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

Enjoyment of human rights 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, Muluka-Anne Miti-Drummond, in accordance with Human Rights Council resolutions [28/6](#) and [46/12](#).

* [A/78/150](#).



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

Climate change and persons with albinism

Summary

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, focuses on the impact of climate change on persons with albinism. She addresses the particular impact of climate change on persons with albinism, given their susceptibility to skin cancer, mostly owing to lack of or inefficient protection against harsh ultraviolet rays or sun exposure. The report further addresses a number of human rights-related challenges of climate change on persons with albinism, including in the context of discrimination based on colour and disability, the right to the enjoyment of the highest attainable standard of health, the right to education, the right to employment and the right to life. Climate change could impinge on the full enjoyment of those rights and have a disproportionate impact on persons with albinism. The report also contains examples of good practice and several recommendations to address the various challenges related to climate change. The Expert hopes that the present report will provide the basis for further in-depth studies and analysis on the impact of climate change on persons with albinism, as more pertinent information may become readily available in the future.

I. Introduction

1. The present document is the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond. It is submitted pursuant to Human Rights Council resolutions 28/6 and 46/12.
2. In preparing the report, the Expert sent a questionnaire on 23 March 2023 to various stakeholders, including Member States, civil society organizations and persons with albinism. The Expert received written submissions from and held virtual consultations with 28 stakeholders, the majority of whom were academics and civil society organizations.
3. The report is focused on the impact of climate change on persons with albinism, given their potentially fatal susceptibility to skin cancer, mostly owing to lack of or inefficient protection against harsh ultraviolet rays or sun exposure. It also contains a summary of some of the key activities of the Expert during the reporting period.
4. Persons with albinism are a unique group whose human rights issues have generally gone unnoticed for centuries, resulting in deeply entrenched stigma, discrimination and violence against them across various countries. The complexity and uniqueness of their condition means that their experiences significantly and simultaneously touch on several human rights issues, including, but not limited to discrimination based on colour, discrimination based on disability, reasonable accommodations and adaptations in terms of access to education, the right to the enjoyment of the highest attainable standard of health, and the right to life and bodily integrity. Full enjoyment of these rights should guarantee to persons with albinism protection against harmful traditional practices, such as ritual attacks and killings, trade and trafficking in body parts for purposes of witchcraft, and the abandonment of children.
5. Climate change further impinges on the enjoyment of rights by persons with albinism. The Expert hopes that the present report on climate change and persons with albinism will provide the basis for further in-depth studies and analysis on the impact of climate change on persons with albinism, as more pertinent information may become readily available in the future.

II. Activities of the mandate holder

6. During the period from November 2022 to June 2023, the Expert undertook various activities, some of which are highlighted below.
7. Capacity-building activities included human rights training for albinism groups in Zambia, organized in collaboration with Amnesty International, in January 2023. It was followed by a visit to the session of the African Committee of Experts on the Rights and Welfare of the Child for the Zambian groups in Maseru, in April. Together with the civil society team of the Office of the United Nations High Commissioner for Human Rights, the Expert carried out an online training session in December, followed by an in-person training session, in Geneva, in March, for leaders of European albinism groups to strengthen their capacity to engage with the United Nations. Human rights training for albinism leaders from Francophone African countries was organized in conjunction with the Fondation Pierre Fabre, in Abidjan, Côte d'Ivoire, in June.
8. In February, the Expert spoke at a conference on albinism hosted by the Africa Albinism Network, in the United Republic of Tanzania; gave a virtual presentation to students of the School of International and Political Studies, along with the Global Albinism Alliance; and participated in a meeting on children with disabilities in

Africa, organized by the African Committee of Experts on the Rights and Welfare of the Child. In March, she presented at a webinar hosted by the Disability and Care Reform Community of Practice, on the topic “Addressing stigma and discrimination to prevent separation of children”. In April, she participated in the forty-first session of the African Committee of Experts on the Rights and Welfare of the Child, where she and other representatives of the albinism movement participated in a panel discussion on children with albinism in Africa, held during the plenary meeting of the session.

9. In May, the Expert spoke on the topic of disability, inclusion and health at the inaugural conference of the Stellenbosch Disability Research Hub and carried out visits to academic institutions in the Western Cape, South Africa. She also hosted two round tables. The first round table was held in conjunction with Amnesty International, in Zambia, at the end of January, and engaged members of the justice sector and persons with albinism, with the aim of better understanding the obstacles to access to justice for persons with albinism in that country. In June, together with Staffordshire University, the Expert hosted the second round table, on albinism, in the United Kingdom of Great Britain and Northern Ireland, with the aim of gaining an understanding of the specific situation of persons with albinism in that country.

10. The Expert continued to work on the elimination of harmful practices related to accusations of witchcraft. In cooperation with the Pan-African Parliament, she officially launched a preliminary report and guidelines for parliamentarians, entitled *Accusations of Witchcraft and Ritual Attacks: Towards Eliminating Harmful Practices and Other Human Rights Violations*.¹ The launch was supported by the Centre for Human Rights of the University of Pretoria. In June, on the margins of the annual meeting of the special procedure mandate holders, the Expert co-organized a consultation with the newly established International Network Against Accusations of Witchcraft and Associated Harmful Practices on Human Rights Council resolution 47/8 on the elimination of harmful practices related to accusations of witchcraft and ritual attacks, and on the recent study on the situation of the violations and abuses of human rights rooted in harmful practices related to accusations of witchcraft and ritual attacks, as well as stigmatization (A/HRC/52/47).

11. On 13 June, the Expert celebrated International Albinism Awareness Day in Geneva, the theme of which was “Inclusion is strength”. To mark the Day, she delivered remarks via video statement.² She worked with the Global Albinism Alliance and the United Nations Educational, Scientific and Cultural Organization Goodwill Ambassador for the fight against racism and discrimination, Xueli Abbing, to host an event to commemorate the International Day. The event was hosted by the International Bureau of Education of the United Nations Educational, Scientific and Cultural Organization and attended by United Nations entities, representatives of diplomatic missions in Geneva and special procedure mandate holders.

III. Definitions

A. Climate change

12. Earth’s climate system consists of five major components: (a) the atmosphere (the layer of gases that surrounds the Earth); (b) the hydrosphere (Earth’s water); (c) the cryosphere (Earth’s frozen water); (d) the lithosphere (Earth’s outer layer); (e) and the biosphere (the layer of Earth where life exists, including all living

¹ Available at www.ohchr.org/en/documents/tools-and-resources/pan-african-parliament-guidelines-accusations-witchcraft-and-ritual.

² Available at www.youtube.com/watch?v=S2ygR7fOQ6I.

organisms), as well as the interactions between those components. Climate in a broad sense is the state of the climate system.³

13. In article 1 of the United Nations Framework Convention on Climate Change, climate change is defined as a change of climate which is attributed directly or indirectly to human activity that alters the composition of the global atmosphere and which is in addition to natural climate variability observed over comparable time periods. In the definition a distinction is made between climate change attributable to human activities altering the atmospheric composition and climate variability attributable to natural causes.

B. Albinism

14. Albinism is a rare, non-contagious, genetically inherited condition that affects people worldwide, regardless of ethnicity or gender. It most commonly results in the lack of melanin pigment in the hair, skin and eyes (oculocutaneous albinism), causing vulnerability to sun exposure. The prevalence of albinism is disputed, but current estimates vary between 1 in 14,000 and 1 in 17,000 people in Western societies. In some African countries, the incidence rate of albinism is estimated to be as high as 1 in 500 people.⁴ The Pacific region, where many island States are among the nations most affected by climate change, has potentially one of the highest prevalence rates of albinism in the world, at around 1 person in 700 for oculocutaneous albinism type 2.⁵ Albinism is still profoundly misunderstood, socially and medically. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths influenced by superstition, leading to their marginalization and social exclusion. Owing to their visual impairment and high susceptibility to skin cancer, persons with albinism are also considered as persons with disabilities.

