizations of persons with albinism from Southern, East and West Africa, Latin America, Europe, North America and Asia.[8] A total of 221 representatives of persons with albinism participated in the consultations. The Independent Expert is grateful to all parties that contributed to the process.

[1] A/HRC/31/63, para. 2.

[2] A/HRC/49/56, para. 1.

[3] See https://www.ohchr.org/en/special-procedures/ie-albinism.

[4] See https://www.ohchr.org/sites/default/files/documents/issues/albinism/cfis/10th-anniversry/2024-09-20-colombia-inputs-report-ie-albinism-en.pdf.

[5] See https://www.ohchr.org/sites/default/files/documents/issues/albinism/cfis/10th-anniversry/2024-09-20-lebanon-inputs-report-ie-albinism-ar.pdf.

[6] See https://www.ohchr.org/sites/default/files/documents/issues/albinism/cfis/10th-anniversry/2024-09-20-mauritius-inputs-report-ie-albinism-en.pdf.

[7] See https://www.ohchr.org/sites/default/files/documents/issues/albinism/cfis/10th-anniversry/2024-09-20-south-africa-inputs-report-ie-albinism-en.pdf.

[8] The consultation with organizations of persons with albinism in Southern and East Africa was held on 2 October 2024, 81 participants attended; the consultation with organizations of persons with albinism in West Africa was held on 3 October 2024, 57 participants attended; the consultation with organizations of persons with albinism in Latin America was held on 1 October 2024, 63 participants attended; an interview was held with an organization of persons with albinism from Asia on 31 October 2024; a consultation for organizations of persons with albinism in Europe and North America was held on 22 November 2024, 19 participants attended.

II. Overview of work of mandate since 2015

4. Prior to 2013, little attention was given by the United Nations to the specific human rights concerns affecting persons with albinism apart from periodic references.[9] Critics of the United Nations engagement on albinism have argued that the Organization was slow to recognize the serious nature of the human rights abuses faced by persons with albinism. The adoption of resolution 23/13 on attacks and discrimination against persons with albinism, resolution 24/33 on technical cooperation for the prevention of attacks against persons with albinism and resolution General Assembly resolution 69/170, by which the Assembly declared 13 June as International Albinism Awareness Day, marked a turning point in the United Nations engagement on albinism. The adoption of those resolutions, the preliminary report of the Office of the United Nations High Commissioner for Human Rights (OHCHR) on persons with albinism,[10] the report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons "living with" albinism[11] and the appointment of the Independent Expert on the enjoyment of human rights by persons with albinism set the tone for more consistent engagement by the United Nations.

A. Summary of thematic work conducted

5. Over the past 10 years, 18 thematic reports have been produced under the mandate. The present report is the nineteenth thematic report. Ten annual thematic reports have been presented to the Human Rights Council and nine to the General Assembly.[12] The reports covered critical issues affecting persons with albinism, expanded on the applicable international human rights framework, identified good practices and provided recommendations for addressing relevant key human right concerns.

Advancing international awareness and development of human rights standards applicable to persons with albinism

6. Although recognized in principle, the rights of persons with albinism have often been overlooked.[13] The mandate has played a central role in mainstreaming the rights of persons with albinism, contributing to their integration in global, regional and national human rights framework. The thematic reports of the mandate, notably the report on applicable international human rights standards and related obligations addressing the issues faced by persons with albinism,[14] have been instrumental in highlighting the key international human rights standards and the correlating obligations of States in this regard. A key contribution of the mandate has been in defining the violations against persons with albinism within the framework of the Convention on the Rights of Persons with Disabilities, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime.[15] The report on applicable international human rights standards and subsequent reports have described how discrimination, coupled with the failure of States to adequately protect persons with albinism against attacks (constituting acquiescence on the part of the

[9] Special procedures of the Human Rights Council, including the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the Special Rapporteur on the rights of persons with disabilities, have included albinism-related abuses in their work.

[10] A/HRC/24/57.

[11] A/HRC/28/75.

[12] Thematic reports of the Independent Expert on the enjoyment of human rights by persons with albinism, 2015–2024, including A/79/175, A/78/167, A/77/199 and A/HRC/49/56.

[13] See https://www.ohchr.org/en/topic/albinism.

[14] See A/72/131.

[15] Ibid.

State), place such attacks firmly within the definition of torture and have further shown that such attacks can constitute a form of trafficking for the exploitation of body parts.[16]

Developing an understanding of root causes of discrimination and harmful practices, against persons with albinism

7. Developing an understanding of root causes of discrimination and harmful practices, particularly attacks against persons with albinism, has been a priority for the mandate. In her initial report to the General Assembly, the first mandate holder, Ikponwosa Ero, identified a complex interplay of factors, including myths and misconceptions about albinism, witchcraft beliefs and ritual practices, poverty, all of which contribute significantly to attacks against persons with albinism and exacerbate pre-existing contexts of discrimination and stigma.[17] Building on that report, the following thematic report[18] deepened the understanding of harmful practices related to practices of witchcraft as one of the root causes of the attacks. The erroneous belief that the body parts of persons with albinism can be used in medicine, charms and amulets by practitioners of witchcraft to create muti or juju to ward off illnesses or bad luck is a key driver of harmful practices against persons with albinism.[19] In the 2022 report on harmful practices and hate crimes targeting persons with albinism,[20] the Independent Expert undertook a more in-depth examination of such harmful practices and how they may amount to hate crimes.

Recognition of multiple and intersectional discrimination experienced by persons with albinism

8. In their reports, the mandate holders have highlighted the multiple forms of discrimination faced by persons with albinism, underscoring how intersectional factors such as gender, age, disability, poverty and skin colour compound discrimination against persons with albinism, in particular women and children. This compounded discrimination exacerbates their vulnerability to human rights violations, including stigma, social exclusion, economic hardship and violence. In the 2020 report of the Independent Expert on women and children impacted by albinism, women with albinism and mothers of children with albinism were shown to often bear the brunt of this compounded discrimination.[21] In a 2022 report, the Independent Expert examined the discrimination experienced by women and children with disabilities who are refugees and internally displaced and their vulnerability to gender-based violence, exploitation and exclusion from education.[22]

Advancing economic, social and cultural rights of persons with albinism

9. The Independent Experts have increased global awareness of the economic, social and cultural rights of persons with albinism and encouraged States and other actors to adopt concrete measures to address these issues. In their reports, the Independent Experts have primarily highlighted the barriers experienced by persons with albinism in the realization of their right to education, health, employment and adequate housing.

10. The rights to inclusive education and access to healthcare have been recurring themes of the mandate. The report on protection of persons with albinism[23] and the report on the right to education,[24] among others, highlight the systemic barriers to education faced by persons with albinism while showcasing good practices and offering recommendations to improve their inclusion and well-being. Key challenges identified involved stigma, discrimination,

[16] Ibid., paras. 33–39.
[17] A/71/255, paras. 15–20.
[18] A/HRC/34/59.
[19] Ibid., paras. 27–38.
[20] A/HRC/49/56.
[21] A/HRC/43/42, paras. 11–17.
[22] A/77/199, paras. 50–53.
[23] A/75/170, sect. V.B.
[24] A/HRC/55/45, sects. III, V and VI.

bullying, including by teachers, and misconceptions, as well as inadequate accommodations such as assistive devices, large print materials and protection from sun exposure.[25]

11. In her report on the rights to health of persons with albinism,[26] the then Independent Expert, Ikponwosa Ero, outlined health challenges associated with albinism, including susceptibility to ultraviolet-induced skin cancer, visual impairments and systemic barriers to accessing healthcare. The report underscores the role of socioeconomic and environmental factors, such as limited access to sunscreen, vision aids and affordable healthcare, in creating disparities.[27] It also addresses the psychological toll of societal stigmatization and the fear of attacks, particularly in regions where harmful myths about albinism are prevalent.

