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Social development

Social development challenges faced by persons with albinism

Report of the Secretary-General

Summary

Pursuant to General Assembly resolution [74/123](#), the present report contains an analysis of the main social development challenges faced by persons with albinism. It takes into consideration the specific challenges faced by women and children and focuses primarily on barriers in access to health, education, employment and participation in political, social, civic and cultural life. It pays specific attention to the impact of the coronavirus disease (COVID-19) crisis on persons with albinism and provides a framework based on human rights to ensure that persons with albinism are not left behind in the COVID-19 response and recovery. The report also includes updated information on existing policy responses at the international, regional and national levels. Recommendations are made on key actions needed to ensure that COVID-19 response and recovery measures are inclusive of persons with albinism and guarantee their human rights, social inclusion and well-being.



I. Introduction

1. In its resolution [74/123](#), the General Assembly expressed concern that persons with albinism were disproportionately affected by poverty, owing to the discrimination and marginalization that they face, and recognized the need for resources to develop and implement programmes to prevent and combat prejudice and create an environment conducive to respecting their rights and dignity. In the resolution, the Assembly requested the Secretary-General to present to it a report on the various social development challenges faced by persons with albinism, taking into consideration the specific needs of women and children, including those related to social inclusion, health, education and employment, and measures taken, with recommendations for further action to be taken by Member States and other relevant stakeholders to address identified challenges.

2. At the seventy-second session, the Secretary-General presented to the General Assembly a comprehensive report on the social development challenges faced by persons with albinism ([A/72/169](#)), which provided a framework for conceptualizing and removing barriers to social inclusion. At the seventy-fourth session, the Secretary-General presented to the Assembly a second report on the same issue ([A/74/184](#)), focusing on the environmental and attitudinal barriers faced by persons with albinism worldwide. The issues raised and the information contained in those reports are still highly relevant.

3. Drawing on the above-mentioned reports, the present report is focused on the impact of the coronavirus disease (COVID-19) crisis on the social development and human rights situation of persons with albinism. Building on the human rights-based approach to development, it identifies key principles and actions necessary for ensuring that COVID-19 response and recovery measures are inclusive of persons with albinism and adequately address the specific challenges faced.

4. In November 2021, a questionnaire was sent to Member States, non-governmental organizations (NGOs) and United Nations entities. Responses were received from three Member States (Brunei Darussalam, Jordan and Mexico) and 21 NGOs, civil society representatives and research institutes.¹ In addition to the information received, the present report includes information presented by the Independent Expert on the enjoyment of human rights by persons with albinism in her reports to the General Assembly and the Human Rights Council, as well as a review of recent literature relevant to the topic.

5. Social development is concerned with processes of change that lead to improvements in human well-being, social relations and social institutions, notably by enabling all people to reach their full potential ([A/72/169](#), paras. 6–9). It is closely related to social inclusion, which is the ability of all individuals to participate fully in economic, social, political and cultural life. Discrimination, stigma and lack of access to services and material resources are major drivers of social exclusion that continue to underpin group-based socioeconomic differences worldwide. The global COVID-19 crisis has exposed and deepened pre-existing inequalities, exclusion and

¹ Africa Albinism Network, Albinism Advocacy for Access South Africa, Albinism Association of Turkey, Albinism Foundation of Zambia, Alive Albinism Initiative, Asociación de Albinos de la República Dominicana, Associação das Pessoas com Albinismo na Bahia, Associação Ze Manuel Pinto, Association pour la promotion des albinos au Cameroun, Corporación Albinos Chile, Divine Connexion Worldwide, Engage Now Africa, Facts and Norms Institute, Fundación Nacional de Albinismo Simplemente Amigos de Argentina, Global Albinism Alliance, Organization for the Integration and Promotion of People with Albinism, Source of the Nile Union of Persons with Albinism, Standing Voice, The Albino Foundation, as well as civil society representatives from Honduras and Venezuela (Bolivarian Republic of).

discrimination. More than two years after the outbreak of the pandemic, evidence indicates that its health, economic and social impacts are being borne disproportionately by social groups in the most vulnerable situations.² The present report discusses the impact of the pandemic on the ability of persons with albinism, who are among the most marginalized groups, to participate fully in economic, social, political and cultural life. It identifies key principles and actions to ensure that they are not left behind in response and recovery efforts.

II. A human rights-based approach to address the social development challenges faced by persons with albinism, including in the context of the COVID-19 crisis

A. Persons with albinism

6. Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people worldwide, regardless of ethnicity or gender. It is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment ([A/HRC/24/57](#), paras. 10–11). Albinism often results in two congenital and permanent health conditions: visual impairment to varying degrees and high vulnerability to skin damage from ultraviolet rays, which can lead to skin cancer.

7. Persons with albinism are found across the globe, with a higher prevalence reported in certain geographically isolated communities. In sub-Saharan Africa, although precise figures are lacking, the average prevalence of persons with albinism has been estimated at between 1 in 5,000 and 1 in 15,000, with a higher prevalence of 1 in 1,000 in some populations in Southern Africa.³ In North America and Europe, the prevalence has been estimated at between 1 in 17,000 and 1 in 20,000.⁴ However, recent studies indicate higher prevalence rates in some areas, such as the Netherlands⁵ (1 in 12,000) and Northern Ireland⁶ (1 in 4,500), suggesting that reported prevalence rates in the region may be underestimated owing to a lack of awareness and diagnosis of the condition. In Latin America and the Caribbean, data are lacking for the total population, but several studies show a moderate to relatively high prevalence within indigenous communities in southern Brazil, southern Mexico and eastern Panama (between 1 in 28 and 1 in 6,500).⁷ In Asia and the Pacific, available information indicates significant variations between countries, with reported occurrences of 1 in

² United Nations, “COVID-19 and human rights: we’re all in this together”, April 2020.

³ Jennifer Kromberg and Prashiela Manga, eds., *Albinism in Africa: Historical, Geographic, Medical, Genetic and Psychosocial Aspects* (San Diego, California, Elsevier, 2018).