IV. Normative and policy frameworks

15. Persons with albinism are protected by existing human rights conventions that guarantee human rights for all persons, as well as those that afford protections for specific groups of persons, such as women or children. These include the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Elimination of All Forms of Discrimination against Women.⁶

16. Persons with albinism also have rights under the Convention on the Rights of Persons with Disabilities, according to which albinism is recognized as a disability. The Convention covers areas such as equality and non-discrimination, reasonable accommodation, effective participation and inclusion in society, gender equality, and accessibility. All of those provisions impose obligations on States parties and other

³ The definition of climate in the narrower sense is the average weather of a particular region or locality over a long period of time, commonly 30 years or more.

⁴ Reinier Bakker and others, "The retinal pigmentation pathway in human albinism: not so black and white", *Progress in Retinal and Eye Research*, vol. 91, (November 2022).

⁵ Ikponwosa Ero and others, *People with Albinism Worldwide: A Human Rights Perspective*. Available at www.ohchr.org/sites/default/files/2022-12/Albinism-Worldwide-Report-2021-EN.pdf.

⁶ For more information, see Office of the United Nations High Commissioner for Human Rights (OHCHR), analytical study on the promotion and protection of the rights of persons with disabilities in the context of climate change (A/HRC/44/30).

duty bearers to ensure that a rights-based approach is taken with regard to persons with disabilities.

17. The Convention on the Rights of Persons with Disabilities contains several other provisions that are applicable to protecting the rights of persons with albinism from being negatively affected by climate change.⁷ These include article 10, which obligates States to ensure the inherent right to life of persons with disabilities, and article 11, pursuant to which States must take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risks, including natural disasters. In addition, article 24, on education, article 25, on health, article 27, on work and employment, and article 28, on standard of living and social protection also safeguard persons with albinism from the adverse consequences that climate change has on social participation. At the core of the Convention is the obligation of State parties to actively involve and consult with persons with disabilities and their representative organizations in decision-making processes concerning issues that have an impact on their lives. Climate change is one of those pressing issues. Other articles – such as article 31, on addressing statistics and data collection, article 32, on international cooperation, and article 33, on national implementation and monitoring) – support the inclusion of persons with albinism in the areas of climate change adaptation, mitigation and loss and damage.

18. The Paris Agreement on climate change strengthens the global response to the threat of climate change by limiting global warming to well below 2 degrees Celsius above pre-industrial levels, while pursuing efforts to limit it to 1.5 degrees Celsius. The Paris Agreement does not contain reference to persons with albinism specifically, but in its preamble it is acknowledged that States parties should, when taking action to address climate change, respect, promote and consider their respective obligations with regard to human rights, including with respect to persons with disabilities. Subsequent decisions related to the United Nations Framework Convention on Climate Change have reaffirmed the rights of persons with disabilities alongside other groups. For instance, in the Glasgow Climate Pact, adopted at the twenty-sixth session of the Conference of the Parties to the United Nations Framework Convention on Climate Change, the obligations of States parties to include persons with disabilities in climate action is explicitly recognized (see document [FCCC/PA/CMA/2021/10/Add.1](#)).

19. In the Sendai Framework for Disaster Risk Reduction 2015–2030 it is recognized that persons with disabilities are disproportionately affected by disasters, and the importance of ensuring that disaster risk reduction strategies are inclusive and address the specific needs of all persons with disabilities is emphasized. In the Sendai Framework the need for the active participation and leadership of persons with disabilities and their representative organizations in all aspects of disaster risk reduction, including planning, implementation and monitoring, is also emphasized. In particular, under the Framework, Governments are called upon to engage with relevant stakeholders, including persons with disabilities, in the design and implementation of policies, plans and standards as part of a people-centred preventive approach to disaster risk.

⁷ No adverse conclusion should be drawn as to the applicability of provisions not listed here.

V. Impact of climate change on the health of persons with albinism

A. Increased ultraviolet radiation and sun exposure

20. The effects of climate change are increasing human exposure to ultraviolet radiation,⁸ and persons with albinism are at disproportionate risk of the health consequences thereof. Ultraviolet radiation is a key cause of skin cancer, and sunlight is the main source of ultraviolet radiation on Earth.⁹ Several factors that are caused by climate change increase the amount of ultraviolet radiation that reaches the Earth's surface, including ozone depletion and decreased cloud cover.¹⁰

21. In the case of global warming, rises in ambient temperature are thought to exacerbate the effect of ultraviolet radiation on the skin and directly increase incidences of skin cancer.¹¹ Global warming further causes changes in human behaviour that increase exposure to the sun, such as spending more time outdoors or wearing less clothing,¹² in particular among populations that cannot afford or gain access to mitigation measures, such as air conditioning or shade. Changes caused by other climate impacts, such as decreased rainfall, may also increase the amount of time that people spend outdoors.¹³ Incidences of skin cancer have been increasing globally as a result of climate change; in North-West Europe, it is expected that there will be an additional 90 million cases of skin cancer by 2050.¹⁴

22. Persons with albinism globally are at much higher risk of developing skin cancer from ultraviolet radiation exposure compared with the general population. In the Africa region, it is estimated that persons with albinism are up to 1,000 times more likely to develop skin cancer, compared with the general population.¹⁵ In the region, an estimated 98 per cent of persons with albinism reportedly do not live beyond 40 years of age because of sun exposure, with skin cancer being responsible for at least four fifths of these premature deaths.¹⁶ In a recent article published in Malawi, climate change was highlighted as an existential threat to Malawians with albinism, given the high mortality from skin cancer over the past few years.¹⁷

23. Persons with albinism who develop skin cancer can also be left with lasting skin damage and scars, even if they recover from the underlying cancer.¹⁸ Therefore, climate change impacts that increase human exposure to ultraviolet radiation

⁸ Eva Rawlings Parker, "The influence of climate change on skin cancer incidence: a review of the evidence", *International Journal of Women's Dermatology*, vol. 7, No. 1 (January 2021), pp. 17–27.

⁹ Deevya L. Narayanan, Rao N. Saladi and Joshua L. Fox, "Ultraviolet radiation and skin cancer", *International Journal of Dermatology*, vol. 49, No. 9 (September 2010), pp. 978–986.

¹⁰ Ibid.

¹¹ Caradee Y. Wright and others, "The incidence of skin cancer in relation to climate change in South Africa", *Atmosphere*, vol. 10, No. 10 (October 2019), p. 634.

¹² Ibid., footnote 11.

¹³ Ibid.

¹⁴ A. K. Bharath and R. J. Turner, "Impact of climate change on skin cancer", *Journal of the Royal Society of Medicine*, vol. 102, No. 6 (June 2009), pp. 215–218.

¹⁵ Samson K. Kiprono, Baraka M. Chaula and Helmut Beltraminelli, "Histological review of skin cancers in African Albinos: a 10-year retrospective review", *BMC Cancer*, vol. 14 (March 2014), pp. 1–4.

¹⁶ Esther Nakkazi, "People with albinism in Africa: contending with skin cancer", *The Lancet*, vol. 394 (10198) (August 2019), pp. 553 and 554.

¹⁷ Henry K. Mhango, "Climate change posing existential threat to Malawians with albinism", *The National*, 3 July 2023.

¹⁸ Farai Maunganidze, Kudakwashe Machiha and Martha Mapuranga, "Employment barriers and opportunities faced by people with albinism: a case of youths with albinism in Harare, Zimbabwe", *Cogent Social Sciences*, vol. 8, No. 1 (2022).

disproportionately affect the right to life of persons with albinism and their right to the highest attainable standard of health.