Implications of emerging global challenges on persons with albinism

12. During her tenure, the present Independent Expert, Muluka-Anne Miti-Drummond, has drawn attention to critical and often overlooked issues affecting persons with albinism, including climate change and migration, and the need to recognize those working on albinism-related issues as human rights defenders. Spotlighting these issues has contributed to a greater understanding of the implications of such global challenges on persons with albinism and the need to integrate their experiences into broader emerging global discussions to ensure no one is left behind.[28]

13. The mandate was the first international mechanism to clearly recognize the impact of climate change on persons with albinism. As emphasized in the report on the impact of climate change on persons with albinism, the disproportionate risks of skin cancer, educational exclusion and social stigma are exacerbated by gaps in global and national policies that fail to account for the intersecting vulnerabilities of persons with albinism.[29] In the report, the Independent Expert also considers the disproportionate impact of climate change-related natural disasters, including increased risk of injuries during the disasters, and advocates for inclusive climate adaptation and mitigation strategies, while highlighting promising practices, such as government-led sunscreen distribution programmes and community-based protective initiatives. However, she critically notes the persistent exclusion of persons with albinism from international and national climate dialogues. Furthermore, refugees, asylum seekers and internally displaced persons with albinism have oftentimes been invisible in global discussions on migration. In the report on people with albinism on the move, the Independent Expert highlights that persons with albinism and their families mainly flee their homes or countries owing to fear or experiences of violent physical attacks, extreme forms of persecution and discrimination.[30]

14. Human rights defenders with albinism are a crucial yet vulnerable group, given their dual exposure to discrimination, first as individuals with albinism and second as advocates challenging systemic injustices. In her report on human rights defenders working on albinism,[31] the Independent Expert analyses the challenges faced by those defenders, emphasizing the lack of recognition for their work, as many are not identified as human rights defenders.[32] She also examines specific risks defenders face, such as stigmatization, intimidation and threats to their safety.[33] In addition, examples of good practices, such as collaboration with international human rights organizations, the few human rights awards presented to defenders working on albinism and capacity-building initiatives, are highlighted in the report.[34]

15. In the most recent report of the mandate, the Independent Expert explores the drivers for the separation of children with albinism from families, including the threat of attacks

[25] Ibid., sect. III.
[26] A/HRC/37/57, sects. III, IV and V.
[27] Ibid., paras. 66–69.
[28] A/73/181.
[29] A/78/167, para. 52.
[30] A/77/199, paras. 10–15.
[31] A/HRC/52/36.
[32] Ibid., paras. 20–21.
[33] Ibid.
[34] Ibid., sect. VI.

against them.[35] She challenges the perception of some authorities that the most appropriate response to the poverty and lack of access to services, such as education, health care, social protection and family support, experienced by children with albinism is their institutionalization, ostensibly for their own protection. As an alternative, the Independent Expert emphasizes the importance of family care and recommends the implementation of measures to prevent family separation, implementation of childcare reform and the use of kinship care and foster care rather than institutionalization. She does, however, recognize that there may be exceptional circumstances that may require small scale residential care, although she cautions this must be done with certain safeguards in place.

16. Contrary to a common misconception, that the reports cover only concerns in the African continent, all of the reports of the mandate focus on concerns of persons with albinism throughout the globe.[36] However, as most of the research by academics and civil society organizations has been focused on countries in Africa, more information has been received from that region. In addition, due to the grave nature of attacks against persons with albinism in Africa, groups of persons with albinism from the African continent have been more actively engaged in demanding their rights and have tended to be more active in responding to calls for input coming from the mandate.

B. Country visits

17. The mandate holders have conducted 11 country visits since 2015 and produced reports analysing the situation in those countries. The independent experts have conducted an average of one visit a year. They have visited Brazil and Panama in Latin America; Fiji in the Asia-Pacific; Kenya, Lesotho, Madagascar, Malawi, Mozambique, South Africa and United Republic of Tanzania in Africa; and, most recently, the United States of America. The choice of countries to visit has been motivated by several factors. Most of the country visits in Africa were carried out in response to reports of attacks against persons with albinism, although there were no reported cases of attacks in Lesotho. In some cases, for example in relation to Panama, the visit was motivated by a relevant law coming into force in the country.[37] In the case of the United States, the mandate holder also wanted to highlight a rarer form of albinism, Heřmanský Pudlák Syndrome, which is prevalent in Puerto Rico.[38] Various factors, including the coronavirus disease (COVID-19) pandemic and the bureaucratic nature of extending invitations to mandate holders in some countries, prevented the mandate holders from obtaining invitations from other countries. In this regard, the Independent Expert would like to highlight and commend the speedy and unprecedented invitation to her from the Government of Lesotho at its own initiative.

18. The recommendations made to countries following the visits have spanned several themes, including calls to undertake legislative and policy reforms, conduct situational analysis, collect disaggregated data, engage organizations representing persons with albinism and improve healthcare access. Although the extent to which countries have implemented the recommendations varies, the submissions received show that all the countries visited have made commendable efforts towards their implementation.[39] For instance, Kenya, Malawi and the United Republic of Tanzania have all gathered data on the prevalence of albinism through their censuses, in line with the recommendation made by the then Independent Expert following her visits. Kenya, Malawi, Mozambique and the United Republic of Tanzania, have also developed comprehensive national action plans on albinism, in fulfilment of the recommendation to execute the Regional Action Plan on Albinism 2017–2021.

19. The United Republic of Tanzania has initiated widespread public education campaigns to combat discrimination and violence against persons with albinism, revised the

[35] A/79/175, sect. IV.

[36] See, for example, A/74/190 and A/74/190/Corr.1.

[37] A/HRC/55/45/Add.1, para. 15.

[38] OHCHR, “UN albinism expert to visit the United States”, 4 October 2024, available at https://www.ohchr.org/en/media-advisories/2024/10/un-albinism-expert-visit-united-states.

[39] See A/HRC/46/32, paras. 39–40, for more examples on how countries have implemented recommendations made by the first Independent Expert during country visits.

Penal Code Act, which criminalizes attacks against persons with albinism and recognizes such attacks as hate crimes, and developed the National Albinism Health Programme and National Strategy for Inclusive Education to foster inclusive education and access to healthcare services.[40] Panama had already adopted a law protecting the rights of persons with albinism, including recognizing albinism as a disability, and calling for the provision of sunscreen, access to health services, reasonable accommodations and assistive devices.[41] The Independent Expert made recommendations for the development of a framework to ensure implementation of the law,[42] and the Government has since approached her, requesting assistance in this regard. South Africa passed the Prevention and Combating of Hate Crimes and Hate Speech Act,[43] heeding calls to expedite the passing of the hate speech bill.[44] The country has also created a National Strategic Framework on Self-Representation (2021) and a National Strategic Framework for Awareness Raising (2022).[45]

C. Communications

20. The Independent Experts have utilized communication procedures to address specific human rights issues and cases of alleged violations to the human rights of persons with albinism by Member States. These communications provided an opportunity to raise awareness of abuses, placing international pressure on Governments and encouraging protective policies for persons with albinism. From 2015 to 2023, the Independent Experts issued 26 communications, which included urgent appeals, allegation letters and "OL" (other letters).[46] Cases have been submitted to the Independent Expert by, inter alia, individuals, victims, family members and civil society organizations.