⁴ The National Institutes of Health of the United States of America estimates the frequency of oculocutaneous albinism worldwide to be 1 in 20,000 (see <https://medlineplus.gov/genetics/condition/oculocutaneous-albinism>). The National Organization for Albinism and Hypopigmentation, a national group serving persons with albinism in the United States, reports the frequency of albinism to be between 1 in 18,000 and 1 in 20,000 in the United States (see www.albinism.org/information-bulletin-what-is-albinism).

⁵ Charlotte C. Kruijt and others, “The phenotypic spectrum of albinism”, *Ophthalmology*, vol. 125, No. 12 (December 2018).

⁶ Natasha Healey and others, “Are worldwide albinism prevalence figures an accurate reflection? An incidental finding from a Northern Ireland study”, *British Journal of Ophthalmology*, vol. 98, No. 7 (July 2014).

⁷ Charles M. Woolf, “Albinism (OCA2) in Amerindians”, *Yearbook of Physical Anthropology*, vol. 128, No. S41 (2005); and Irèn Kossintseva and Jan Dutz, “The moon children of Kuna Yala: albinism in San Blas islands of Panama – review, directions in research and aid”, *Journal of the American Academy of Dermatology*, vol. 64, No. 2, Supplement 1 (February 2011).

47,000 in Japan,⁸ 1 in 18,000 in China,⁹ 1 in 16,000 in New Zealand¹⁰ and 1 in 700 in Tuvalu¹¹ and Fiji.¹²

8. Most people with albinism are persons with disabilities as a result of the interaction between their condition, mainly visual impairment and lack of pigmentation, and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. As stressed by the Independent Expert, attitudinal barriers have a tremendous effect not only on the inclusion and participation of persons with albinism, but also on their ability to exercise their rights on an equal basis with others (A/76/166, para. 2). Such barriers usually emanate from a general lack of knowledge and understanding of the condition and accompanying misinformation, myths and beliefs. They often result in stigmatization and discrimination.

9. Persons with albinism face discrimination on the basis of disability, including the denial of reasonable accommodation. They also face racial discrimination, stigmatization and bullying because of their appearance, notably their skin colour. These grounds intersect in a manner that mutually reinforces and aggravates discrimination. Persons with albinism may also experience further multiple and intersecting forms of discrimination because of gender, sex, age and other status.

10. Discrimination is a major driver of social exclusion that underpins socioeconomic differences worldwide. It prevents persons with albinism from fully participating in society and enjoying their human rights on an equal basis with others. Persons with albinism are less likely to have access to high-quality health, education and employment and to participate in the community (see A/72/169 and A/74/184). They are also disproportionately affected by poverty, notably in developing countries and the least developed countries. Persons with albinism face similar barriers and issues in all regions of the world. However, the degree to which they occur and the impact on individuals' lives vary from country to country, depending on the general level of socioeconomic development, the availability of resources, social norms, their hypervisibility and climatic conditions, among other things.

B. Impacts of the COVID-19 pandemic

11. The rapid spread of COVID-19 infections amounting to a global pandemic¹³ has plunged the world into a global public health emergency crisis, with far-reaching economic, social and political consequences. Many States, some with the support of the international community, have deployed large-scale public health emergency responses to reduce infection and prevent deaths. Many States have adopted extraordinary measures to slow virus transmissions through physical distancing, quarantine, isolation, lockdowns, curfews, school closures, travel restrictions and limits on gatherings.

⁸ Jennifer Kromberg, "Epidemiology of albinism", in *Albinism in Africa: Historical, Geographic, Medical, Genetic, and Psychosocial Aspects*, Jennifer Kromberg and Prashiela Manga, eds. (San Diego, California, Elsevier, 2018).

⁹ Ibid.

¹⁰ A/74/190 and A/74/190/Corr.1, para. 39.

¹¹ Helene C. Johanson and others, "Inheritance of a novel mutated allele of the OCA2 gene associated with high incidence of oculocutaneous albinism in a Polynesian community", *Journal of Human Genetics*, vol. 55, No. 2 (February 2010).

¹² A/HRC/40/62/Add.1, para. 14.

¹³ The World Health Organization (WHO) declared COVID-19 a global pandemic on 11 March 2020, see Tedros Adhanom Ghebreyesus, Director General of WHO, opening remarks at the media briefing on COVID-19, 11 March 2020.

12. The pandemic and the measures taken in response to it have triggered an economic and social crisis with an important impact on individuals, families and communities.¹⁴ It has plunged the world economy into a recession that threatens sustainable development and risks reversing progress made in the fight against poverty and inequalities.¹⁵ The crisis is directly affecting people's livelihoods and human rights.¹⁶ For instance, congestion in hospitals and health institutions has reduced access to non-COVID-related health care and treatment. Lockdowns have limited access to work, education and basic services. Unemployment and food insecurity have risen to unprecedented levels in many countries. The widespread closure of schools interrupted the education of more than 1 billion children in 2020.¹⁷

13. Although the crisis affects all members of society, evidence shows that its social, economic and human rights consequences are disproportionately borne by the most marginalized populations.¹⁸ Concerns have been raised about its impact on persons with disabilities, of which persons with albinism are a constituency, in particular regarding barriers in access to health care, education and information and the heightened risk of violence, isolation and poverty.¹⁹ Although the situation of persons with albinism during the pandemic has largely been underreported worldwide, information received for the present report indicates that, as with other marginalized groups, persons with albinism have, owing to the pandemic, been at risk of facing even greater barriers, inequalities, discrimination and exclusion in access to basic services and the enjoyment of their human rights.

14. The crisis has also been marked by an increase in verbal abuse, harassment and violence against historically stigmatized groups. Persons with albinism have not been spared, and there has been an alarming rise in harmful practices against them and scapegoating reported in some countries.²⁰

C. A human rights-based approach to address the impacts of the COVID-19 pandemic on persons with albinism

15. The human rights-based approach to development provides an effective framework for achieving the full participation of persons with albinism in society on an equal basis with others. In 2020, the Secretary-General, in his call to action for human rights, affirmed that human rights were at the core of development and underpinned the 2030 Agenda for Sustainable Development, putting non-discrimination, participation and inclusion at its centre.²¹ The international human rights framework provides States with a legally binding structure for achieving

¹⁴ United Nations, "Shared responsibility, global solidarity: responding to the socio-economic impacts of COVID-19", March 2020.