24. In addition to skin cancer, ultraviolet radiation and sun exposure also causes a range of other problems for persons with albinism. Persons with albinism are more susceptible to sunburn and skin photoageing, which can lead to lentigines (small, flat, brown spots), freckles and heavy wrinkling of the skin.¹⁹ Exposure to excessive sunlight also exacerbates problems with eye health. The eyes of persons with albinism are more sensitive to bright light and many individuals experience extreme discomfort from exposure. Glare from sunlight can also exacerbate existing concerns with visual perception.

25. Climate change impacts that increase the amount of human exposure to ultraviolet radiation may also increase the amount of ultraviolet radiation that individuals are exposed to indoors. In Brazil, the previous Independent Expert met with persons with albinism, including babies as young as 8 months old, who had been burned indoors as a result of exposure to ultraviolet rays in inadequate housing conditions and a lack of protection devices such as sunscreen ([A/HRC/46/32/Add.1](#), para. 60).

26. As human exposure to ultraviolet radiation increases owing to climate change, access to mitigation measures, such as broad-spectrum high sun protection factor sunscreen, protective clothing (e.g. hats and long-sleeved tops made of dense, ultraviolet-resistant material) and environmental modifications (e.g. shaded coverings, ultraviolet protective window film), are vital to ensure that persons with albinism enjoy the highest attainable standard of health. As such, sunscreen is essential for persons with albinism and is a life-saving product similar to essential medications. However, research shows that persons with albinism are disproportionately more likely to experience poverty compared with the general population.²⁰ At the same time, the high levels of ultraviolet protection required by persons with albinism mean that the products they need are usually more expensive and difficult to obtain compared with non-ultraviolet protective alternatives on the market. Products such as sunscreen are also depleted rapidly as a result of regular use. Therefore, many persons with albinism simply cannot afford the costs associated with these products, including the costs associated with travelling to buy them.

27. There are few government initiatives globally that provide free or low-cost sunscreen and protective gear, and where such schemes are available (e.g. through health services) they may not be easily accessible to all persons with albinism. In several countries, many persons with albinism, in particular those living in rural or remote areas, are unable to access health-care services within or close to their communities.²¹ Consequently, they may be required to undertake long journeys outdoors to buy needed protective products or access health services, thereby increasing their exposure to ultraviolet radiation and elevating their risk of skin cancer and other skin damage.

28. There is very poor awareness among many health professionals about the health needs of adults and children with albinism, including with respect to sun protection and skin cancer.²² There have been cases where persons with albinism presenting with skin cancer have been turned away by providers with only a bandage because cancerous lesions have been misinterpreted as a normal part of their condition.²³ Other

¹⁹ Ibid., footnote 12.

²⁰ Ikponwosa Ero and others, *People with Albinism Worldwide*.

²¹ Ibid.

²² Barbara Astle and others, "Global impact of climate change on persons with albinism: a human rights issue", *The Journal of Climate Change and Health*, vol. 9 (January–February 2023).

²³ Ikponwosa Ero and others, *People with Albinism Worldwide*.

key stakeholders, such as teachers and employers, frequently lack knowledge about the health needs of persons with albinism. Some individuals with albinism also have gaps in their awareness of how to protect themselves from ultraviolet radiation. Even where understanding of the existing health needs of persons with albinism among different stakeholders is high, the information received by the Expert suggests that levels of knowledge about how climate change may exacerbate those health issues or bring new health concerns is low.

B. Exposure to disasters and extreme weather events

29. Climate change has increased the frequency and intensity of climate and weather extremes, including heatwaves, heavy rainfall events, drought and weather that causes wildfires. Adverse impacts from tropical cyclones, with related losses and damages, have also increased due to sea level rises.²⁴ A submission received from Japan referred to heatwaves becoming commonplace; in 2019, an intense heatwave killed over 100 people and led to thousands being hospitalized. A recent report found that, over the past 50 years, a disaster related to either a weather, climate or water hazard has occurred every day, on average, killing over 100 people globally and causing \$202 million in losses daily.²⁵ Information received by the Expert highlighted that, in the United Republic of Tanzania, agricultural livelihoods are being threatened by increasing temperatures, longer dry spells and unpredictable and intense rain events. In Malawi, the impact of climate change over the past 30 years has been catastrophic. In March 2023, the country was hit by Cyclone Freddy, the longest-running cyclone on record, and, in 2022, by two other cyclones.

30. Persons with disabilities are disproportionately at risk of the health consequences of extreme weather events – and persons with albinism are no exception. Specific data on health outcomes for persons with albinism is scarce, but the mortality rate of persons with disabilities across many disaster situations is up to four times higher than that of persons without disabilities.²⁶ During and after disaster situations, persons with albinism, like persons with disabilities more broadly, are at increased risk of further disability and adverse health effects compared with the general population.²⁷ Some persons with albinism also have additional health conditions, which increases their vulnerability in disaster situations.

31. Like other persons with disabilities, persons with albinism are often unable to prepare effectively for disasters or keep themselves safe when disasters occur because of barriers located in the environment around them. Early warnings about disasters in written or other visual formats (e.g. warning signs containing flashing lights) are not accessible to persons with albinism who have visual impairments. In addition, during disaster situations, persons with albinism may be unable to safely navigate environmental hazards to find shelter because of their visual impairment. At the same

²⁴ Intergovernmental Panel on Climate Change, “Summary for policymakers”, in *Climate Change 2022: Impacts, Adaptation and Vulnerability – Contribution of Working Group II to the Sixth Assessment Report of the Intergovernmental Panel on Climate Change* (Cambridge, Cambridge University Press, 2022), pp. 3–33. Available at www.ipcc.ch/report/ar6/wg2/downloads/report/IPCC_AR6_WGII_SummaryForPolicymakers.pdf.

²⁵ World Meteorological Organization, *The Atlas of Mortality and Economic Losses from Weather, Climate and Water Extremes (1970–2019)* (Geneva, 2021).

²⁶ Takashi Izutsu, and others, *Disability-inclusive Disaster Risk Reduction and Humanitarian Action: An Urgent Global Imperative – Report of the United Nations Department of Economic and Social Affairs Public Forum*.

²⁷ *Building Disability-inclusive Societies in Asia and the Pacific: Assessing Progress of the Incheon Strategy* (United Nations publication, 2018).

time, they may be separated from assistive devices or their usual support networks (e.g. family members) because of the disaster situation.²⁸

32. Structures in use as temporary shelters or facilities may not provide sufficient protection from sun exposure for persons with albinism. In addition, after extreme weather events, widespread destruction means that significant trip hazards remain in the immediate physical environment. This is a danger for many persons with albinism because of their visual impairment. Consequently, these individuals may be restricted in their daily lives and livelihood opportunities in the aftermath of disaster events.

33. In common with other persons with disabilities, persons with albinism are likely to be forgotten or excluded in disaster planning, management and response at the community and national levels, thereby increasing the risk that they will experience adverse health outcomes during extreme weather events.²⁹ Stigma and discrimination, as well as a lack of awareness of the needs of persons with albinism in disaster situations, are drivers of exclusion.

34. Disasters cause disruptions to food security, water, sanitation and hygiene, and infrastructure, shelter and basic services, including health care. Disasters and their impacts (e.g. loss of the family home, forced migration) also lead to significant mental health consequences.³⁰ These disruptions are devastating for all, but persons with albinism are among the least resilient to these shocks. For instance, where disasters disrupt access to health care, persons with albinism are unable to access sunscreen, protective wear and visual aids, not to mention any medicines or treatment they may need. At the same time, lack of shelter and infrastructure and disruption to transport networks mean that persons with albinism may spend significantly more time exposed to the sun, thus increasing their risk of skin cancer. The disruption to services caused by disasters may persist for months or even years, contributing to significant long-term health inequalities.