21. Most communications relate to attacks, mutilations, killings and the trafficking of body parts.[47] For example, in relation to Zambia, the communication dealt with several allegations of attacks in the same country.[48] In the case of Democratic Republic of Congo, the communications dealt with threats and intimidation directed at a human rights defender with albinism advocating for persons with albinism.[49] In another instance, an urgent appeal was issued regarding access to healthcare for a woman with albinism in Nigeria,[50] and another contained recommendations for two bills pending at the Brazilian Parliament that address the enjoyment of human rights by persons with albinism.[51]

22. Only eight replies have been received to the communications, despite repeated requests, revealing a significant gap in State engagement and compliance. The lack of responses severely limits the effectiveness of mandate holders in addressing abuses, as State cooperation is essential for verifying allegations and ensuring accountability.

23. Although there have only been 26 communications, there have been hundreds of additional attacks resulting in death and many other violations. The limited knowledge of many persons with albinism of their human rights results in individuals being unaware that their experiences constitute a violation of those rights. Furthermore, even those who have the capacity to exercise their rights find that the United Nations procedures for reporting cases

[40] See A/HRC/37/57/Add.1, sect. V, for the list of recommendations made to the United Republic of Tanzania.
[41] Law No. 210 of 2021 (in Spanish) (https://vlex.com.pa/vid/ley-n-210-declara-866012171).
[42] A/HRC/55/45/Add.1, para. 82.
[43] Act No. 16 of 2023 (https://www.gov.za/documents/acts/prevention-and-combating-hate-crimes-and-hate-speech-act-16-2023-english-sepedi-14).
[44] A/HRC/43/42/Add.1, para. 108.
[45] See https://www.ohchr.org/sites/default/files/documents/issues/albinism/cfis/10th-anniversry/2024-09-20-south-africa-inputs-report-ie-albinism-en.pdf.
[46] See https://spcommreports.ohchr.org/TmSearch/Mandates?m=266.
[47] See communications MWI 2/2023, TZA 1/2023, MDG 2/2022 and ZMB 4/2021, amongst others. All communications mentioned in the present report are available at https://spcommreports.ohchr.org/Tmsearch/TMDocuments.
[48] See communications ZMB 1/2016 and ZMB 4/2021.
[49] See communication COD 6/2022.
[50] See communication NGA 3/2022.
[51] See communication BRA 16/2019.

are inaccessible. United Nations procedures for reporting information for communications assumes that complainants are literate and have access to an Internet to complete the online form. Even when people are literate, the process fails to consider the oral tradition of some cultures that places an emphasis on talking to individuals, rather than writing, to report concerns. The inaccessible procedure of reporting, the low level of literacy among those affected and the secrecy and fear that surrounds attacks means that many cases are not reported, or are insufficiently reported, making it difficult for the mandate holder to respond, as required by the United Nations.

D. Stakeholder engagement and cooperation with other bodies

24. During their tenures, both Independent Experts have engaged with numerous stakeholders and cooperated with various bodies to strengthen the implementation of the rights of persons with albinism. The first Independent Expert provided a summary of the achievements and accomplishments of her tenure as mandate holder, from 2015 to 2021, in her report to the Human Rights Council of March 2021, including details of her public engagements, research, working visits and technical support provided to governmental and non-governmental bodies.[52]

25. The current Independent Expert has built on this work. Since her appointment in 2021, she has authored several academic papers and conducted independent research, including on challenges faced by persons with albinism in the United Kingdom of Great Britain and Northern Ireland,[53] as well as on barriers to accessing justice by persons with albinism in Zambia, thus contributing to building a robust body of evidence-based work. She has further collaborated with academic institutions and facilitated human rights capacity-building workshops for European albinism groups, online in December 2022, and in Geneva in March 2023; for Francophone albinism groups from across Africa in Côte d'Ivoire in May 2023, and for Lusophone groups from Mozambique in October 2023.[54]

26. The current Independent Expert has also collaborated with African institutions, including the African Committee of Experts on the Rights and Welfare of the Child, participating in several of the Committee's ordinary sessions and other engagements. In 2024, she worked with the Committee in arranging a Day of General Discussion on the Solutions to the Challenges faced by Children with Albinism during its forty-third ordinary session, held from 15 to 25 April 2024, in Maseru, Lesotho, and in the development of a concept note and an outcome statement.[55] Building on work of the first mandate holder, she has supported the adoption of the Pan-African Parliament Guidelines on the Elimination of Harmful Practices Related to Accusations of Witchcraft and Ritual Attacks, including a report released in March 2023.[56] The guidelines provide a practical instrument for parliamentarians across the continent in bringing attention to these harmful practices and accelerating their elimination. In 2023, the Independent Expert submitted an amicus curiae brief related to the allegations of human rights violations against persons with albinism in the United Republic of Tanzania before the African Court on Human and Peoples' Rights.[57] The case was heard

[52] A/HRC/46/32.

[53] Muluka-Anne Miti-Drummond and others, "Persons with albinism and their right to health, education and employment in the UK: preliminary research findings" (2024).

[54] A/HRC/55/69/Add.1, p. 97.

[55] For the concept note, see https://www.acerwc.africa/sites/default/files/2024-04/Concept%20Note%20-%20%20DGD%20children%20with%20Albinism.pdf; for the outcome statement see https://www.acerwc.africa/sites/default/files/2024-04/DGD%20Outcome%20Statement%20EN.pdf.

[56] Pan-African Parliament, "Guidelines for parliamentarians on accusations of witchcraft and ritual attacks: towards eliminating harmful practices and other human rights violations" (2023), available at https://www.theinternationalnetwork.org/latest/pan-african-parliament-launched-its-guidelines-for-parliamentarians-on-accusations-of-witchcraft-and-ritual-attacks.

[57] African Court on Human and Peoples' Rights, "African Court concludes public hearing in Application No. 019/2018, *Centre for Human Rights and Others vs. the United Republic of Tanzania* on alleged human rights violations of persons with albinism in Tanzania", 12 September 2024, available at https://www.african-court.org/wpafc/african-court-concludes-public-hearing-in-

in September 2024 during the Court's seventy-fourth ordinary session in 2024 and the Independent Expert participated in the hearing as an amicus.

27. The Independent Expert has also engaged United Nations agencies during her country visits and the course of her other activities. In 2023, she worked with the Office of the United Nations High Commissioner for Refugees (UNHCR) to ensure the inclusion of persons with albinism in a discussion paper on exploring the intersectionality of international refugee protection and the Convention on the Rights of Persons with Disabilities.[58] She has worked with the United Nations Children's Fund (UNICEF) on issues related to child protection, including through participating in UNICEF webinars.[59] Furthermore, in collaboration with the Global Albinism Alliance and other organizations, she applied to have broad-spectrum sunscreen re-added to the World Health Organization (WHO) Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children in December 2022.[60]

28. The Independent Expert has further hosted and participated in public engagements to raise awareness, exchange information and promote good practices regarding the enjoyment of human rights by persons with albinism. The conferences, round-table discussions and other engagements were aimed at mainstreaming albinism in the disability movement and in other areas of human rights, including migration, refugees, human rights defenders, climate change, trafficking and child rights.