¹⁵ *Financing for Sustainable Development Report 2021* (United Nations publications, 2021).

¹⁶ United Nations, "COVID-19 and human rights".

¹⁷ United Nations Educational, Scientific and Cultural Organization (UNESCO), "Global monitoring of school closures", COVID-19 Impact on Education database. Available at <https://en.unesco.org/covid19/educationresponse#schoolclosures>; and United Nations, "Shared responsibility, global solidarity".

¹⁸ United Nations, "COVID-19 and human rights"; and *Financing for Sustainable Development Report 2021*.

¹⁹ Office of the United Nations High Commissioner for Human Rights (OHCHR), "Statement on COVID-19 and the human rights of persons with disabilities", 9 June 2020; and OHCHR, "COVID-19 and the rights of persons with disabilities: guidance", 29 April 2020.

²⁰ OHCHR, "Witchcraft killings of people with albinism rose during pandemic – UN expert", 29 July 2021; Amnesty International, "Afrique austral: le COVID-19 met les personnes albinos particulièrement en danger", 12 June 2020; and Julian Kossoff, "People with albinism are being blamed for the spread of the coronavirus in Africa because of their 'whiteness'", 13 June 2020.

²¹ United Nations, António Guterres, "The highest aspiration: a call to action for human rights".

the Sustainable Development Goals and their related targets. It underpins the pledge in the 2030 Agenda to leave no one behind and reach the furthest behind first, which is especially relevant to persons with albinism.

16. In the context of the pandemic, the Secretary-General further reaffirmed the importance of human rights for a sustainable recovery.²² He underlined the importance of addressing structural inequalities through a holistic and inclusive approach anchored in human rights. Under international law, States have the obligation to ensure that all COVID-19-related actions are free from discrimination and take into consideration the intersections of disability, colour, gender and age, among other factors. By implementing their obligations under international human rights law and fulfilling the commitments of the 2030 Agenda, States will also be able to safeguard the rights and well-being of persons with albinism.

17. Under international human rights law, persons with albinism have the same fundamental rights as any other individual or group. In the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, it is recognized that human rights are applicable to all people. The general principles of equality and non-discrimination enshrined in these instruments guarantee the full enjoyment of human rights by persons with albinism on an equal basis with others, support their full and effective participation in society and provide for the protection of a range of rights that are instrumental for achieving their social development, including the rights to the highest attainable standard of mental and physical health, education, work and adequate housing.

18. The rights of persons with albinism are also guaranteed and protected under other international human rights conventions. The Committee on the Rights of Persons with Disabilities indicated that persons with albinism are covered within the definition of persons with disabilities and their rights are guaranteed and protected under the Convention on the Rights of Persons with Disabilities ([CRPD/C/18/D/22/2014](#), paras. 8.1–8.7). The Convention includes measures aimed at ensuring that the lives and rights of persons with disabilities are appropriately protected in the face of the COVID-19 pandemic.²³ The Committee on the Elimination of Racial Discrimination recognized that discrimination based on the pale skin colour associated with albinism amounts to racial discrimination on the basis of colour ([CERD/C/ZAF/CO/4-8](#), paras. 20–21). Moreover, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child contain international human rights standards relevant for women and girls with albinism, as well as mothers of children with albinism and children with albinism.

19. A human rights-based approach to COVID-19 is essential for ensuring that persons with albinism are not left behind in response and recovery measures. Such an approach must take into account the specific ways in which the COVID-19 crisis has affected persons with albinism and ensure that the social development and human rights challenges faced are addressed adequately in both the immediate response to the pandemic and the longer-term recovery phase. Key principles and actions for the design and implementation of COVID-19 policy responses that are

²² United Nations, “COVID-19 and human rights”.

²³ In article 11 of the Convention on the Rights of Persons with Disabilities it is established that States parties should take all possible measures to ensure the protection and safety of persons with disabilities in the national response to situations of risk and humanitarian emergencies. This comprises measures in all areas of life of persons with disabilities, including the protection of their access to the highest attainable standard of health without discrimination, general well-being and prevention of infectious diseases, and measures to ensure protection against negative attitudes, isolation and stigmatization that may arise in the midst of the crisis.

non-discriminatory and inclusive of persons with albinism are set out in section IV below.

III. Impacts of the COVID-19 crisis on persons with albinism

A. Discrimination, stigma and social exclusion

20. The pandemic has exacerbated the stigma of persons with albinism in societies in which myths, wrong beliefs, misinformation and misconceptions already surround this medical condition. According to information received, persons with albinism have been associated with the disease in several countries. Because of the colour of their skin, they have been seen as carriers of a white person's disease.²⁴ In Rwanda, there have been reports of rumours spreading that persons with albinism were more vulnerable to contracting the virus or that they would more easily succumb to it owing to their supposedly weaker immune system.²⁵ In Zimbabwe, persons with albinism reportedly feared the development of additional myths, such as that sleeping with a person with albinism could cure the disease or that their body parts could be used in vaccines.²⁶

21. During the pandemic, killings of and attacks on people with albinism have increased. Some people plunged into poverty as a result of the crisis have turned to witchcraft in the hope that using the body parts of persons with albinism would bring them good luck and wealth.²⁷

22. This association of persons with albinism with COVID-19 has further fuelled pre-existing discrimination and exclusion from the community and affected persons with albinism psychologically.²⁸ They have felt at greater risk of verbal abuse and attacks, leading them to adopt additional cautious and vigilant behaviours, thus hindering even more their ability to participate in various aspects of political, social and cultural life.

B. Health

23. The pandemic has put pressure on health systems, often resulting in the disruption of some essential health services. Lockdowns, restrictions on movement and disruptions of supply chains have also made access to health care and treatment more difficult in many countries. The pressure has been more acute in countries with already underresourced health systems.

24. These disruptions and perturbations disproportionately affect those who require continuous medical care, such as persons with albinism. In several countries, persons with albinism in need of urgent dermatological services could not access them because medical facilities prioritized COVID-19 patients.²⁹ NGOs that provide health

²⁴ OHCHR, "The COVID-19 pandemic and harmful practices impacting persons with albinism: accusations of witchcraft and ritual attacks ('HPAWR')", July 2020.