35. Persons with albinism who have been forcibly displaced from their original communities by extreme weather events are at elevated risk of health impacts affecting all displaced persons, such as lack of access to services,³¹ and health impacts specific to persons with albinism, such as extreme sun exposure. The Expert received reports that care packs given to persons with albinism affected by Cyclone Freddy did not include sun protection products. The Expert also received information that, in Mozambique,³² an organization working on issues concerning persons with albinism visited resettlement centres for the victims of Cyclones Eloise and Idai. It identified cases in which children and adolescents with albinism were being housed in humanitarian tents that were not appropriate for their condition owing to the heat accumulating inside, causing discomfort and skin damage.

36. The health of children with albinism, as well as the health of children in the wider population, is threatened by malnutrition owing to food scarcity precipitated by disaster events. Evidence suggests that, when vulnerable families struggle to maintain nutritious diets following climate shocks, there are far-reaching impacts on child

²⁸ World Health Organization (WHO), *Global Report on Health Equity for Persons with Disabilities* (Geneva: 2022).

²⁹ See comments of the Chair of the Committee on the Rights of Persons with Disabilities in Sarah Johnson, “Disabled people are ‘lost and excluded’ when disasters hit, says UN advocate”, *The Guardian*, 28 March 2023. Available at www.theguardian.com/global-development/2023/mar/28/disabled-people-are-lost-and-excluded-when-disasters-hit-says-un-advocate.

³⁰ Sy A. Saeed and Steven P. Gargano, “Natural disasters and mental health”, *International Review of Psychiatry*, vol. 34, No. 1 (2022), pp. 16–25.

³¹ Patricia Schwerdtle, Kathryn Bowen and Celia McMichael, “The health impacts of climate-related migration”, *BMC Medicine*, vol. 16, No. 1 (2018), pp. 1–7.

³² Submission from Associação Defendendo Os Nossos Direitos, Mozambique.

health, including with regard to their physical growth and cognitive skills.³³ These impacts affect all children, but it is the very poorest households that are the least resilient to hardships when climate shocks hit. Albinism, and disability more generally, is a significant risk factor for poverty,³⁴ and having a child with albinism is likely to push caregivers – in particular, mothers – into poverty.³⁵ In some countries, over four fifths of mothers of children with albinism are thought to be impoverished.³⁶ As such, children with albinism and their households are among the most vulnerable to the climate-related shocks precipitated by extreme weather events.

C. Other health impacts

37. Global health is threatened by a lack of clean air, water and food scarcity, heat stress, and infectious diseases caused by changing weather and climate patterns.³⁷ These changes are not only happening suddenly, as in the case of extreme weather events, but are also occurring gradually through impacts such as recurrent droughts, crop failures and rising average temperatures, slowly eroding the health and well-being of populations worldwide. Between 2030 and 2050, climate change is expected to cause approximately 250,000 additional deaths per year from malnutrition, malaria, diarrhoea and heat stress.³⁸

38. Children born to mothers who have experienced droughts or disasters while pregnant have been shown to possess poorer cognitive and non-cognitive skills into adolescence.³⁹ Among the general population, there is even evidence that the health of children can be affected by climate-related impacts before they have been born or even conceived. Malnutrition experienced by adolescent girls as a result of rainfall shocks⁴⁰ before they become pregnant has been found to lead to stunting⁴¹ among their offspring.⁴² Persons with albinism, like persons with disabilities more broadly, are disproportionately at risk of the health consequences of these myriad climate

³³ Paul Dornan, María José Ogando Portela and Kirrily Pells, “Climate shocks, food and nutrition security: evidence from the Young Lives cohort study”, Oxfam Research Reports (Oxford, University of Oxford, September 2014).

³⁴ Health conditions like albinism are associated with both direct and indirect costs. Direct costs refer to the expenses associated with managing a condition, such as medical bills, rehabilitation, assistive devices and transportation costs. Indirect costs refer to the broader economic and social consequences that can lead to decreased income, limited job opportunities and financial instability. Discrimination in education and employment, leading to lower wages and reduced job opportunities, is an example of an indirect cost experienced by persons with albinism. When an adult or child with albinism requires additional support from a household member, it limits the time that the latter can spend on income generation and is another example of an indirect cost.

³⁵ Ikponwosa Ero and others, *People with Albinism Worldwide*.

³⁶ Ibid.

³⁷ Penelope J. S. Stein and Michael A. Stein, “Climate change and the right to health of people with disabilities”, *The Lancet Global Health*, vol. 10, No. 1 (January 2022).

³⁸ WHO, “Climate change and health”, fact sheet, 30 October 2021. Available at www.who.int/news-room/fact-sheets/detail/climate-change-and-health.

³⁹ Grace Chang, Marta Favara and Rafael Novella, “The origins of cognitive skills and non-cognitive skills: the long-term effect of in-utero rainfall shocks in India”, *Economics & Human Biology*, vol. 44 (January 2022).

⁴⁰ Rainfall shocks refer to unexpected or extreme changes in the amount of rainfall in a particular area. In areas that are heavily reliant on agriculture, a sudden decrease in rainfall can lead to crop failure, loss of livestock and reduced yields, devastating local communities. Excessive rainfall can lead to landslides, flooding and disruption of economic activities.

⁴¹ Stunting refers to a condition in which children have a lower height-for-age than is considered normal for their age group.

⁴² Andreas Georgiadis and others, “Maternal undernutrition in adolescence and child human capital development over the life course: evidence from an international cohort study”, *Economica*, vol. 88, No. 352 (October 2021), pp. 942–968.

impacts. Certain groups of persons with albinism are especially vulnerable to climate-related health impacts, such as children and individuals with albinism who have other existing health conditions.

39. Climate change is also worsening mental health.⁴³ Beyond the mental health consequences precipitated by sudden, traumatic climate impacts, such as extreme weather events, the gradual loss of natural environments and changing ways of life may cause individuals to experience “ecological grief” and “ecological anxiety”.^{44,45} Persons with albinism who are also members of Indigenous communities⁴⁶ may be especially likely to experience ecological grief; moreover, in some Indigenous communities, the prevalence of albinism is estimated to be as high as 1 in 28 persons.⁴⁷ The loss of local or traditional ecological knowledge, such as the ability to know or predict seasonal weather patterns, has been suggested as a key mechanism of ecological grief.⁴⁸ Ecological grief and ecological anxiety are new concepts and further research is needed to understand how persons with albinism specifically experience their effects.

VI. Impact on other areas of life

A. Livelihoods

40. The livelihoods of an estimated 2.5 billion people depend on agriculture, with small-scale farmers, herders and fishers generating more than half of all global agricultural production.⁴⁹ Most the world’s poorest people are also those living in rural areas that rely on agricultural livelihoods.⁵⁰ Climate change is disproportionately affecting the livelihoods of these people and displacing agriculture-dependent communities in many populations around the world. In submissions received from Malawi and the United Republic of Tanzania it was described how droughts and unpredictable weather patterns have precipitated food insecurity for persons with albinism, forcing them to farm for longer hours under blistering sun and in unbearable heat. In Zimbabwe, 78 per cent of persons with albinism who were interviewed by a local civil society organization said that they worked as street vendors, meaning that

⁴³ WHO, *Mental health and climate change: policy brief* (Geneva, 2022).

⁴⁴ The impacts of climate change on the environment is becoming a lived experience for more and more people worldwide. “Ecological grief” and “ecological anxiety” are two relatively new concepts to describe the psychological and emotional consequences of anticipated or actual environmental changes. Ecological grief is the emotional response to loss, degradation and destruction of the natural world, including ecosystems, species and habitats, and associated way of life. Ecological anxiety refers to the psychological distress, fear and unease that individuals experience in response to the threats and uncertainties associated with environmental change, in particular perceptions of environmental or climate doom. Other terms have also been used in the literature to refer to these or related concepts, such as “solastalgia”.

⁴⁵ Hannah Comtesse and others, “Ecological grief as a response to environmental change: a mental health risk or functional response?”, *International Journal of Environmental Research and Public Health*, vol. 18, No. 2 (January 2021), p. 734.