III. Advances in the right of persons with albinism across the world in the last decade

A. Developments at the international level

29. Over the last decade, there has been a strengthened global commitment to safeguarding the rights and dignity of persons with albinism. This has included a notable increase in the number of submissions received, questions raised and recommendations and observations made by the treaty monitoring bodies. The Committee against Torture, the Committee on Economic, Social and Cultural Rights, the Committee on the Elimination of Discrimination against Women, the Committee on the Elimination of Racial Discrimination, the Committee on the Rights of Persons with Disabilities, the Committee on the Rights of the Child and the Human Rights Committee have all reached concluding observation relating to persons with albinism in the past 10 years.

30. The Committee on the Rights of the Child has highlighted discrimination, violence and social exclusion faced by children with albinism in countries such as Malawi, Mozambique and the United Republic of Tanzania. [61]For instance, the United Republic of Tanzania was urged to end the practice of institutionalizing children with albinism in shelters,[62] while Malawi was pressed to enforce laws and provide free sunscreen and medical support.[63]

application-no-019-2018-centre-for-human-rights-and-others-vs-tanzania-on-alleged-human-rights-violations-of-persons-with-albinism-in-tanzania/.

58 Toju Popo, "Exploring the intersectionality of international refugee protection and the 2006 Convention on the Rights of Persons with Disabilities," 2020, available at https://www.internationaldisabilityalliance.org/sites/default/files/discussion_paper_crpd_and_refugee_law_final_2023.docx.

59 ESARO Regional Learning Platform – Care Reform, "Webinar: the care of children with albinism and disability inclusive care reform", 10 December 2024, available at https://www.youtube.com/watch?v=UmYq_T3D73k.

60 "Application to add broad-spectrum sunscreen to the World Health Organization Model List of Essential Medicines and Model List of Essential Medicines for children", 16 December 2022.

61 CRC/C/TZA/CO/3-5, paras. 25, 29 and 30; CRC/C/MWI/CO/3-5, para. 26; CRC/C/MOZ/CO/3-4, para. 29; and CRC/C/SWZ/CO/2-4, paras 26 and 42.

62 CRC/C/TZA/CO/3-5, para. 31.

63 CRC/C/MWI/CO/3-5, para. 27.

31. The Committee on the Elimination of Discrimination against Women has condemned ritual killings, abductions and sexual violence targeting women and girls with albinism in Burundi, Mozambique and the United Republic of Tanzania.[64] Similarly the Committee against Torture has examined the situation of persons with albinism, emphasizing that persecution and physical assaults leading to the death and mutilation of persons with albinism fall under the scope of the Convention.[65] The Committee on the Elimination of Racial Discrimination, in its review of reports submitted by Namibia and Zambia, expressed concern at the colour discrimination experienced by persons with albinism from those countries.[66]

32. The Human Rights Committee has addressed discrimination and violence against persons with albinism when discussing non-discrimination and vulnerable groups.[67] In 2018 it adopted general comment No. 36 (2018) on the right to life, which contains a specific reference to persons with albinism, requiring special measures of protection by the State because of their vulnerability.[68]

33. The Committee on the Rights of Persons with Disabilities has recognized albinism as a disability under its definition, emphasizing the need for inclusive policies.[69] It dealt with three communications relating to attacks against persons with albinism[70] and identified attacks, mutilations and trafficking in body parts as extreme forms of disability-based discrimination. Countries including Kenya,[71] Senegal[72] and Zambia[73] were urged to adopt legal measures to protect persons with albinism and combat harmful practices tied to superstitions. While it is encouraging to see treaty bodies addressing violations against persons with albinism, it is concerning that, so far, this view has only been raised in relation to African countries, thus perpetuating the misconception that violations against persons with albinism only relate to attacks and are only present in Africa. The Independent Expert urges treaty bodies to include questions on albinism in reviews of countries outside Africa.

34. The Secretary-General has issued a number of reports highlighting the social development challenges faced by persons with albinism.[74]

35. More special procedure mandate holders have addressed issues related to albinism through various statements, communications, reports and public engagements in the past 10 years. The Special Rapporteur on the rights of persons with disabilities, the Special Rapporteur on violence against women, its causes and consequences, the Special Rapporteur on extrajudicial, summary or arbitrary executions, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance have all engaged on albinism issues.

36. United Nations agencies have also been key contributors to discussions of the issue. UNICEF has published studies on best practices for protecting persons with albinism,[75] the International Organization for Migration (IOM) has released a situational analysis on

[64] CEDAW/C/BDI/CO/5-6, paras. 24 (c), 34 (b), 46 (a); CEDAW/C/MOZ/CO/3-5, para. 42 (c); and CEDAW/C/TZA/CO/7-8, paras. 18 (b) and 42.

[65] CAT/C/BDI/CO/3, paras. 43–44.

[66] CERD/C/ZMB/CO/17-19, para. 29; and CERD/C/NAM/CO/16-18, paras. 24–25.

[67] CCPR/C/SWZ/CO/1, para. 22; CCPR/C/KEN/CO/4, paras. 10–11, 18 (f) and 34 (c); CCPR/C/NAM/CO/3, para. 8; and CCPR/C/BDI/CO/3, para. 45.

[68] CCPR/C/GC/36, paras. 23 and 61.

[69] CRPD/C/18/D/22/2014, para. 7.6.

[70] Ibid.; see also *Y v. United Republic of Tanzania* (CRPD/C/20/D/23/2014); and *Z v. United Republic of Tanzania* (CRPD/C/22/D/24/2014).

[71] CRPD/C/KEN/CO/1, para. 20 (a) and (c).

[72] CRPD/C/SEN/CO/1, paras. 14, 18, 28 (a), 30 (a) and 44 (b).

[73] CRPD/C/ZMB/CO/1, paras. 16 (c), 20 (a) and (b), 31 (e), 34 (c), 48 (b) and 50 (c).

[74] A/76/769 and A/72/169.

[75] Redson E. Kapindu, "Study on challenges and best practices in investigations, prosecutions and sentencing in offences against persons with albinism in Malawi", report submitted to UNICEF, March 2018, available at https://www.ohchr.org/sites/default/files/Documents/Countries/MW/StudyInvestigationsProsecutionCasesMarch2018.pdf.

Mozambique[76] and the United Nations Development Programme (UNDP) has developed educational resources for children with albinism.[77] These efforts reflect growing institutional engagement to address the unique challenges faced by persons with albinism globally.

B. Developments at regional level

37. While regional bodies such as the European Union have shown interest and commitment in relation to the situation of persons with albinism, there can be no doubt that the African Union has been the pioneer in the development of standards to address the situation of persons with albinism in Africa. Over the last decade, the African Union has implemented different measures to address issues affecting persons with albinism through its organs and mechanisms. In January 2018, it adopted the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, which entered into force in August 2024. The Protocol explicitly recognizes persons with albinism as a constituency of persons with disabilities.