²⁵ Submission by Organization for the Integration and Promotion of People with Albinism.

²⁶ Submission by Alive Albinism Initiative.

²⁷ Submission by Albinism Foundation of Zambia; and UN News, "Witchcraft killings of people with albinism have risen during the COVID-19 pandemic, says UN expert", 29 July 2021.

²⁸ Amnesty International, "Coronavirus – Southern Africa: persons with albinism especially vulnerable in the face of COVID-19", 13 June 2020; and Channel Africa, "African Union of persons with albinism discuss COVID-19 impact", podcast, 20 September 2021. Available at <https://omny.fm/shows/albinism-report/african-union-of-persons-with-albinism-discuss-cov>.

²⁹ Submissions by Albinism Advocacy for Access South Africa, Alive Albinism Initiative, Engage Now Africa, Standing Voice, Source of the Nile Union of Persons with Albinism and The Albino Foundation.

services to persons with albinism in remote areas, such as dermatological and ophthalmological mobile clinics and sunscreen distribution, had to interrupt their services.³⁰ Disruptions in the supply of sunscreen lotions were also reported in Brazil, Malawi and Zambia.³¹ NGOs based in Australia, Canada, France and the United States of America reported that the pandemic had caused delays in the comprehensive diagnosis of albinism, which is essential to designing a personalized care pathway for each person with albinism.³² This has had a severe impact on the right to life and the right to the highest attainable standards of living of persons with albinism. Without access to dermatological screening and sunscreen lotions, there has been a marked deterioration of skin conditions among the albinism community, with a high number of cases of skin cancer reported in several countries.

25. In terms of access to prevention, containment and treatment of COVID-19, persons with albinism have the same rights as the rest of the population, but additional barriers have been reported in several countries in terms of the availability, accessibility and acceptability of these measures.³³ An important obstacle relates to access to information about the virus and treatment in formats accessible to persons with albinism. In some countries, persons with albinism have been reluctant to receive the vaccine owing to a lack of research and information about its effects on persons with albinism.³⁴ In countries where affordable health services and treatment are scarce, persons with albinism who live in poverty could not afford hospital fees for COVID-19 treatment.³⁵

C. Education

26. During the pandemic, most States temporarily closed education institutions.³⁶ They adopted remote learning practices as a way to mitigate the impact on students' learning processes using the Internet, television, radio and social media. The closure disrupted other dimensions of school life, such as access to school meals and opportunities to engage in play and sports with peers. These measures affected all students, but those in vulnerable situations, including persons with albinism, felt the consequences disproportionately because of the lack of equipment, accessible materials, Internet connection and support necessary for them to follow remote educational programmes.³⁷

27. Information received shows that remote learning practices exacerbated barriers to education for students with albinism in a number of ways. In many countries, students with albinism, as with other students from poor families and those living in remote areas, often did not have access to the technological devices required to follow online classes and/or experienced connectivity issues, making it impossible for them to attend remote learning programmes.³⁸ When students with albinism were able to connect, they faced additional barriers because of the lack or delay in the

³⁰ Submissions by Organization for the Integration and Promotion of People with Albinism, Source of the Nile Union of Persons with Albinism and Divine Connexion Worldwide.

³¹ Submissions by Albinism Foundation of Zambia, Standing Voice and Associação das Pessoas com Albinismo na Bahia.

³² Submission by Global Albinism Alliance.

³³ Submissions by Alive Albinism Initiative, Albinism Foundation of Zambia, Association pour la promotion des albinos au Cameroun and Source of the Nile Union of Persons with Albinism.

³⁴ Submission by Albinism Foundation of Zambia.

³⁵ Submission by Alive Albinism Initiative.

³⁶ UNESCO, "Global monitoring of school closures", COVID-19 Impact on Education database.

³⁷ United Nations, "Policy brief: the impact of COVID-19 on children", 15 April 2020.

³⁸ Submissions by Alive Albinism Initiative, Corporación Albinos Chile, Engage Now Africa and Fundación Nacional de Albinism Simplemente Amigos de Argentina.

implementation of accommodation needed for them to be able to study from home.³⁹ Owing to visual impairments, many of them were unable to read on screens and were not provided with assistive programmes. Alternative learning arrangements were not always available for students attending boarding schools. It was also reported that students with albinism experienced visual and musculoskeletal fatigue because of prolonged exposure to screens without accommodation.⁴⁰ These barriers resulted in a high level of school dropouts among students with albinism during school closures, making it even more difficult for them to catch up with other students when school resumed.⁴¹

28. The crisis also exacerbated barriers to attendance at school in some countries. For example, it was reported that in Rwanda physical distancing had created additional barriers for students with albinism to follow classes because they were not able to sit as close to the board as before or consult with their peers.⁴² In Zambia, some children with albinism were reported to have stopped going to school for fear of being attacked.⁴³

29. The disruption of education and training has made it even harder in some cases for young people, including students with albinism, to successfully transition from education and training to work.⁴⁴

D. Work, employment and livelihoods

30. The COVID-19 crisis has had a devastating impact on work, employment and livelihoods.⁴⁵ It has led to increased unemployment, underemployment, losses in labour and business income and an increase in informality and insecurity of work and income. This major labour shock has had a disproportionate impact on individuals in the informal economy, insecure forms of work and low-skilled jobs,⁴⁶ among which persons with albinism are overrepresented in many countries owing to the barriers and discrimination that they face (A/74/184, paras. 34–36 and 56–58). Such workers are often not eligible for social protection or unemployment assistance and are therefore at greater risk of falling into extreme poverty.⁴⁷

31. Information received indicates that a significant share of persons with albinism have experienced layoffs, income loss and unemployment during the pandemic in many countries.⁴⁸ The self-employed and those working in the private sector and informal economy have been most affected. As with other workers in precarious situations, many persons with albinism were excluded from benefit and compensation

³⁹ Submissions by Albinism Advocacy for Access South Africa, Albinism Association of Turkey, Fundación Nacional de Albinism Simplemente Amigos de Argentina, Corporación Albinos Chile, Divine Connexion Worldwide, Engage Now Africa, Global Albinism Alliance, Organization for the Integration and Promotion of People with Albinism, Source of the Nile Union of Persons with Albinism and The Albino Foundation.