⁴⁶ An Indigenous community is a group of people who share a cultural and historical connection to a specific geographic area or region. Members of Indigenous communities often derive their sense of self and their group identity from their relationship with the land. This includes the land’s physical characteristics, its usage and the knowledge associated with it.

⁴⁷ Ikponwosa Ero and others, *People with Albinism Worldwide*.

⁴⁸ Ashlee Cunsolo and Neville R. Ellis, “Ecological grief as a mental health response to climate change-related loss”, *Nature Climate Change*, vol. 8, No. 4 (April 2018), pp. 275–281.

⁴⁹ Food and Agriculture Organization of the United Nations, “Increasing the resilience of agricultural livelihoods” (Rome, 2016).

⁵⁰ Food and Agriculture Organization of the United Nations, *The Future of Food and Agriculture: Trends and Challenges* (Rome, 2017).

they were regularly exposing themselves to the sun without appropriate protection. In addition, as a result of a state of emergency declared in the country, in 2016, three out of five farmers had been unable to plant any crops, leading to food insecurity for 2.44 million people. Several million jobs outside of agriculture depend on the environment, such as the biofuel, renewable energy, pharmaceutical, chemical and ecotourism industries. In 2014, these industries (including agriculture) accounted for 1.2 billion jobs, equivalent to 40 per cent of global employment and 16 per cent of total employment in the European Union.

41. Persons with albinism globally are less resilient to all types of climate-related shocks that disrupt livelihoods because of the existing barriers they face with regard to gaining access to education and securing employment. Climate-related impacts lead to job losses. Persons with albinism experience greater difficulty in transitioning to new jobs because of existing barriers, such as stigma and discrimination. In Nigeria, some prospective employers have been found to hold strong perceptions of persons with albinism having “repulsive” body odour that would discourage colleagues and customers from a shared workspace.⁵¹ In Japan, persons with albinism have been rejected after job interviews because of the colour of their hair, while, in Colombia, some employers have been unwilling to hire persons with albinism because of perceived liability for sunburn and skin damage at work.⁵² Owing to barriers such as stigma and discrimination, many persons with albinism work for themselves in informal trades,⁵³ many of which involve dangerous levels of sun exposure.

42. Persons with albinism face specific challenges when it comes to securing and maintaining employment because of barriers to ensuring their occupational health and safety; these challenges are worsened by climate change. In particular, persons with albinism regularly require assistive devices, such as visual aids, sun protection gear and workplace adaptation in order to minimize their exposure to the sun. All persons with disabilities, including persons with albinism, have the right to reasonable accommodations such as those described above so that they can safely participate in the labour market. As climate change continues to increase exposure to the sun, the occupational health and safety of persons with albinism will continue to be at particularly increased risk.

B. Forced displacement and environmental migration

43. According to the Special Rapporteur on the promotion and protection of human rights in the context of climate change, 59.1 million people worldwide were internally displaced in 2021, most of them displaced by climate-related disasters.⁵⁴ Moreover, climate change also has a significant influence on existing patterns of migration, with more and more people becoming “climate migrants”.⁵⁵ These individuals and their families are leaving their homes in response not only to sudden disasters but also

⁵¹ Esther T. Ololajulo and Sharon A. Omotoso, “The double jeopardy of women with albinism in Ibadan, Nigeria: breaking the unemployment barrier”, *Disability & Society* (2023), pp. 1–18.

⁵² Ikponwosa Ero and others, *People with Albinism Worldwide*.

⁵³ *Ibid.*

⁵⁴ OHCHR, “‘Intolerable tide’ of people displaced by climate change: UN expert”, press release, 13 June 2022. Available at www.ohchr.org/en/press-releases/2022/06/intolerable-tide-people-displaced-climate-change-un-expert.

⁵⁵ The International Organization for Migration (IOM) has defined climate migration as the movement of a person or groups of persons who, predominantly for reasons of sudden or progressive change in the environment owing to climate change, are obliged to leave their habitual place of residence, or choose to do so, either temporarily or permanently, within a State or across an international border. For more information, see *Glossary on Migration* (Geneva, IOM, 2019). Available at https://environmentalmigration.iom.int/sites/g/files/tmzbd11411/files/iml_34_glossary.pdf.

slower-moving climate impacts, such as rising sea levels. Estimates of the number of environmental migrants in the coming years range from between 25 million and 1 billion by 2050.⁵⁶ There is currently little data on how many persons with albinism are forcibly displaced or have migrated owing to environmental factors.

44. For persons with albinism working in agriculture, migration may be the only response that they deem feasible to climate-related loss of livelihoods, thus emphasizing the greater risk that climate change poses for persons with albinism who engage in agricultural work. The Expert has previously highlighted instances in which persons with albinism who rely on subsistence farming and spend a great deal of time in the sun are often compelled to relocate to regions with lower temperatures and less sunny climates to safeguard their health (see [A/77/199](#)). In Malawi, according to a submission received, it was observed that persons with albinism are relocating within the country from zones of sustained high temperature to areas of lower temperature in order to reduce their risk of skin cancer.

45. Not all persons with albinism are able to migrate in response to climate change, such as those individuals who have additional health needs. Anticipated difficulty in securing employment owing to stigma and discrimination related to their condition may also deter some individuals with albinism from migrating to urban areas. In Kiribati, Solomon Islands and Tuvalu, in recent research on persons with disabilities more broadly, additional challenges to migration after disaster events were identified, including not being granted visas and not being allowed to cross borders, as well as barriers to enrolling in social protection programmes or health care.⁵⁷ Consequently, in some cases, family members of persons with albinism may migrate without them. However, many persons with albinism whose family members migrate for environmental reasons face greater difficulties compared with individuals in other households with migrant family members. Where family members do migrate, persons with albinism have less recourse to caregiving support, such as help with securing sun protection cream or assistive devices. In a submission received by the Expert from the United Republic of Tanzania, a “vicious cycle” was described, whereby areas affected by natural disasters become cheaper places in which to live. Since they cannot afford to live in safer zones, persons with albinism cannot migrate in response to natural disasters and are therefore more exposed to the risk of disasters in the future. Moreover, because of poverty, persons with albinism are being forced to migrate to disaster-affected areas, as staying in safer, more expensive areas is becoming beyond their means.

C. Access to education

46. Climate change has a direct impact on education. Climate-related impacts disrupt livelihoods, meaning that some parents are no longer able to afford school costs (e.g. transport, school materials) and that children may be taken out of school to support income-generation activities. In some cases, families are displaced or migrate owing to climate-related changes. Collectively, these impacts lead to a drop in school attendance, increased numbers of children who are out of school and poor educational performance.⁵⁸

47. Climate-related impacts exacerbate the existing disparities that children with albinism face when it comes to gaining access to education. Children with albinism

⁵⁶ IOM, *IOM Outlook on Migration, Environment and Climate Change* (Geneva, 2014).

⁵⁷ Pacific Disability Forum, “Disability and climate change in the Pacific: findings from Kiribati, Solomon Islands, and Tuvalu” (August 2022).

⁵⁸ United Nations Children’s Fund, *It Is Getting Hot: Call for Education Systems to Respond to the Climate Crisis* (Bangkok, 2019).

are more vulnerable to negative health outcomes as a result of climate-related impacts, for example, because their households are more likely to be poorer and less resilient to climate shocks. These health impacts in turn magnify existing disparities that children with albinism experience in their educational journeys. While a child without albinism who has experienced malnutrition because of climate change may experience poorer educational participation and learning outcomes, a similarly affected child with albinism must contend with the impact of malnourishment on educational participation and learning outcomes and the negative impact caused by other barriers, such as inaccessible learning materials and attitudinal barriers. As a result of poverty or hardship and to avoid school-related costs, some families may choose to withdraw a child with albinism from school rather than their siblings because of concerns over their child's learning ability.⁵⁹

48. At the same time, climate change is causing specific risks with regard to the education of children with albinism. Harsh or prolonged sun exposure mean that the eyes of children with albinism are more exposed to glare; consequently, affected children have greater difficulty seeing classroom content and concentrating on their learning. Concurrently, while more frequent extreme sun exposure at and on the way to school poses grave health risks for children with albinism in the form of skin cancer, other health consequences, such as sunburn, are also very painful and disruptive to their education and learning.⁶⁰

49. When schools and other educational infrastructure are directly disrupted by climate-related impacts, such as extreme weather events, children with albinism face specific barriers to their educational participation and to mitigate learning loss. Structures, such as temporary classrooms and tents, used in the aftermath of disaster events may not be sufficient to protect the skin of persons with albinism. In addition, remote learning methods used during and after disaster events are often not fully accessible to persons with albinism and other persons with visual impairments, meaning that these learners miss out on vital teaching and learning.