38. The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, adopted by the African Commission on Human and Peoples' Rights, builds on existing work of the African human rights system, including the adoption of the resolution on the attacks on persons with albinism in Malawi in 2016, and endorses the Regional Action Plan on Albinism in Africa (2017–2021).[78]

39. The Plan of Action to End Attacks and Other Human Rights Violations Targeting People with Albinism in Africa (2021–2031) was adopted by the Executive Council of the African Union in 2019.[79] It replaced the Regional Action Plan on Albinism in Africa (2017–2021).[80] At the same time, the African Union made the decision to establish a mandate for a Special Envoy for Persons with Albinism.[81] The African Union has yet to appoint the Special Envoy. In 2021, under the leadership of the African Union (Department of Health, Humanitarian Affairs and Social Development), in collaboration with the Independent Expert on albinism, an implementation strategy for the above-mentioned African Union Plan of Action was developed and embedded into the African Union Plan of Action and Implementing Strategy to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031).

40. On 17 May 2018, the Pan-African Parliament endorsed the Regional Action Plan on Albinism in Africa (2017–2021) in the a resolution on persons with albinism in Africa.[82] In 2019, the Pan-African Parliament adopted a resolution on concrete measures for the promotion and protection of the rights of persons with albinism in Africa.[83] In that resolution, the Parliament condemned the attacks on persons with albinism and the violation of their human rights and called for regional cooperation to address cross-border crimes affecting persons with albinism.[84] The Parliament authorized the drafting of guidelines aimed at ending harmful practices related to accusations of witchcraft and ritual attacks affecting persons with albinism.[85] In the lead-up to the adoption of the resolution, the Independent Expert made presentations on the Regional Action Plan and the situation of persons with albinism on the

[76] Viktoria Perschler, *Situation Analysis on the Human Rights and Protection of Persons with Albinism in Mozambique with a Special Focus on Human Trafficking* (Maputo, IOM, 2019), available at https://unicri.it/sites/default/files/2019-10/IOM_PWA_REPORT_ENG_P2.pdf.

[77] Sierra Leone Association of Persons with Albinism, "Albinism: an information booklet for teachers in Sierra Leone" (UNDP, 2023); and Clarence Sebastian Foundation, "School kit for parents of Albino children" (UNDP, 2023).

[78] ACHPR/Res.373(LX)2017.

[79] EX.CL/Dec.1063 (XXXV), para. 20 (ii).

[80] African Commission on Human and Peoples' Rights, resolution 373 (LX) 2017.

[81] EX.CL/Dec.1063 (XXXV), para. 22.

[82] Document PAP.4/PLN/RES/05/MAY.18.

[83] Document PAP.5/PLN/RES/08/MAY.19

[84] Ibid., paras. 1 and 7.

[85] See https://pap.au.int/en/news/press-releases/2021-04-20/pap-validates-proposed-guidelines-concrete-actions-end-harmful.

continent to the members of the Committee on Justice and Human Rights of the Pan-African Parliament and to the Parliament during its plenary session.

41. The African Committee of Experts on the Rights and Welfare of the Child conducted fact-finding missions in Malawi (2022)[86] and the United Republic of Tanzania (2015)[87] to investigate abuses and highlight challenges faced in those countries. In its resolution 19/2022, the Committee expressed serious concern over ongoing violations of the rights of children with albinism, emphasizing their incompatibility with the African Charter on the Rights and Welfare of the Child.[88] The Committee is currently in the process of developing a guidance note for States on how to report on the situation of children with albinism in their countries.[89]

42. In 2017 the European Parliament adopted resolution 2017/2868 on the situation of persons with albinism in Africa, notably in Malawi, in which it also endorsed the Regional Action Plan on Albinism in Africa (2017–2021) and called upon the European Union and its member States to, inter alia, support efforts to address the rights of persons with albinism on the basis of non-discrimination and social inclusion by providing the necessary financial and technical assistance.[90] In addition, in 2020, through the President of the European Commission, all forms and manifestations of hatred and intolerance that are incompatible with the values of respect for human dignity have been outlawed.[91]

43. At the subregional level, the Southern African Development Community (SADC) adopted the Declaration on the Protection of Persons with Albinism during its forty-fourth summit in Harare.[92] Among the notable elements of the Declaration is the call for countries in the region to add sunscreen to their national essential drug lists.[93]

IV. Developments in the field of albinism rights at the national level around the world

44. Influenced by developments at regional and global levels, there has been progress in the implementation of the rights of persons with albinism at national level around the world over the last decade. The Independent Expert notes that the examples provided below are not exhaustive and looks forward to receiving other examples from more countries to help paint a more comprehensive portrait of such progress.

A. Legal recognition of albinism as a disability

45. There has been increasing global acknowledgement and support for the recognition of persons with albinism as individuals with disabilities in accordance with article 2 of the Convention on the Rights of Persons with Disabilities over the last decade. For example, in

[86] Report of the African Committee of Experts on the Rights and Welfare of the Child Working Group on Children with Disabilities in Africa on the fact-finding mission on the situation of children with albinism in the Republic of Malawi, 29–31 August 2022.

[87] "Report on investigative mission on the situation of children with albinism in temporary holding shelters – the United Republic of Tanzania" (Addis Ababa, 2016).

[88] Resolution No 19/2022 of the Working Group on Children with Disabilities on the situation of children with albinism in Africa.

[89] Report on the forty-second session of the Committee, document ACERWC/RPT (XLII), para. 125.

[90] Resolution 2017/2868(RSP) on the situation of persons with albinism in Africa, notably in Malawi.

[91] Communication from the European Commission to the European Parliament and the Council of Europe, "A more inclusive and protective Europe: extending the list of EU crimes to hate speech and hate crime" (COM/2021/777), available at https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/combatting-discrimination/racism-and-xenophobia/extending-eu-crimes-hate-speech-and-hate-crime_en.

[92] Communiqué of the forty-fourth Ordinary Summit of SADC Heads of State and Government, 17 August 2024, Harare, Zimbabwe, available at https://www.sadc.int/latest-news/communique-44th-ordinary-summit-sadc-heads-state-and-government-17th-august-2024-harare.

[93] Southern African Development Community, Declaration on the Protection of Persons with Albinism, 2024, available at https://www.ohchr.org/en/documents/statements/declaration-protection-persons-albinism.

Uganda, the Persons with Disabilities Act was adopted in 2020[94] and in Ghana, the Persons with Disability Amendment Bill, adopted in 2020,[95] explicitly recognizes albinism as a disability. The Persons with Disabilities Act, adopted by Malawi in 2024,[96] and the Discrimination against Persons with Disabilities (Prohibition) Act, adopted in Nigeria in 2018,[97] contain a social model of disability, enabling the recognition of albinism as a disability. Other countries recognize persons with albinism as persons with disabilities on the grounds of their visual impairment alone rather than their skin sensitivity. This seems to be the case in many European countries, including Denmark, Italy and Norway according to consultations held.

B. Albinism specific national action plans and legislation

46. In most countries, the rights of persons with albinism are generally addressed within the framework of general policies and legislation that promote equality, non- discrimination and the inclusion of persons with disabilities or within rare disease frameworks. However, in the last decade, albinism-specific policies and laws have started to emerge. For example, Guinea,[98] Panama,[99] Puerto Rico[100] and the Province of San Juan in Brazil,[101] have adopted specific legislation on the rights of persons with albinism. Argentina and Brazil have also proposed such laws. The Governments of Angola,[102] Malawi,[103] Mozambique,[104] Uganda[105] and the United Republic of Tanzania[106] have adopted national action plans on albinism, albeit some with different names, over the last 10 years. In Malawi there are ongoing efforts to review and update the national action plan on persons with albinism, which ended in 2022. Nigeria also has a national policy on albinism, which was created in 2019 by the Federal Ministry of Education. Similarly, South Africa and Togo are in the process of actively developing their plans. The implementation of the plans has been hindered in some countries by limited funding, inadequate awareness and lack of capacity within implementing institutions.