⁴⁰ Submission by Corporación Albinos Chile and Global Albinism Alliance.

⁴¹ Submission by Organization for the Integration and Promotion of People with Albinism.

⁴² Ibid.

⁴³ Submission by Albinism Foundation of Zambia.

⁴⁴ International Labour Organization (ILO), “Global call to action: for a human-centred recovery from the COVID-19 crisis that is inclusive, sustainable and resilient”, 2021.

⁴⁵ Ibid.

⁴⁶ Ibid.

⁴⁷ ILO, “Social protection spotlight: Extending social protection to informal workers in the COVID-19 crisis – country responses and policy considerations”, 8 September 2020.

⁴⁸ Submissions by Fundación Nacional de Albinism Simplemente Amigos de Argentina, Albinism Foundation of Zambia, Source of the Nile of Persons with Albinism, Organization for Integration and Promotion of People with Albinism, Divine Connexion Worldwide, Standing Voice, Albinism Advocacy for Access South Africa and The Albino Foundation.

schemes in some countries. The exclusion of persons with albinism from food assistance programmes for persons with disabilities was also reported.⁴⁹

32. According to information received, the shift from office-based to remote home-based work was in some cases done without taking into account the specific needs of persons with albinism related to their condition. Workspace accommodations, such as large or double screens and other adaptive and assistive devices available in normal office workspaces, were not made available for working from home or were made available late.⁵⁰

33. The crisis also had a negative impact on the business opportunities of persons with albinism. For example, it was reported that in Ghana and Malawi persons with albinism who owned small businesses experienced reduced demand for goods and services owing to customers' fear of contracting the virus.⁵¹

E. Access to justice

34. The pandemic has placed a strain on the administration of justice. Closures and reduced capacity of courts have resulted in delays in legal processes and judicial proceedings in many countries. This has had a disproportionate impact on persons with albinism in countries where they are at heightened risk of attacks and gender-based violence, since victims face additional barriers in reporting attacks and seeking justice.⁵² For example, the organization Standing Voice reported that in Malawi delays in the administration of justice had had a negative impact on the processing of cases of attacks against persons with albinism because the quality of evidence had deteriorated over time.⁵³ Restrictions on movement and other preventive measures also made it more difficult for persons with albinism, and others, who were subject to attacks and gender-based violence to report such incidents to law enforcement officers.⁵⁴

F. Women and girls

35. The COVID-19 crisis has had differential impacts on women and men. Evidence shows that women may be at greater risk of contracting the virus owing to their role as caregivers and social and health workers.⁵⁵ Violence against women and girls has intensified across the world since the outbreak of the pandemic.⁵⁶ The need to prioritize COVID-19-related treatment may result in scaling down the provision of sexual and reproductive health services, thus making women more at risk of maternal mortality, unintended pregnancies and other adverse sexual and reproductive health outcomes.⁵⁷

⁴⁹ Submissions by Albinism Advocacy for Access South Africa.

⁵⁰ Submission by Global Albinism Alliance.

⁵¹ Submissions by Engage Now Africa and Standing Voice.

⁵² Submission by Standing Voice.

⁵³ Ibid.

⁵⁴ Submissions by Albinism Advocacy for Access South Africa and Standing Voice.

⁵⁵ OHCHR, "COVID-19 and women's human rights: guidance", 15 April 2020; and United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women), "Spotlight on gender, COVID-19 and the SDGs: will the pandemic derail hard-won progress on gender equality?", 2020.

⁵⁶ Ramya Emandi and others, *Measuring the Shadow Pandemic: Violence against Women during COVID-19* (UN-Women, 2021).

⁵⁷ United Nations, "Policy brief: a disability-inclusive response to COVID-19"; and International Planned Parenthood Federation, "COVID-19 pandemic cuts access to sexual and reproductive healthcare for women around the world", 9 April 2020.

36. Even in normal circumstances, women and girls with albinism, as well as mothers of children with albinism, are more likely than other women and girls to be targets of sexual and physical violence (see [A/HRC/43/42](#)). Research and information on the differential impact of the pandemic on them is lacking, but the information received suggests that they disproportionately face the challenges experienced by other women. For instance, in Malawi and South Africa, NGOs working on albinism have reported an increase in cases of gender-based violence against women with albinism.⁵⁸ Victims experienced increased difficulty in reporting such incidents to law enforcement officers during lockdowns, and protection services were disrupted owing to budget cuts. The pandemic has also made access to sexual and reproductive health services more challenging for women and girls with albinism.⁵⁹

37. Women and girls with albinism have been at greater risk of attacks during the COVID-19 crisis because of the gender dimension of some myths and misbeliefs, such as the belief that sexual intercourse with a woman with albinism can cure the disease or bring good luck ([CEDAW/C/TZA/CO/7-8](#), para. 18 (b)). Women with albinism and mothers of children with albinism who are already highly vulnerable to isolation and poverty are likely to face even greater difficulty in securing a livelihood for themselves and their children during the pandemic.

G. Children

38. The crisis has exacerbated some of the challenges and barriers faced by children with albinism. They are usually at higher risk of attacks for witchcraft and ritual practices because of the belief that the innocence of the victim increases the potency of the witchcraft. The Independent Expert has expressed concern at the alarming increase in attacks against and ritual killings of children with albinism in the context of the pandemic.⁶⁰ Information received indicates that some parents have taken children with albinism out of school because of the fear of attacks, thus further exacerbating barriers in access to education.⁶¹

39. Although research and information on the mental health impact of the pandemic on children with albinism is currently lacking, the information received suggests that lockdowns have had a contrasted impact on the mental health of children with albinism.⁶² As with other children, whereas some of them enjoyed spending more time with their parents, others reportedly experienced emotional and mental strain owing to the lack of in-person interaction with their peers and feelings of loneliness.⁶³

H. Political will and resource mobilization

40. The Independent Expert and several NGOs have expressed concern over the reduction of funding to support services for persons with albinism and the deprioritization of their issues from political agendas because of the COVID-19 crisis ([A/HRC/46/32](#), para. 72). For example, it was reported that in Argentina the discussion of the national albinism law by the Senate was interrupted owing to the

⁵⁸ Submissions by Albinism Advocacy for Access South Africa and Standing Voice.