D. Freedom from violence and discrimination

50. Myths and misconceptions about albinism and persons with albinism are common worldwide. In Africa, where persons with albinism are very visible, the condition is linked to superstition and harmful practices related to witchcraft accusations and ritual attacks, which, in turn, leads to marginalization and social exclusion. There have been cases of offences having been committed against persons with albinism, including killings, mutilations, rapes, grave robberies and trafficking in persons and body parts.⁶¹ In a number of African countries, the body parts of persons with albinism are believed to contain magical properties, which, when used in potions or spells, can bring good fortune.⁶² Elsewhere in the world, where attacks on persons with albinism are rarer, persons with albinism are still subject to damaging misconceptions, including that they cannot learn or complete normal tasks or that albinism is contagious.⁶³

⁵⁹ Ikponwosa Ero and others, *People with Albinism Worldwide*.

⁶⁰ Patricia M. Lund and Julie S. Taylor, "Lack of adequate sun protection for children with oculocutaneous albinism in South Africa", *BMC Public Health*, vol. 8, No. 1 (30 June 2008), pp. 1–8.

⁶¹ Ikponwosa Ero and others, *People with Albinism Worldwide*.

⁶² Nora Groce and Jeremy McGeown, "Witchcraft, wealth and disability: reinterpretation of a folk belief in contemporary urban Africa", Leonard Cheshire Disability and Inclusive Development Centre Working Paper Series, No. 30 (London, University College London, 2013).

⁶³ Ikponwosa Ero and others, *People with Albinism Worldwide*.

51. The conditions brought about by specific climate-related impacts, such as extreme weather events, increase the risk that persons with albinism will be subject to stigma, discrimination and violence. Disasters precipitate resource scarcity and are thought to exacerbate disability-related stigma and discrimination.⁶⁴ At the same time, conditions after disasters are less secure and lead to an elevated risk of persons with albinism being attacked. A submission received by the Expert, from Malawi, contained reports that persons with albinism who had been housed in temporary displacement camps in the aftermath of Cyclone Freddy, in March 2023, reported an increased sense of vulnerability to attack and threat to their security.

52. Extreme weather events magnify pre-existing inequalities and have been linked to increased rates of violence against women.⁶⁵ Women and girls with albinism experience high rates of violence and abuse, meaning that their vulnerability to violence is elevated further still in disaster situations.⁶⁶ According to a submission received by the Expert, other changes brought on by climate change, such as less secure working practices (e.g. longer distances to travel to collect clean water), may also exacerbate existing risks of violence and abuse for women and girls with albinism. Additional intersecting identities, such as race, colour, gender identity, socioeconomic status and sexual orientation, further increase the vulnerability that individual women and girls with albinism have to violence in disaster situations and in response to climate impacts, more generally.

53. The Expert has previously highlighted, in conjunction with the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on extrajudicial, summary or arbitrary executions, the fact that cyclones and drought in Madagascar are fuelling attacks on persons with albinism owing to dangerous mythical beliefs that rituals involving their body parts will bring good fortune.⁶⁷ Attacks on persons with albinism, who are blamed for famine and drought, have also been identified in the United Republic of Tanzania.⁶⁸ In addition, according to information received by the Expert, persons with albinism are not allowed in some communities, in Ghana, because their presence is thought to stop the rain from falling. Thus, if a child with albinism is born in such a community, he or she may be killed to ensure that the rainfall is not impeded. The communities also believe that the ritual sacrifice of body parts of persons with albinism will lead to better harvests. Globally, further research and data is needed to understand the extent to which persons with albinism experience stigma, discrimination and violence owing to climate change.

VII. Inclusion in climate action

54. States must engage in climate action to ensure a comprehensive global response to climate change, including action focused on climate change adaptation. Climate change adaptation refers to strategies and measures taken to minimize the negative impacts of climate change and is key to ensuring that societies are climate-resilient. In the context

⁶⁴ Mark Priestley and Laura Hemingway, “Disability and disaster recovery: a tale of two cities?”, *Journal of Social Work in Disability & Rehabilitation*, vol. 5, Nos. 3 and 4 (2007), pp. 23–42.

⁶⁵ Alyssa M. Thurston, Heidi Stöckl and Meghna Ranganathan, “Natural hazards, disasters and violence against women and girls: a global mixed-methods systematic review”, *BMJ Global Health*, vol. 6, No. 4 (April 2021).

⁶⁶ Ikponwosa Ero and others, *People with Albinism Worldwide*.

⁶⁷ OHCHR, “Madagascar: UN experts urge protection for people with albinism amid attacks”, press release, 28 February 2022. Available at www.ohchr.org/en/press-releases/2022/02/madagascar-un-experts-urge-protection-people-albinism-amid-attacks.

⁶⁸ Mohamed Daghar, “Buried alive: Tanzania’s albinos pay the price for superstition”, ENACT, 17 March 2022. Available at <https://enactafrica.org/enact-observer/buried-alive-tanzanias-albinos-pay-the-price-for-superstition>.

of extreme weather events, adaptation can help to reduce the severity of disasters by building more climate-resilient preparedness and response infrastructure, such as early warning systems. In terms of health, climate impacts not only lead to deteriorating access to and quality of health services but also increase the cost of providing health care, as the health of populations worsens year on year.⁶⁹ Adaptation is crucial to ensuring that the capacity of health systems to manage and protect the health of populations around the world is preserved. In the labour market, climate adaptation can prevent job losses and stimulate new employment opportunities. Education systems must also be adapted to climate-related impacts. Climate change education is critical to ensure that all persons are knowledgeable about current and future climate-related impacts and can take steps to ensure their safety and the safety of their families. Persons with albinism must be included in all climate change adaptation efforts.

55. Climate change mitigation and loss and damage are also important elements of climate action. Climate change mitigation is a concept related to adaptation that refers to the efforts made to reduce the amount of greenhouse gases that are released into the atmosphere in order to slow down the pace of climate change. While adaptation seeks to prepare for and cope with the changes that are already happening now or are expected to happen in the future, mitigation aims to prevent further harm to the planet. By 2030, the unavoidable economic losses owing to climate change are projected to reach at least \$290 billion,⁷⁰ and discussions concerning loss and damage have been held at the twenty-seventh session of the Conference of Parties to the United Nations Framework Convention on Climate Change (see document FCCC/PA/CMA/2022/10/Add.1, decision 2/CMA.4). It is crucial that all climate action, including that focused on climate change mitigation and loss and damage, is inclusive of persons with albinism and responsive to their needs.

56. Persons with albinism, like persons with disabilities more broadly, are frequently excluded from climate action taken at the local and national levels. The Expert received several reports from organizations of persons with albinism in which it was stated that persons with albinism are frequently not consulted in local and national climate action and decision-making by Governments. While many persons with albinism are aware of the changing environment around them in terms of their lived experience, knowledge about climate change more broadly is poor, including about how persons with albinism can support climate change adaptation and mitigation efforts.