C. Data on albinism

47. Disaggregated data on albinism remains limited in many parts of the world. However, a few countries have made an effort to collect such data, and Côte d'Ivoire, Kenya, Malawi, Namibia, Sierra Leone and the United Republic of Tanzania have included questions on albinism in their national censuses. Noteworthy results include the 2018 census in Malawi, which showed that persons with albinism represented approximately 0.8 per cent of the total

[94] Act No. 3 of 2020, Schedule 3 (sect. 1), available at https://media.ulii.org/media/legislation/18449/source_file/c3d75a987b07b64e/2020-3.pdf.

[95] Persons with Disabilities Amendment Bill, 2020, sects. 62 (3) and 82 and first schedule (7), available at https://www.disabilityrightsfund.org/wp-content/uploads/Persons-with-Disabilities-Amendment-Bill-20202.pdf.

[96] Persons with Disabilities Act 2024, sect. 2, available at https://www.macoha.mw/public/assets/uploads/publications/240812090242_Persons%20with%20Disabilities%20Act,%202024.pdf.

[97] Discrimination against Persons with Disabilities (Prohibition) Act, sect. 57 (b), available at https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Nigeria_Discrimination-Against-Persons-with-Disabilities-Prohibition-Act-2018.pdf.

[98] Law No. 0016/AN of 2021.

[99] Law No. 210 of 2021.

[100] Law No. 109 of 2022.

[101] Law No. 2635-Q.

[102] National Action Plan for the Protection and Promotion of the Human Rights of Persons with Albinism, 2023–2027.

[103] National Action Plan on Persons with Albinism in Malawi, 2018–2022.

[104] Multisectoral Action Plan to Address the Issue of the Protection of Persons with Albinism, 2015.

[105] National Action Plan for Persons with Albinism, 2020–2025

[106] National Action Plan on the Rights and Welfare of Persons with Albinism, 2024.

population.[107] In Kenya, according to the 2019 census, 0.02 per cent of the population, or 9,729 people, have albinism.[108] However, these numbers are contested by the disability community. Other countries, such as Argentina, Mali and Panama, have established frameworks that mandate or encourage the collection of statistics on albinism. The Province of Misiones in Argentina has a law requiring the creation and maintenance of database on persons with albinism. In Mali, a mobile phone application on albinism (*YEFEKE*), available to download free of charge, was created to, inter alia, to collect data on persons with albinism.[109] There are countries that have also collected data on albinism through demographic health surveys. For example, in 2019, China started a national registry for rare diseases; persons with albinism are included and all cases diagnosed are included in the national register.[110]

D. Inclusion of albinism in climate change adaptation policies

48. Although climate change has exacerbated the health inequalities and contributed to the exclusion of persons with albinism from education, employment and many other aspects of social participation, persons with albinism have received little attention in this context. In 2022 only 37 of 192 States parties to the Paris Agreement have referred to people with disabilities in their nationally determined contributions.[111]

49. Many countries have simply noted the heightened vulnerability of people with disabilities to climate change impacts (Eswatini, Maldives, Mexico, Togo and Zimbabwe).[112] Other States identify people with disabilities as a segment of the population requiring specific adaptation measures (Fiji, Mauritius, Moldova, Papua New Guinea and the United Republic of Tanzania). With regard to persons with albinism, only the Central African Republic has mentioned persons with albinism in its national climate adaptation policies.[113]

E. Healthcare goods and services essential for persons with albinism

50. Several Governments, including Colombia, Ecuador, Fiji, Ghana, Kenya, Malawi, South Africa, Uganda and the United Republic of Tanzania, have initiatives providing free or subsidized sunscreen and sun protective clothing, access to dermatological services and skin cancer screening, detection and treatment and awareness campaigns to educate persons with albinism and their families about the importance of sun protection.[114] Studies published on the impact of such interventions have shown that these interventions, where implemented, have significantly improved the health outcomes of persons with albinism.

51. Furthermore, the majority of national action plans on albinism adopted to date include measures to ensure access to sunscreen, protective clothing and regular dermatological check-ups and skin cancer treatments. Other countries have added sunscreen on their national essential drug lists. Those countries include Australia, in 2018; Kenya, in 2023; South Africa, in 2020; and the United Republic of Tanzania, in 2021.[115] While most countries specify sun

[107] National Statistical Office, *2018 Malawi Population and Housing Census: Main Report* (2019), para. 3.7.

[108] Development Initiatives, "Status of disability in Kenya: statistics from the 2019 census", background paper, May 2020, p. 7.

[109] Association des Blogueurs du Mali, "*YEFEKE*: une application pour promouvoir les droits des albinos au Mali", 17 July 2020.

[110] Jian Guo and others, "National Rare Diseases Registry System (NRDRS): China's first nation-wide rare diseases demographic analyses", *Orphanet Journal of Rare Diseases*, vol. 16 (2021).

[111] Disability Inclusive Climate Action Research Programme, Status Report on Disability Inclusion in National Climate Commitments and Policies, 2022, p. 2.

[112] Ibid., p. 4.

[113] Ibid., p 18.

[114] Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (2020), pp. 27 and 28.

[115] National Department of Health of South Africa, *Standard Treatment Guidelines and Essential Medicines List for South Africa: Primary Healthcare Level*, 7th ed. (2020); Ministry of Health of

protection factor (SPF) 30+, Kenya has included SPF 50+ on its list. Brazil and New Zealand[116] are apparently considering the inclusion of sunscreen on their lists.

F. Measures addressing attacks, violence and trafficking of persons with albinism

52. According to the organization Under the Same Sun, in the last decade there have been 731 recorded attacks against persons with albinism in 31 countries,[117] although the actual number is believed to be higher. Governments have taken a variety of measures aimed at preventing such attacks, including community policing programmes aimed at increasing vigilance at the local level, for example, in Burundi, Madagascar, Malawi, South Africa and Zambia..[118] The South African Police Service has established a specialized unit, focused on vulnerable groups, including persons with albinism, and has conducted awareness campaigns in border areas, particularly in provinces identified as hotspots for human and body trafficking of persons with albinism. In Zambia, the appointment of an influential human rights defender with albinism, John Chiti, to the police commission helped create a sense of security and protection among persons with albinism.[119]

53. Countries such as Madagascar, Malawi, Mozambique, South Africa, the United Republic of Tanzania and Zambia have prosecuted perpetrators of attacks against persons with albinism. In Malawi, on several occasions the high court has imposed the maximum sentence of life imprisonment for murder in cases where the victim was a person with albinism.[120] Most notable was the sentencing of three men to 155 years imprisonment for the murder of a man with albinism in 2022. Malawi has trained relevant police officers in the handling of offences concerning persons with albinism, and the police in Malawi and Mozambique have signed memorandums of understanding to facilitate investigations.[121]

54. Malawi and South Africa have taken additional legislative measures to strengthen their justice systems to provide protections for persons with albinism. Malawi has amended its Anatomy Act to impose stiffer penalties for crimes involving the abduction, murder or trafficking of persons with albinism. The Act is also aimed at criminalizing the unauthorized possession of human tissues. The Prevention and Combating of Hate Crimes and Hate Speech Act in South Africa includes attacks against persons with albinism within the ambit of hate crimes.