⁵⁹ Submission by Standing Voice.

⁶⁰ OHCHR, "Witchcraft killings".

⁶¹ Submissions by Albinism Advocacy for Access South Africa, Albinism Foundation of Zambia and Source of the Nile Union of Persons with Albinism.

⁶² Submissions by Albinism Advocacy for Access South Africa and Albinism Foundation of Zambia.

⁶³ Ibid.

outbreak of the pandemic.⁶⁴ In Turkey, it was reported that the Rare Diseases Commission of the Grand National Assembly had postponed its consultation with organizations of persons with albinism after the outbreak.⁶⁵ In Malawi and Uganda, civil society organizations reported a decrease in donor funding to support programmes and workplans for persons with albinism in the region.⁶⁶

IV. Key principles and actions for COVID-19 response and recovery inclusive of persons with albinism

41. The inclusion of persons with albinism in the COVID-19 response and recovery is a vital part of achieving the pledge to leave no one behind. This section contains an outline of key principles and actions for making the COVID-19 response and recovery inclusive of persons with albinism, which are based on the key human rights principles of non-discrimination, protection, meaningful participation and inclusion, accountability as well as the need for data collection.

42. The policy brief on a disability-inclusive response to COVID-19 issued by the Secretary-General and the guidelines on COVID-19 and the rights of persons with disabilities issued by the Office of the United Nations High Commissioner for Human Rights (OHCHR) provide useful guidance for addressing the barriers faced by persons with albinism owing to their disabilities. Yet, an approach based exclusively on the disability framework would fail to encompass the complexity of intersecting discrimination faced by persons with albinism. While building on the disability-inclusive approach, the present report identifies recommendations tailor-made for persons with albinism to ensure that attention is given to their specific issues and needs.

43. Recommendations are made for both the immediate COVID-19 response and the medium term, to ensure that the social development and human rights challenges faced by persons with albinism are adequately addressed during the recovery phase. In that regard, the Secretary-General draws attention to the recommendations made in previous reports ([A/72/169](#) and [A/74/184](#)), as they remain highly relevant in the current context.

A. Non-discrimination and equality

44. COVID-19 response and recovery measures must prohibit discrimination on the basis of disability, colour and all other discriminatory grounds.⁶⁷ States must recognize and take measures to address the disproportionate impact of the COVID-19 crisis on persons with albinism. They should also take proactive steps to ensure that persons with albinism equally benefit from COVID-19 response measures.

45. Persons with albinism experiencing multiple and intersecting forms of discrimination because of their sex, age, gender identity, sexual orientation, ethnicity and race, location, legal status and economic status, among other factors, are more likely to carry a heavier burden stemming from the immediate and long-term consequences of the COVID-19 pandemic. COVID-19 response and recovery

⁶⁴ Submission by Fundación Nacional de Albinism Simplemente Amigos de Argentina.

⁶⁵ Submission by Albinism Association of Turkey.

⁶⁶ Submission by Source of the Nile Union of Persons with Albinism and Standing Voice.

⁶⁷ Convention on the Rights of Persons with Disabilities, art. 5; Convention on the Rights of the Child, art. 2 (1); International Convention on the Elimination of All Forms of Racial Discrimination, art. 1; and International Covenant on Economic, Social and Cultural Rights, art. 2 (2).

measures must thus respond to the multiple and intersecting forms of discrimination faced by persons with albinism to ensure that the most marginalized among them are not left behind.

46. Under international human rights law, States have an obligation not only to prohibit discrimination, but also to ensure substantive equality, including for persons with albinism.⁶⁸ In the context of the COVID-19 crisis, States must take actions to ensure reasonable accommodation for and accessibility of information, facilities and services.⁶⁹ The subsections below provide further guidance with regard to health, education, work, employment and livelihood.

Health

47. Regarding the right to health, States should take all appropriate measures to ensure access for persons with albinism to health services and provide them with the same range, quality and standard of health care, including mental health services, as those provided to other persons during the COVID-19 pandemic.⁷⁰ They must prohibit the denial of treatment on the basis of albinism and repeal any discriminatory provisions. They must ensure that persons with albinism have equal access to testing, vaccines and treatment for COVID-19 by making those services available, affordable and physically accessible. States must ensure that health information related to COVID-19 is available and disseminated in formats and languages accessible to persons with albinism and promote research on the impact of vaccines and treatments, if any, on persons with albinism.

48. States must also continue providing to persons with albinism the specific health services and treatment they need because of their condition. In particular, they must ensure the continued supply of sunscreen lotions and access to dermatological and ophthalmological screening and treatment and to visual assistive devices. In the short term, support services provided to persons with albinism, such as mobile clinics and the distribution of sunscreen lotions, should be considered essential services and be continued at all times, even during lockdowns.

49. During the recovery phase, States should integrate albinism into national health policies to comprehensively address the health issues related to the condition. They should urgently put in place programmes for skin cancer screening and treatment for persons with albinism to protect their right to life. They must ensure the accessibility of sunscreen lotions and eye care services at all times for persons with albinism, notably by making it free of charge or at reduced cost for them. They must also ensure the availability and accessibility of assistive technology devices for those with visual impairments.

50. States should conduct training of and awareness-raising among health workers to prevent discrimination based on possible prejudice and bias against persons with albinism. They must also ensure that family and caregivers are provided with adequate information and support upon the birth of a child with albinism.

⁶⁸ International Convention on the Elimination of All Forms of Racial Discrimination, arts. 1 and 2, and Committee on the Elimination of Racial Discrimination, general recommendation No. 32 (2009) on the meaning and scope of special measures in the Convention; and International Covenant on Economic, Social and Cultural Rights, art. 2 (2), and Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights.

⁶⁹ Convention on the Rights of Persons with Disabilities, arts. 2 and 5; and Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018) on equality and non-discrimination.