57. The Expert did not receive any information confirming that specific groups of persons with albinism have participated in climate discussions at the international level, including at the Conference of the Parties to the United Nations Framework Convention on Climate Change. To date at Conferences of the Parties, the rights of persons with albinism have been included in discussions on the rights of persons with disabilities more broadly. However, the rights of persons with disabilities in the context of climate change have received minimal attention at those Conferences, where there is currently no formally recognized and specific constituency⁷¹ for persons with disabilities. Persons with albinism, like persons with disabilities more broadly, are also affected by several barriers that reduce their likelihood of being able to participate in Conferences of the Parties or other meetings held under the United Nations Framework Convention on Climate Change policy cycle. These barriers

⁶⁹ WHO, *Operational Framework for Building Climate Resilient Health Systems* (Geneva, 2015).

⁷⁰ Tracy Carty and Lyndsay Walsh, *Footing the bill: fair finance for loss and damage in an era of escalating climate impacts*, Oxfam Briefing Paper (Oxford, Oxfam International, June 2022).

⁷¹ In the context of the Conference of the Parties, a constituency is a group of organizations that share similar interests and concerns regarding the impacts of climate change and are working together to address the issue. There are currently nine constituencies, including groups representing Indigenous Peoples, young people, women and environmental organizations.

include issues of accessibility, including with regard to venues hotels and transport networks in the cities where such meetings are held. Other issues, such as lack of funding for grass-roots organizations in the global South, lack of formal official papers for groups displaced by climate change and problems with regard to securing visas, all contribute to lower participation by those individuals most affected by climate change, including persons with albinism. The Special Rapporteur on the promotion and protection of human rights in the context of climate change has drawn attention to a “participation disconnect”, meaning that those who are most affected and suffering the greatest losses are the least able to participate in current decision-making within the Conference of the Parties to the United Nations Framework Convention on Climate Change (see A/77/226). Persons with albinism are among those most affected by this participation disconnect.

58. To ensure that persons with albinism are adequately represented in climate action across different forums, it is essential to include them in climate dialogue beyond that focused on disability. The voices of persons with albinism should be integrated into dialogue and initiatives taken by other groups, such as those within existing United Nations Framework Convention on Climate Change constituencies, including those representing Indigenous Peoples’ organizations, women and gender issues, and young people. Like other social groups, persons with albinism possess heterogeneous backgrounds across multiple intersectional characteristics. When persons with albinism are able to share their perspective alongside members of other social groups (e.g. women and young people), climate dialogue will be enriched.

59. According to a recent systematic analysis, only 45 State parties to the Paris Agreement currently refer to persons with disabilities, persons with health conditions or those with chronic illnesses in their climate adaptation policies. Moreover, where such references are made, they are cursory in nature. It was also reported that no State parties to the Paris Agreement currently refer to persons with disabilities in their climate mitigation policies.⁷² Persons with albinism, like persons with disabilities more broadly, are disproportionately affected by climate change and must be adequately considered in national climate policies.

60. Data is needed to facilitate the effective inclusion of persons with albinism in climate action. At the current time, data on the impact of climate change on persons with disabilities, in general, is deficient.⁷³ Current methods of measuring disability in censuses and national surveys do not include specific reference to persons with albinism.⁷⁴ States should consider the use of additional questions to gather data on the situation of persons with albinism, including with respect to climate change. For example, in its 2019 census, the Government of Kenya asked an additional question about albinism after the standard disability module.⁷⁵

⁷² McGill Centre for Human Rights and Legal Pluralism and the International Disability Alliance, “Status report on disability inclusion in national climate commitments and policies” (June 2022). Available at https://www.internationaldisabilityalliance.org/sites/default/files/drcc_status_report_english_0.pdf.

⁷³ Aleksandra Kosanic and others, “An inclusive future: disabled populations in the context of climate and environmental change”, *Current Opinion in Environmental Sustainability*, vol. 55 (April 2022).

⁷⁴ The Washington Group short set of questions on functioning are a set of survey questions designed to estimate the number of individuals with disabilities in a population. The questions are grouped into six domains: seeing, hearing, mobility, cognition, self-care and communication. Each domain has a set of questions about the individual’s ability to perform specific activities related to that domain.

⁷⁵ OHCHR, “Counting groups left behind: a stellar step for inclusion in Kenya”, 27 November 2019. Available at www.ohchr.org/en/stories/2019/11/counting-groups-left-behind-stellar-step-inclusion-kenya.

VIII. Good practices

61. Most initiatives that help to mitigate the impacts of climate change or concern climate action and that are applicable to persons with albinism also target persons with disabilities more broadly. The United Nations Framework Convention on Climate Change has adopted a four-year action plan under the Glasgow work programme on Action for Climate Empowerment, which includes the inclusive participation of persons with disabilities, as well as other groups such as women, children and Indigenous Peoples (see document [FCCC/CP/2022/10/Add.2](#)). Some States offer disability-related social protection schemes, which can help to alleviate poverty and indirectly aid the purchase of sun protection products. Some States also have specific policies or laws that serve to give priority to persons with disabilities in disaster management and response. Persons with albinism also benefit from initiatives designed to educate the general population about climate change and support protective action, provided that such initiatives are made accessible to them. The Skin Cancer Foundation maintains a list of recommended products for ensuring reliable ultraviolet radiation protection, including sunscreen, clothing, and window and outdoor shade products, although it is mainly focused on the United States of America.⁷⁶ The Global Albinism Alliance referred to the SunSmart smartphone application, launched by the World Health Organization, the World Meteorological Organization, the United Nations Environment Programme and the International Labour Organization. The application integrates country-level data sources on weather and ultraviolet radiation levels to provide users with five-day forecasts.⁷⁷ It highlights when sun protection is required and summarizes health advice in an easy-to-understand format. The Expert was also able to identify some promising practices by States and civil society actors that are specifically for persons with albinism.

A. Availability of low-cost and effective sun protection products and access to health care

62. States must ensure that persons with albinism can gain access to health services that can diagnose, monitor and treat health complications that arise from extreme sun exposure, such as skin cancer. States must also ensure that persons with albinism can easily gain access to free or low-cost, effective sun protection products at all times. These products include high sun protection factor sunscreen of 50 and above and clothing such as long-sleeved tops and wide-brim hats.

63. Some Governments are providing free sun protection products and health screening to persons with albinism, and the Expert received submissions to this effect from the African region.⁷⁸ In Kenya, the National Council for Persons with Disabilities has been providing free sunscreen to persons with albinism through public hospitals, as well as long-sleeved T-shirts and wide-brim hats. The programme is decentralized to hospitals at county level in order to provide better access to persons with albinism living in different regions of Kenya. According to a submission received by the Expert, the Governments of Malawi and the United Republic of Tanzania have partnered with the organization Standing Voice on a skin cancer

⁷⁶ See www.skincancer.org/recommended-products/.

⁷⁷ WHO, “SunSmart Global UV App helps protect you from the dangers of the sun and promotes public health”, press release, 21 June 2022. Available at www.who.int/news/item/21-06-2022-sunsmart-global-uv-app-helps-protect-you-from-the-dangers-of-the-sun-and-promotes-public-health.

⁷⁸ In some States, free sunscreen may be provided to persons with albinism by regional or local governments. In previous research carried out by the Expert, it was found that the Brazilian municipality of Salvador has been distributing free sunscreen since 2006.

prevention programme that has reached a collective total of over 8,500 persons with albinism across both countries. The programme ensures that persons with albinism receive a free six-month supply of sunscreen and other protective wear, as well as skin screening and treatment for precancerous lesions. In addition, financial investment is made to support locally based producers of sun protection products. In the United Republic of Tanzania, Standing Voice is also supporting the local production of sun protection products, as well as livelihoods, through a community centre that supports persons with albinism and their families to make wide-brim hats, with over 9,500 of them being produced and distributed annually. In South Africa, the National Departments of Health and Social Development have a budget designated for persons with albinism that can cover essential health services. However, there is a need to strengthen implementation of those services, in particular at the provincial level. Outside of the Africa region, in countries such as Türkiye, some State support has been provided for sunscreen provision, and some government agencies provide, albeit modest, payments for basic visual aids.