G. Recognition of attacks against persons with albinism as a ground for asylum

55. Over the course of the last decade, some countries have come to recognize albinism-related persecution as a valid ground for granting asylum under international law, particularly when individuals face risks of violence, discrimination or ritualistic harm.

Kenya, *Kenya Essential Medicines List 2023* (Nairobi, 2023); and Ministry of Health, Community Development, Gender, Elderly and Children of the United Republic of Tanzania, *Standard Treatment Guidelines and National Essential Medicines List for Tanzania Mainland*, 6th ed. (Dodoma, 2021).

116 Minister of Health, *Government Policy Statement on Health 2024–2027* (Wellington, Ministry of Health, 2024).

117 Under the Same Sun, *Reported attacks: re: persons with albinism*, 2024.

118 Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (2020), pp. 13 and 14; A/HRC/52/36/Add.1, para. 74.

119 Ari Daniel, “He's a singer, a cop and the inspiration for a Netflix film about albinism in Africa”, NPR, 10 September 2023, available at https://www.npr.org/sections/goatsandsoda/2023/09/10/1198675534/a-new-netflix-film-follows-a-boy-growing-up-with-albinism-in-zambia.

120 Carmel Rickard, “Tough court sentence could mark shift on albinism murders in Malawi”, African LII, 14 May 2021, available at https://africanlii.org/articles/2021-05-14/carmel-rickard/tough-court-sentence-could-mark-shift-on-albinism-murders-in-malawi; and High Court of Malawi, *The State v. Samson Kaumba*, Criminal Case No. 2 of 2015, Judgment, 15 June 2016.

121 Ministry of Justice and Constitutional Affairs, *Handbook for Investigators, Prosecutors and Magistrates on Offences Concerning Persons with Albinism* (2016).

Countries such as France and the United States evaluate albinism-related cases on the grounds of persecution based on membership in a particular social group.[122] The European Union guidelines suggest that attacks targeting persons with albinism can constitute valid grounds for asylum when State protection is inadequate.[123] The issue of asylum and albinism has also been recognized legally through precedent cases, such as *JA (child – risk of persecution) Nigeria v. The Secretary of State for the Home Department*, a 2016 case involving a 7-year-old boy with albinism, in which a judge in the United Kingdom noted, in relation to albinism, that "if there is a failure to provide necessary protection against persecution … then there is a proper basis for finding that [persons with albinism] are refugees".[124] In that same case, the court further held that the widespread societal discrimination, threats of violence and ill-treatment might amount to real persecution in relation to a child in circumstances where it would not amount to such in respect of an adult.[125] In New Zealand, a young man with albinism qualified for asylum because he was deemed to belong to the group of "persons with disabilities". Canada and the United States have both granted asylum to individuals with albinism from regions where they are at significant risk due to ritualistic killings or societal discrimination.

H. Social protection services targeting persons with albinism

56. To date, few countries have implemented social protection programmes specifically targeting or prioritizing persons with albinism; more countries have social protection programmes for persons with disabilities that persons with albinism can access, in principle, but are not always able to in practice. Obstacles to accessing disability grants for persons with albinism include failure to recognize albinism as a disability or the requirement that severe disability be assessed using specific medical models.

57. Examples of good practice include the Tanzania Social Action Fund, a social cash transfer programme that provides financial assistance to vulnerable households, including those with members who have albinism.[126] The Government also provides transportation assistance to some students with albinism who live in remote areas and those who attend special needs schools. Good practices can also be found in Canada,[127] France,[128] Sweden,[129] Thailand[130] and the United Kingdom,[131] as well as in the form of financial assistance for persons with disabilities for which persons with albinism may qualify.

[122] Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (2020), p. 15.

[123] See https://www.google.com/url?sa=t&source=web&rct=j&opi=89978449&url=https://euaa.europa.eu/sites/default/files/EASO-Guidance-on%2520MPSG-EN.pdf&ved=2ahUKEwj6tJLR_fGKAxUAQEEAHQTkHzUQFnoECBYQAQ&usg=AOvVaw3_-tnsNieenGtAMXh6blUQ.

[124] Upper Tribunal, Immigration and Asylum Chamber, Case No. 00560, Decision, 24 November 2016, para. 8, available at https://tribunalsdecisions.service.gov.uk/utiac/2016-ukut-560.

[125] Ibid., paras. 15–16.

[126] Tanzania Social Action Fund, "Vision and mission", available at http://www.tasaf.org/index.php/about-us/vision-and-mission.

[127] Government of Canada, "Registered Disability Savings Plan", available at https://www.canada.ca/en/employment-social development/programs/disability/savings.html.

[128] Béatrice Valdes, "European Social Policy Network thematic report on social protection for people with disabilities: France" (Brussels, European Commission, 2022).

[129] Johanna Gustafsson and Berth Danermark, "ANED country report on social protection and article 28 of the CRPD – Sweden", Academic Network of European Disability Experts, 2016, available at https://www.disability-europe.net/downloads/753-country-report-on-social-protection-and-article-28-uncrpd-sweden.

[130] Economic and Social Commission for Asia and the Pacific Social Development Division, "Thailand's disability allowance", 2019, available at https://www.socialprotection-toolbox.org/practice/thailands-disability-allowance.

[131] Miti-Drummond and others, "Persons with albinism and their right to health, education and employment in the UK".

58. In many European countries, persons with albinism may qualify for subsidies, tax exemptions and rebates, access to free services or products and cash transfers, depending on the extent of their visual impairment. In the United Kingdom, depending on their age, persons with albinism often meet the criteria for Disability Living Allowance or a Personal Independence Payment.[132] Both programmes are intended to help with the costs of having a long-term disability and can be used for costs beyond those associated with visual impairment. Other countries, particularly in Europe and Latin America, provide free or subsidized travel for persons with disabilities; persons with albinism qualify for such travel.

I. Raising awareness of the rights of persons with albinism

59. Countries have made significant progress in raising awareness about albinism. Many have used the International Albinism Awareness Day established by the United Nations in 2014 as a platform to educate communities on albinism, dispel myths surrounding the condition, combat discrimination and promote the rights of persons with albinism. They have also adopted different measures to raise awareness, including educational campaigns, advocacy events and community outreach, as well as through public art and cultural programmes. South Africa observes an Albinism Awareness Month in September to promote understanding and inclusion of persons with albinism[133] and the Ugandan Parliament holds an annual Albinism Charity Walk. The innovative use of beauty pageants, popularly known as "Mr. and Miss Albinism", has spread across the African continent as a popular tool for awareness-raising. Civil society organizations play a pivotal role in these efforts. The need for continued awareness raising remains critical, particularly in regions where people with albinism still face violence, discrimination and marginalization.

J. Representation of persons with albinism in the media, political life and the public sphere

60. The representation of persons with albinism in the media and in culture have historically been negative; they are often portrayed as mythical villains or objects of ridicule. However, advocacy has led to progress in recent years. Films like *Can You See Us?* (Zambia, 2022),[134] *This World – Born Too White* (2017)[135] and *The Boy from Geita* (2014)[136] offer humanizing depictions of their struggles and resilience. Similarly, campaigns like #NotGhosts[137] and models such as Diandra Forrest and Shaun Ross have positively reshaped public perceptions. Despite these advances, mainstream film industries, notably Hollywood, remain slow to embrace actors with albinism, leaving it to African and independent cinema to advance progress on the issue.[138]

61. Inclusion in public and political life has improved, with countries like Côte d'Ivoire, Kenya, Malawi, South Africa and the United Republic of Tanzania appointing persons with albinism to high-profile roles, including as parliamentarians, government officials and commissioners. One such prominent individual is Abdallah Saleh Possi, the Permanent Representative of the United Republic of Tanzania to the United Nations Office and other

[132] See https://www.gov.uk/browse/benefits/disability.

[133] Government of South Africa, "Albinism Awareness Month", available at https://www.gov.za/news/events/health-awareness-events/albinism-awareness-month.

[134] Anna Menta, "*Can You See Us* true story: how a Zambian singer with albinism inspired the drama on Netflix", Decider, 28 August 2023.

[135] BBC Media Centre, "Born Too White", available at https://www.bbc.co.uk/mediacentre/proginfo/2017/08/born-too-white.

[136] See https://www.imdb.com/title/tt3605760/.

[137] United Nations News, "'Not ghosts but human beings:' UN rights office launches website on albinism", 5 May 2015, available at https://news.un.org/en/story/2015/05/497862.

[138] Acacia, "Hollywood's inaccurate portrayal of albinism isn't just hurtful, it's dangerous", Blind Beginnings, available at https://www.blindbeginnings.ca/blog-archive/hollywoods-inaccurate-portrayal-of-albinism-isnt-just-hurtful-its-dangerous.

international organizations in Geneva. The appointment of persons with albinism to high level roles helps to combat marginalization and enhance their visibility.[139]

62. Additionally, persons with albinism have been recognized as human rights defenders. Notable figures in the field of human rights include the Kenyans, Isaac Mwaura (2016),[140] and Jake Epelle (2021),[141] as well as the appointment of Xueli Abbing as Goodwill Ambassador of the United Nations Educational, Scientific and Cultural Organization for the Fight against Racism and Discrimination[142] in 2022, underscoring their growing recognition. While these advancements highlight their contributions, there remains an urgent need to expand their platforms and ensure their protection against persistent challenges.

K. Budget allocation for albinism groups and programmes

63. A few Governments, specifically Kenya, Malawi and Nigeria, have started providing budget support for albinism programmes. In some cases, a small portion of a national budget is allocated directly to relevant albinism associations to carry out programmes, while the rest is allocated to public institutions for the implementation of specific measures. The Government of Kenya, for example, has set aside a substantial annual budget of 100 million Kenyan shillings (nearly $1 million) for initiatives targeted at the health, education and protection of Kenyan nationals with albinism since 2013.[143]

L. Other positive initiatives

64. Other positive initiatives have included the monitoring of rights abuses through the work of national human rights institutions in countries such as Malawi,[144] Namibia,[145] the United Republic of Tanzania[146] and Zambia.[147] To that effect, Amnesty International, in collaboration with the Open Society Initiative, has developed a manual to assist national human rights institutions in promoting and protecting the rights of persons with albinism.

65. Some States have developed mechanisms for the advancement of the rights of persons with albinism, for example, the establishment of national albinism task forces. In most countries such bodies are multisectoral government bodies, comprising albinism groups, government agencies, national human rights institutions and representatives from the relevant sectors, including disability, health, education, justice and the private sector.

66. The development of policies and legislation that promote the inclusive education of learners with albinism is another example of further positive initiatives. Fiji,[148] Nigeria,[149] Sierra Leone[150] and the United Republic of Tanzania,[151] have adopted inclusive education policies and, in 2020, the Government of Togo issued a circular to facilitate the support of

[139] United Nations Office at Geneva, “New Permanent Representative of Tanzania presents credentials to the Director-General of the United Nations Office at Geneva”, 23 October 2023.

[140] Hilary Kimuyu, “Former MP Isaac Mwaura appointed Government Spokesperson”, Nairobi News, 5 October 2023.

[141] Policy and Legal Advocacy Centre, “Albino Foundation’s Jake Epelle receives human rights award”, 17 December 2021.

[142] See https://www.unesco.org/en/goodwill-ambassadors/xueli-abbing.

[143] A/HRC/40/62/Add.3, para. 40.

[144] Malawi Human Rights Commission, “Concept paper: addressing challenges in the implementation of National Action Plan for Persons with Albinism”, October 2021.

[145] Office of the Ombudsman, *Report on the Public Hearings on Discrimination and Other Challenges Facing Persons with Albinism in Namibia* (2022).

[146] Fatma Abdu, “Tanzania: Commission issues recommendations for protecting people with albinism”, AllAfrica, 26 April 2015.

[147] Zambia Monitor, “Rights Commission urges responsible exercise of free speech on social media, condemns attacks on albinos”, 18 August 2024.

[148] Ministry of Education, Heritage and Arts, Policy on Special and Inclusive Education.

[149] National Policy on Albinism in Nigeria.

[150] Ministry of Basic and Senior Secondary Education, National Policy on Radical Inclusion in Schools.

[151] Ministry of Education and Vocational Training, National Strategy on Inclusive Education 2009–2017.

students with albinism in schools.[152] In addition, Panama and the Province of Misiones in Argentina[153] have specific laws on albinism, including in the area of education. Many States, however, have continued to enrol students with albinism in segregated schools even though there is a move towards more inclusive education. Furthermore, in cases where inclusive education policies exist, implementation has remained a challenge.

V. Priorities for the mandate in coming years

67. The Independent Expert will continue addressing attacks and violence against individuals with albinism while ensuring their inclusion in critical human rights discussions, including those related to climate change. Efforts will also centre on mainstreaming albinism issues into broader human rights frameworks and addressing concerns in regions where individuals with albinism remain "invisible" or overlooked. Additional attention will be given to rare forms of albinism, such as Heřmanský Pudlák Syndrome, to further expand understanding of the condition and to address overlooked challenges.

VI. Conclusion and recommendations

68. **The tenth anniversary of the mandate marks a critical moment for an assessment of progress made in advancing the rights of persons with albinism by the mandate holders and other actors globally. Over the course of the last decade, mandate holders have engaged, advocated and reported on a wide range of issues with regard to albinism. While significant progress has been made in advancing the human rights of persons with albinism, the Independent Expert reiterates that much more needs to be done to address the ongoing challenges and concerns faced by persons with albinism. This requires concerted action at both the national and international levels, as well as cooperation and partnerships between States and non-State organizations.**

69. **The Independent Expert recommends that:**

(a) **States continue engaging on albinism issues in Africa;**

(b) **States and United Nations bodies increase engagement on concerns of persons with albinism outside of Africa;**

(c) **States continue to engage with the mandate, including through extending invitations, making timely submissions to calls for inputs interactive dialogue and responding to communications;**

(d) **States and others implement the existing recommendations of the mandate.**

[152] Komi Mawouli Gbebe, "Inclusive education and dignity of children with disability in Togo", *Iris Journal of Educational Research*, vol. 1, No. 1 (2023).

[153] Law XVII – No. 107, available at https://digestomisiones.gob.ar/archivospdf/1688643534_Ley%20XVII%20-%20N%20107%20Texto%20Definitivo.pdf.