⁷⁰ International Covenant on Economic, Social and Cultural Rights, art. 12; and Convention on the Rights of Persons with Disabilities, art. 25.

Inclusive education

51. Regarding access to education, States must ensure that remote learning is inclusive and accessible to all, including to learners with albinism.⁷¹ They should ensure that the latter have access to the technological devices required to participate in remote learning practices (such as Internet connection, computers or tablets, television, radio and smartphones). They must provide them with the assistive devices and reasonable accommodation they need to participate fully in remote learning, such as magnification or dictation software, screen readers, accessible and adapted educational materials and extra time to complete assignments. States should provide guidance, training and support for school authorities, teachers, parents and caregivers of students with albinism on inclusive education through remote learning. Teachers should also be encouraged to establish close coordination with parents and caregivers of students with albinism.

52. States must ensure that return-to-school programmes are inclusive for learners with albinism. Given the wider learning and achievement gap experienced by learners with albinism during remote learning, school authorities and teachers should be encouraged to provide accelerated education plans, upgrading plans or remedial programmes for them. States should provide assistive devices and reasonable accommodation to learners with albinism so they can participate in class while respecting physical distancing measures. This includes adapting the lighting and positioning of materials, providing large print materials and magnifiers and ensuring that learners with albinism are not exposed to the sun as a result of the implementation of sanitary measures.

53. During the recovery phase, States should promote inclusive education for learners with albinism in mainstream education by providing educational institutions with the adequate means to equip classrooms, provide assistive devices to learners with albinism and train teachers on albinism and supportive measures to accommodate learners with albinism. In countries where students with albinism are eligible for disability-related schemes, States must ensure that disability related applications and accommodations in schools are not unnecessarily delayed.

Work, employment and livelihood

54. States should ensure that specific measures for persons with albinism are included in financial support programmes aimed at mitigating economic hardship during the COVID-19 crisis, giving priority attention to those living in poverty.⁷² They should provide financial aid to persons with albinism without any income and those who find their income reduced, such as lump sum payments, tax relief measures and the subsidization of goods. They should ensure that persons with albinism are included in, and effectively benefit from, support schemes for persons with disabilities, such as food assistance.

55. States should ensure that new work arrangements and conditions are accessible to, and inclusive of, persons with albinism.⁷³ This can be done by creating incentives (e.g. tax credits, subsidies and technical guidance) for employers of persons with albinism to provide reasonable accommodation to persons with albinism that may be

⁷¹ International Covenant on Economic, Social and Cultural Rights, art. 13; and Convention on the Rights of Persons with Disabilities, art. 24.

⁷² International Covenant on Economic, Social and Cultural Rights, art. 11; and Convention on the Rights of Persons with Disabilities, art. 28.

⁷³ Convention on the Rights of Persons with Disabilities, art. 27.

required for teleworking, including desktop equipment and assistive devices for online meeting platforms.

56. During the recovery phase, States should consider adopting and ensuring the effective implementation of special measures to promote employment and access to income-generating activities for persons with albinism, such as employment quotas, subsidies, microcredit programmes and capacity-building programmes.⁷⁴ They must also ensure that persons with albinism have effective access to social protection and poverty reduction programmes.

B. Protection

57. Persons with albinism, especially women and children, have been at a heightened risk of attacks and verbal abuse since the COVID-19 outbreak in some countries.⁷⁵ States must ensure that reporting mechanisms, hotlines, emergency shelters and other forms of assistance are accessible to persons with albinism. They should also consider increasing police patrols in reported hotspots for attacks against persons with albinism. They must also ensure that persons with albinism who have been victims of human rights violations have equal access to justice and remedies.

58. States should consider developing and widely disseminating awareness-raising campaigns to debunk myths and misbeliefs that associate albinism with COVID-19. During the recovery phase, they should further strengthen their efforts to address the root causes of discrimination against persons with albinism, notably through awareness-raising campaigns and education and by promoting images of persons with albinism as role models. Awareness-raising campaigns should engage with people at the community level and be adapted to local sociocultural contexts. Persons with albinism should be involved in the design of the campaigns.

C. Meaningful participation and inclusion

59. Persons with albinism, like everyone else, have the right to participate fully and effectively in decisions that affect their lives. States must ensure that persons with albinism and their representative organizations are consulted and actively involved in the planning, implementation and monitoring of COVID-19 response and recovery measures. This is essential to ensure that the response to the pandemic is inclusive of, and responsive to, persons with albinism.

60. An inclusive response to COVID-19 also requires measures to ensure that information and communications about the pandemic and related response measures are accessible to persons with albinism, including those living in remote areas. Access to this information is needed for persons with albinism to be able to take pandemic-related decisions, live independently, isolate or quarantine safely and access health and public services on an equal basis with others. The information should be disseminated using the greatest variety of communication means available and be provided in formats accessible to persons with visual impairments (e.g. captioning and easy-to-read formats) and in all languages spoken in the population.

⁷⁴ International Convention on the Elimination of All Forms of Racial Discrimination, art. 2 (2), and Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights.

⁷⁵ OHCHR, “Witchcraft killings”.

D. Accountability

61. Governments, donors, United Nations agencies and other actors need to establish accountability mechanisms to monitor COVID-19 response and recovery investments and ensure that those investments also reach persons with albinism.

E. Data collection

62. States should collect, compile and disseminate data disaggregated by age, sex and disability at minimum and in accordance with the human rights-based approach to data collection, in order to document the differentiated impact of the COVID-19 crisis on persons with albinism (see [A/HRC/49/60](#)). During the recovery phase, States should promote data collection and research on persons with albinism in order to identify patterns of discrimination and assess progress made towards the attainment of the Sustainable Development Goals, notably by including the variable of persons with albinism in national population censuses and by ensuring mandatory registration of births and deaths of persons with albinism.

V. Policy responses to the social development challenges faced by persons with albinism, including in the context of the COVID-19 crisis

A. International responses

63. At the international level, the situation of persons with albinism continues to garner increased attention. Since 2013, five resolutions on the matter have been adopted by the General Assembly, and six by the Human Rights Council. International Albinism Awareness Day has been celebrated on 13 June by the United Nations (see Assembly resolution [69/170](#)), as well as in scores of countries, since 2015.