64. Wider civil society is also active in ensuring that persons with albinism are protected. The organization Beyond Suncare produces sunscreen that is tailor-made for persons with albinism.⁷⁹ Similar activities are carried out by the Fondation Pierre Fabre.⁸⁰ According to a submission received by the Expert, the NGO Valeur Albinos provides sunscreen and other protective products to adults and children in remote areas of Benin and raises awareness of their correct usage. It also pays for persons with albinism to gain access to skin screenings, eye tests and other prescribed tests and medication.

65. The Global Albinism Alliance, in conjunction with the Expert, recently called for broad spectrum sunscreen to be added to the World Health Organization Model List of Essential Medicines.⁸¹ In addition, the Global Albinism Alliance is actively engaging with the World Health Organization, as well as with international multi-stakeholder health forums, to raise awareness of the global issue of skin cancer risk for persons with albinism.

B. Capacity-building and funding

66. Persons with albinism must be involved in all aspects of climate action. The organization Africa Albinism Network builds the capacity of civil society organizations working on albinism in the region to engage with policymakers nationally and participate in high-level international human rights meetings, such as the Conference of State Parties to the Convention on the Rights of Persons with Disabilities. This widens the opportunities for persons with albinism to raise issues related to climate change and thus participate in climate change action. They also support stakeholders to implement the African Union Plan of Action on Ending Attacks and Discrimination against People with Albinism,⁸² which is aimed at countering increases in violence and discrimination that may arise owing to climate change impacts.⁸³

⁷⁹ Yolanda Gilaberte and others, “Evaluation of the acceptance and efficacy of a bespoke sun protection package for persons with oculocutaneous albinism living in Malawi”, *International Journal of Dermatology*, vol. 61, No. 3 (7 September 2021), pp. 352–360.

⁸⁰ See www.fondationpierrefabre.org/en/our-programmes/tropical-dermatology/prevention-and-treatment-for-people-with-albinism/.

⁸¹ See https://cdn.who.int/media/docs/default-source/essential-medicines/2023-eml-expert-committee/applications-for-addition-of-new-medicines/a43_sunscreen.pdf?sfvrsn=3533e0d4_2.

⁸² Available at www.ohchr.org/en/documents/tools-and-resources/au-plan-action-ending-attacks-and-discrimination-against-persons.

⁸³ See <https://africaalbinismnetwork.org/wp-content/uploads/2023/04/English-AAN-Pilot-Report-2021-2023.pdf>.

67. Persons who interact with persons with albinism, such as health-care professionals, employers and teachers, frequently do not understand the specific risks that a changing climate poses to persons with albinism. States can support persons with albinism to ensure that they have access to climate change education programmes and that climate change education programmes for the general population cover issues that affect persons with albinism specifically. Information received from Burkina Faso and Japan indicates that the issue of climate change is addressed in the national school curriculum.

68. In Kenya, the civil society organization Black Albinism is raising awareness, in Kajiado, Kitui and Machakos counties, of climate change and its effects. As part of those efforts, it conducts research and runs education and advocacy workshops for persons with albinism and their communities, including parents and community health workers. The programme also trains “climate change champions” – many of whom are persons with albinism themselves – to further spread awareness of climate action in communities. The programme is a good example of how persons with albinism need to be involved not only as recipients but also as providers of climate change education.

69. States must also ensure that climate funding mechanisms are accessible to persons with albinism and can support climate adaptation and mitigation initiatives led by persons with albinism. The Global Greengrants Fund, through its Disability Rights and Climate Justice Advisory Board, awards small grants to organizations to promote the inclusion of climate change in their disability rights agendas. To date, the fund has supported over 250 organizations of persons with disabilities and environmental justice NGOs. This includes projects and organizations that specifically focus on promoting the inclusion of persons with albinism in climate discourse and funding that supports persons with albinism to engage directly in climate action. For example, the Fund has provided funding for the Albinism and Disability Advocacy Centre, in Nigeria, to organize technical training on the impacts of climate change on persons with albinism in Edo state and advocate their special consideration in climate discourse. The Fund has also provided funding to the organization Voice of Disabled Women in Tanzania to provide accessible training and materials to young persons with disabilities (including those with albinism) to plant tree nurseries. The aim is to combat deforestation, which itself disproportionately affects persons with albinism as it removes the shade needed to protect their skin from sun exposure.

IX. Conclusion and recommendations

70. The present report provides a preliminary overview of the impact of climate change on persons with albinism. Foremost among this is the impact on their enjoyment to the right to the highest attainable standard of health, owing to the increased vulnerability to skin cancer. However, the impact of climate change goes far beyond this for persons with albinism and affects the extent to which they are able to participate in all aspects of society. While little research has been done specifically on climate change and albinism, the information available indicates that climate change, in conjunction with exclusion from climate action, is causing persons with albinism to experience violations of a broad spectrum of their human rights, including the right to an adequate standard of living, protection and safety in situations of risk, inclusive education, decent and safe working conditions, freedom from violence and freedom from discrimination. States must act urgently to protect persons with albinism from these negative impacts of climate change.

71. With regard to health, States should:

(a) Add sunscreen to the list of essential drugs and ensure that quality sunscreen and other sun protection products are made available and are physically and financially accessible to persons with albinism and that such products are of an acceptable quality;

(b) Ensure that persons with albinism can gain access to regular screenings and treatment for skin and eye health conditions close to their communities and that they are offered free of charge or at low cost;

(c) Conduct needs assessments with persons with albinism in order to understand when and where they are at risk of skin damage from ultraviolet radiation or heat in indoor or enclosed spaces and implement remedial protection measures;

(d) Incorporate content that highlights the specific risks that climate change poses to persons with albinism into health-care worker training, teacher training curricula, climate education in schools and disability training for employers;

(e) Develop climate change education programmes for persons with albinism and their families to increase knowledge of self-protection practices and build their capacity to participate in climate action;

(f) Ensure that all disaster preparedness, management and response strategies take into account the specific needs of persons with albinism, including protection from violence and discrimination in the aftermath of disaster situations;

(g) Recognize and take steps to protect the health of particularly vulnerable groups of persons with albinism, including women, children, displaced persons and Indigenous populations, from climate-related impacts;

(h) Conduct research on the country-specific impacts of climate change on persons with albinism, including to better understand how the mental health of persons with albinism is being affected by climate change.

72. With regard to other areas of life, States should:

(a) Review existing anti-discrimination laws and legal provisions on occupational health and safety and, where necessary, enact measures to ensure that employers comply with them;

(b) Ensure that social protection is provided or accessible to persons with albinism to mitigate the disproportionate burden of the impacts of climate change on them and their families;

(c) Review and clarify the referral pathways for teachers and school leaders to use to support children with albinism who have experienced or are at risk of the impacts of climate change;

(d) Conduct awareness-raising to inform the public of the causes of climate change in order to combat beliefs that extreme weather events are related to persons with albinism.

73. With regard to climate action, States should:

(a) Support persons with albinism and their representative organizations to participate in climate dialogue and policymaking;

- (b) Involve persons with albinism in the design and delivery of climate action initiatives, including climate education programmes and disaster preparedness, management and response strategies;**
 - (c) Consider the needs of persons with albinism in national climate policies;**
 - (d) Strengthen the collection and use of disaggregated data in relation to persons with albinism and climate change by:**
 - (i) Engaging diverse stakeholders, including persons with albinism, in the development of national indicators and the tracking of national data on climate impacts in relation to persons with albinism, in the framework of the Sustainable Development Goals, in particular Goal 16;**
 - (ii) Ensuring the systematic collection of disaggregated data on persons with albinism, including regarding violence and discrimination against persons with albinism in the context of climate change.**
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