64. In its resolution [47/8](#), adopted on 12 July 2021, the Human Rights Council urged States to condemn harmful practices related to accusations of witchcraft and ritual attacks that result in human rights violations, in particular for persons with albinism.

65. In 2020, in the context of the COVID-19 crisis, the Independent Expert led, and co-organized with other partners, the first online concert for International Albinism Awareness Day, featuring several musicians with albinism, which engaged almost 1 million people. On 28 June 2021, the Independent Expert issued a press release in which she raised concerns over the rise in killings of people with albinism during the pandemic.⁷⁶ In its resolution [46/12](#), adopted on 23 March 2021, the Human Rights Council decided to extend the mandate of the Independent Expert.

66. As an example of field work carried out by OHCHR, in 2019, OHCHR Uganda supported the realization of a study aimed at analysing the situation and state of persons with albinism in the country, with a view to informing the planning and design of effective policies and strategies to address the challenges affecting the albinism community in Uganda.

⁷⁶ Ibid.

B. Regional responses

67. According to the information received through submissions, there have been notable developments at the level of the Africa Union. At its thirty-first session, held in 2019, the Executive Council of the African Union considered the Regional Action Plan on Albinism in Africa (2017–2021) ([A/HRC/37/57/Add.3](#)) and subsequently adopted it as a continent-wide policy, to be known as the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031). At the same session, the African Union decided that a special envoy would be appointed to ensure the implementation of the Plan of Action, which replaced the Regional Action Plan upon the expiration of the latter in mid-2021. While forming part of the larger African Union disability architecture, the African Union Plan of Action takes into account the unique situation of attacks and discrimination faced by persons with albinism.

C. National responses

68. According to the information received, there seem to have been no specific measures taken to date at the national level to address the differentiated impact of the COVID-19 crisis on persons with albinism. It appears that persons with albinism have been covered under the general COVID-19 response and recovery measures and the specific measures for persons with disabilities.

69. Persons with albinism are protected through existing constitutions, legislation and policies relating to fundamental human rights-related principles of equality and non-discrimination, as well as specific legislation on disability, health, inclusive education, employment and rare diseases and conditions ([A/74/190](#), paras. 8, 43, 68 and 99–103; and [A/75/170](#), para. 67). Some States have taken steps to make specific reference to persons with albinism in their legislation, including Argentina, Brazil, Guinea, Kenya, Malawi, Nigeria, Panama and Uganda ([A/74/190](#), para. 9; and [A/75/170](#), para. 67). National action plans containing specific measures promoting the enjoyment of human rights by persons with albinism have been developed in several countries, including Kenya, Malawi, Mozambique, Nigeria, South Africa and the United Republic of Tanzania ([A/74/190](#), para. 11).

D. Responses by civil society organizations

70. Information received includes several examples of initiatives taken by civil society organizations to respond to specific needs of persons with albinism during the pandemic. In Benin, for example, Divine Connexion Worldwide reported having trained 500 teachers on the best ways to teach children with albinism.⁷⁷ In Chile, Corporación Albinos Chile reported the launching, in April 2021, of a guide for teachers and parents of students with albinism.⁷⁸ In Uganda, Source of the Nile Union of Persons with Albinism reported that they provided to children with albinism the devices needed to take part in remote learning, such as mini solar systems, radios and Internet data, and hired teachers to teach some children with albinism at home.⁷⁹ Advocacy with Governments and medical practitioners to draw attention to the situation of persons with albinism during the COVID-19 pandemic was also reported in Nigeria and Uganda.⁸⁰

⁷⁷ Submission by Divine Connexion Worldwide.

⁷⁸ Submission by Corporación Albinos Chile.

⁷⁹ Submission by Source of the Nile Union of Persons with Albinism.

⁸⁰ Submissions by Source of the Nile Union of Persons with Albinism and The Albino Foundation.

VI. Conclusions and recommendations

71. The COVID-19 crisis has exacerbated the discrimination and barriers faced by persons with albinism worldwide, further preventing them from fully participating in cultural, economic, political and social life. Its impact has disproportionately affected persons with albinism in the most vulnerable situations, including those with lower socioeconomic status and those subjected to multiple and intersecting forms of discrimination, especially women and children. A human rights-based approach to COVID-19 response and recovery is required to ensure that persons with albinism are not left behind and are not deprived of the enjoyment of their human rights, social inclusion and well-being. To ensure the realization of those goals, the following eight pillars of action are critical:

(a) Combating discrimination, negative stereotyping and the derogatory characterization of persons with albinism, including the myths and misbeliefs associating them with the COVID-19, through the development and widespread dissemination of awareness-raising campaigns and information;

(b) Ensuring that, throughout the COVID-19 pandemic, quality health services, new educational and work arrangements and all other measures taken to mitigate the economic and social consequences of the COVID-19 crisis are inclusive of, and accessible to, persons with albinism on an equal basis with others, including by preventing discrimination, providing reasonable accommodation and making information available in accessible formats;

(c) Ensuring that persons with albinism have access, at all times, including during the COVID-19 pandemic, to the dermatological and ophthalmological services and treatment they need because of their condition;

(d) Ensuring that persons with albinism and their representative organizations are closely consulted and actively participate in the planning, implementation and monitoring of COVID-19 response and recovery policies and measures, as well as in all other decision-making processes affecting them;

(e) Collecting, compiling and disseminating data on the situation of persons with albinism, including on the differentiated impact of the COVID-19 crisis on this population, in order to identify patterns of discrimination and better formulate laws and policies;

(f) Taking specific measures, such as adopting national action plans, policies and legislation, to promote the human rights of persons with albinism and enhance their social and economic inclusion, including through access to public health services, inclusive education, employment, justice, social protection and poverty reduction programmes, which must be supported by adequate financial and human resources to ensure their effective implementation;

(g) Empowering and supporting civil society organizations working with persons with albinism in effectively performing their tasks, including during the COVID-19 pandemic;

(h) Cooperating fully with relevant human rights mechanisms, including the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism.