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Social development

Social development challenges faced by persons with albinism

Report of the Secretary-General

Summary

The present report contains a discussion of the main social development challenges faced by persons with albinism, taking into consideration the specific challenges faced by women and children and focusing primarily on the barriers in access to health, education, employment and participation in political, social, civic and cultural life. The report also focuses specific attention on the environmental and attitudinal barriers faced by persons with albinism worldwide, provides updated information on the situation of persons with albinism and existing policy responses and includes recommendations for Member States, the international community, civil society organizations and the private sector.

* A/74/50.



I. Introduction

1. In its resolution [72/140](#), the General Assembly expressed concern that persons with albinism were disproportionately affected by poverty, owing to the discrimination and marginalization that they faced, and recognized the need for resources to develop and implement programmes to prevent and combat prejudice and to create an environment conducive to respecting their rights and dignity. In that resolution, the Assembly requested the Secretary-General to present a report on the various social development challenges faced by persons with albinism at its seventy-fourth session.

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, taking into consideration the specific challenges faced by women and children ([A/72/169](#)). The report provided a framework for conceptualizing and removing barriers to social inclusion, with a focus on barriers to access to health care, education, employment and participation in political, social, civic and cultural life. The majority of the issues raised and the information contained in that report remain highly relevant.

3. Drawing on the above-mentioned report and the work of the Independent Expert on the enjoyment of human rights by persons with albinism, the present report focuses specific attention on the environmental and attitudinal barriers faced by persons with albinism worldwide, and provides updated information on the social development situation of persons with albinism and existing policy-related responses.

4. In April 2019, a questionnaire was sent to Member States, non-governmental organizations and United Nations entities. Responses were received from five Member States (Georgia, Guatemala, Senegal, Ukraine and United Republic of Tanzania) and two United Nations organizations (the Economic and Social Commission for Western Asia and the United Nations Office on Drugs and Crime). In addition to the information provided in those responses, the present report includes information presented by the Independent Expert in her reports, 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. Promoting social inclusion requires removing barriers to participation and taking active steps to improve the terms of participation in society for those persons who are excluded. Testimonies gathered by the Independent Expert and information presented in academic publications and news articles suggest that persons with albinism continue to face social exclusion and discrimination worldwide.

II. Barriers to social development faced by persons with albinism

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 in any part or all of the skin, hair and eyes (A/HRC/24/57, paras. 10–11).

7. Persons with albinism are found across the globe, but their proportion vis-à-vis the larger population varies by region. While research is still needed to determine accurate proportions worldwide, estimates indicate that 1 in 17,000 to 20,000 people are affected by oculocutaneous albinism in North America and Europe.¹ In sub-Saharan Africa, the occurrence varies from 1 in 5,000 to 1 in 15,000, depending on the country.² Studies conducted in China and Japan indicate the occurrence of 1 in 18,000 and 1 in 47,000, respectively.³ Studies show that the frequency is much higher in certain geographically isolated communities, with reported rates higher than 1 in 1,000. For example, the frequency of 1 in 1,000 was reported among the Tonga people in Zimbabwe, 1 in 832 among the Vhatavhatsindi populations in South Africa and 1 in 200 to 300 among the Cuna people in Panama.⁴

8. Persons with albinism experience discrimination on the basis of disability, including the denial of reasonable accommodation. Several studies indicate that they face discrimination on the basis of their unusual appearance, in particular their skin colour,⁵ grounds that intersect in a manner that mutually reinforces and aggravates discrimination. Persons with albinism may also experience further multiple and intersecting discrimination on the basis of gender, age, race and other status. Owing to the multiple and intersecting forms of discrimination that they face, persons with albinism are often excluded from access to health care, education, employment and adequate housing. They are also disproportionately affected by poverty, notably in developing and the least developed countries.

9. With the exception of attacks and ritual killings, which have been reported only in certain countries, the issues faced by persons with albinism are global in scope. However, the degree to which these problems 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 and climatic conditions.

B. Legal and policy frameworks for addressing the social development challenges faced by persons with albinism

10. The international human rights framework is essential for ensuring that persons with albinism are capable of participating in society on an equal basis with others. Under international human rights law, persons with albinism have the same fundamental rights other individuals. In the Universal Declaration of Human Rights,

¹ The National Institutes of Health in the United States of America estimates the frequency of oculocutaneous albinism worldwide to be 1 in 20,000 (see <https://ghr.nlm.nih.gov/condition/oculocutaneous-albinism>). The National Organization for Albinism and Hypopigmentation reports the frequency of albinism to be 1 in 18,000 to 1 in 20,000 in the United States (see www.albinism.org/information-bulletin-what-is-albinism/).

² In 2005, the World Health Organization conducted a pilot survey on albinism in Nigeria, South Africa, the United Republic of Tanzania and Zimbabwe. For the results, published in 2006, see Esther S. Hong, Hajo Zeeb and Michael H. Repacholi, "Albinism in Africa as a public health issue", *BMC Public Health*, vol. 6 (2006), and A/HRC/24/57, para. 14.

³ Jennifer Kromberg, "Epidemiology of albinism", in *Albinism in Africa: Historical, Geographic, Medical, Genetic, and Psychosocial Aspects*, Jennifer Kromberg and Prashiela Manga, eds. (Cambridge, Massachusetts, Academic Press, 2018).

⁴ *Ibid.*

⁵ Relebohile Phatoli, Nontembeko Bila and Eleanor Ross, "Being black in a white skin: beliefs and stereotypes around albinism at a South African University", *African Journal of Disability*, vol. 4, No. 1 (2015).

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, including persons with albinism. The general principles of equality and non-discrimination enshrined in these important documents guarantee the full enjoyment of human rights by persons with albinism on an equal basis with others, support the full and effective participation of persons with albinism in society and provide for the protection of a range of rights that are instrumental for achieving social development, including the right to the highest attainable standard of mental and physical health, education, work and adequate housing.

11. International human rights law also includes internationally recognized standards providing protection to specific groups through the Convention on the Elimination of All Forms of Discrimination against Women, 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 Rights of Persons with Disabilities. Owing to the multiple and intersecting forms of discrimination faced by persons with albinism, the combination of various protection frameworks provides the most comprehensive mechanism for the protection and promotion of their human rights (A/72/131).

12. International human rights law also defines States' obligations and duties to respect, protect and fulfil human rights, including taking positive action and removing barriers in order to facilitate the enjoyment of basic human rights, including through the provision of reasonable accommodation.

13. Furthermore, as noted by the Independent Expert, the 2030 Agenda for Sustainable Development is instrumental for the achievement of the enjoyment of human rights by persons with albinism worldwide and, hence, ensuring their full participation in society on an equal basis with others, because it is based on a collective promise to "leave no one behind", beginning with those who are furthest behind. Persons with albinism are among the most vulnerable populations worldwide and should therefore be given priority attention in the implementation of the 2030 Agenda (A/72/131).

C. Notion of barriers in the human rights context

14. Persons with albinism face a number of barriers that prevent them from fully participating in society and enjoying their human rights on an equal basis with others. The notion of barriers has been widely discussed in relation to the enjoyment of human rights by persons with disabilities, of which persons with albinism are a constituency. In the Convention on the Rights of Persons with Disabilities, it is recognized that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". The significant impact that such barriers may have on the enjoyment of human rights by persons with disabilities is also emphasized in the Convention.

15. This approach assists in the understanding of the multiple and intersecting forms of discrimination faced by persons with albinism and their impact in terms of social development. Persons with albinism face both environmental and attitudinal barriers. Environmental or structural barriers include: physical barriers that prevent access to public spaces, workplaces and modes of transportation; barriers to information and communication, such as a lack of screen readers and large print; and institutional barriers, such as seemingly neutral legislation and policies that have a disproportionately negative impact on the abilities of persons with albinism, and a lack of legislation and policies providing an enabling framework.

16. Attitudinal barriers occur when bias, stereotypes and prejudicial attitudes towards persons with albinism lead to discrimination against them, impeding their full participation in all aspects of society. Discrimination against this population can be manifested in the form of avoidance, fear, rejection, negative attitudes and stereotyping; underestimation of their potential and capacities; and bullying, verbal attacks and physical threats. Such behaviour, which usually emanates from misconceptions and ignorance about albinism, results in stigmatization and discrimination, notably on the basis of perceived or actual impairment, including colouring, and the denial to this population of dignity and the full exercise and enjoyment of human rights. Attitudinal barriers are one of the greatest obstacles to achieving equality and social integration.

III. Environmental barriers faced by persons with albinism

A. Environmental barriers

Physical barriers

17. Environmental barriers include those that result from the insufficient development of the basic infrastructure and restricted access to public services. The lack of opportunities that results from the inadequate provision and uneven geographic distribution of public services, such as education, health, transportation and water and sanitation, among others, is an important driver of social exclusion that affects persons with albinism disproportionately.

18. In general, persons with albinism living in lower-income countries, where transportation, communication and health and education services are often insufficiently developed and underresourced, have fewer opportunities to develop their capabilities. According to the latest data available, in 2017, on average, there were fewer than two physicians per 10,000 people in the less developed countries compared with more than 40 physicians per 10,000 people in the developed countries.⁶ The relatively small share of the population with at least some secondary education (between 5 per cent and 57 per cent) illustrates the fact that education standards are generally lower in the less developed countries.⁷

19. Similarly, those living in remote areas are at greater risk of social exclusion than those who live in urban areas. While discrepancies between rural and urban areas exist in numerous countries, recent studies show that the situation continues to be particularly acute in lower-income countries, where the transportation infrastructure is limited.⁸ This makes access to health care, education and other public services disproportionately difficult for persons with albinism living in rural and remote areas.

20. Environmental barriers experienced by persons with albinism result from the lack of access to public transportation, including the absence of readable signage, and a lack of shelter or shade at bus stops.

Institutional barriers

21. The main institutional barrier faced by persons with albinism is the lack of targeted policy responses addressing their specific situation. In general, national

⁶ *Human Development Report 2016: Human Development for Everyone* (United Nations publication, Sales No.: E.16.III.B.1).

⁷ *Ibid.*

⁸ Sheryl Reimer-Kirkham and others, "Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights: a scoping review", *Disability & Society*, vol. 34, No. 5 (February 2019).

policy frameworks recognize persons with albinism as a constituency of persons with disabilities on the basis of their visual impairment solely (A/72/131, para. 8). However, the barriers faced by this population are not exclusively defined by a visual impairment; albinism also involves high vulnerability to skin cancer, as well as to discrimination and harmful practices, in certain countries, owing to lack of pigmentation. Therefore, the policy approach that consists of considering persons with albinism to be persons with a visual impairment does not address the full range of issues that they face.

22. Promoting the human rights and the social inclusion of persons with albinism requires targeted policies that employ an integrated and holistic approach that addresses their specific situation. The aim of such policies should be to remove environmental and attitudinal barriers facing persons with albinism, including through the provision of reasonable accommodation, to allow their inclusion in mainstream institutions, in line with international human rights standards and obligations requiring the adoption of specific measures to ensure the realization of the rights of persons with disabilities and measures of affirmative action to address discrimination. Action in this regard is also consistent with the 2030 Agenda, in which it is stated that specific measures should be taken to enable persons and groups that are left behind to progress at a rate higher than the national average.

23. The lack of visibility within society of persons with albinism, because of the absence of data collection and analysis, is another major institutional barrier to their integration (A/73/181, para. 73). In national settings, specific and detailed demographic and socioeconomic data, by country, continue to be lacking. Disaggregated data on national populations, which are essential to ensuring that all groups, including persons with albinism, are made visible in national statistics, are an essential prerequisite for the design of appropriate policies.⁹ The absence of data prevents the development and implementation of targeted policies and measures to ensure reasonable accommodation and the protection and promotion of the human rights of this population.

B. Impact of environmental barriers on social inclusion

Impact on access to the highest attainable standard of health

24. Persons with albinism are entitled to the highest attainable standard of health without discrimination of any kind. Article 12 of the International Covenant on Economic, Social and Cultural Rights provides the most comprehensive normative framework in this respect. In the Convention on the Rights of Persons with Disabilities, the right to the enjoyment of the highest attainable standard of health, without discrimination based on disability, is also recognized. Under the Convention, States have a duty to provide reasonable accommodation to accelerate or achieve the de facto equality of persons with disabilities in order to ensure access to the right to the highest attainable standard of health. The 2030 Agenda also includes specific targets that are particularly relevant, namely: universal health coverage; access to quality essential health-care services; financial risk protection; and access to affordable essential medicines and vaccines.

25. High vulnerability to skin cancer continues to be the most pressing health issue faced by persons with albinism worldwide.¹⁰ The risk of developing skin cancer is

⁹ In Sustainable Development Goal 17, target 18, there is a call for a significant increase in the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts.

¹⁰ See A/72/169, para. 30, and A/HRC/37/57.

about 60 times lower for people with dark skin than for those with fairer skin. In regions close to the equator, where the frequency of albinism is relatively high, persons with albinism are exposed to extreme ultraviolet radiation, which exacerbates their risk of developing skin cancer. The risk is particularly acute for those who live in rural areas and are likely to be outdoors during daylight hours. Recent studies show that, in sub-Saharan Africa, skin cancer is the major cause of mortality for persons with albinism.¹¹

26. The condition of albinism also includes vision impairment in nearly all cases, resulting from refractive and non-refractive impairment. Most often, the impairments can be improved, but are often not treated completely, through the use of optical devices (A/72/169, para. 28). Accommodating the visual needs of persons with albinism is an essential prerequisite for enabling them to fully develop their potential and participate in social life. However, the use of assistive devices by persons with albinism continues to be low, in particular in lower-income countries.

27. The low availability of health services, specifically specialized services, such as ophthalmological services, dermatological services and genetic counselling, continues to be a critical barrier, in particular in lower-income countries. When available, such services are often concentrated in urban centres and are prohibitively expensive. In many instances, persons with albinism cannot afford required services and goods, such as sunscreen, highly protective clothing, early screening for skin cancer, skin cancer treatment and vision-care devices. The low availability and accessibility of health-care services affects persons with albinism disproportionately.

28. In order to mitigate the situation, targeted services and initiatives for persons with albinism, such as mobile clinics offering dermatological and ophthalmological services, sunscreen, screening and treatment for skin cancer, as well as HIV treatment, have been developed by non-governmental and governmental agencies in lower-income countries. The initiatives have contributed directly to improving the health of persons with albinism, in particular in rural and remote areas. Specialized in scope, these initiatives do not enable access to comprehensive health care.

29. Removing environmental barriers requires that general and specialized health services be made available as near as possible to local communities in which persons with albinism live. In addition, it is essential that vision care and preventive and curative care for skin cancer be made affordable, including through: the distribution of free sunscreen; targeted public health programmes, as well as public health education on protection against the sun and sun avoidance; and the provision of health insurance schemes tailored to the needs of persons with albinism.

Impact on access to inclusive education

30. The right to inclusive education is guaranteed under the Convention on the Rights of Persons with Disabilities. Therefore, all persons should have access to education without discrimination on an equal basis with others and be valued according to their capabilities. The right to inclusive education is an “empowerment right”, which enables individuals to develop their capabilities and realize other rights, such as the right to health, justice, decent work and an adequate standard of living. Under the Convention on the Rights of Persons with Disabilities, States have an obligation to provide reasonable accommodation to support students with disabilities, including students with albinism. Furthermore, in Goal 4 of the 2030 Agenda, it is affirmed that inclusive and equitable education is essential for the social development of all, including persons with albinism.

¹¹ Patricia M. Lund and Mark Roberts, “Prevalence and population genetics of albinism: surveys in Zimbabwe, Namibia, and Tanzania” in *Albinism in Africa*.

31. In practice, students with albinism continue to have limited access to education, and high dropout rates and low levels of educational attainment have been reported. When access to education is provided, children with albinism are often educated in segregated educational environments, such as special schools for blind persons. In such institutions, pupils with albinism do not have access to appropriate protective and assistive devices, which could significantly enhance their visual capabilities and thus their academic performance. Equipment and assistive devices are not usually covered by State budgets, which puts the sustainability of education for this population at risk ([A/HRC/40/62/Add.1](#), paras. 42–44).

32. Environmental barriers to inclusive education for children with albinism include a lack of resources. Inclusion in mainstream education is particularly challenging in countries in which the education system is understaffed, schools are crowded and there is poor infrastructure. The denial of reasonable accommodation is another important barrier.

33. Removing barriers to education with a view to encouraging the social inclusion of persons with albinism requires raising the awareness of educators and providing reasonable accommodation that allows for the inclusion of pupils with albinism in mainstream secondary education. Measures of accommodation may include using mobile blackboards; allowing students with albinism to sit at the front of the classroom or to walk up to the board; providing low-vision devices, large-print materials and a copy of the teacher's notes; and allowing students extra time to complete reading tasks. School playgrounds should offer shelter from direct sunlight, and rules regarding school uniforms should be flexible in order to ensure that students with albinism can cover up sufficiently to protect themselves from sun exposure throughout the year.

Impact on access to employment and income opportunities

34. Under international human rights law, States have the core obligation to ensure non-discrimination and the equal protection of employment, in particular for disadvantaged and marginalized individuals and groups. In article 6 of the International Covenant on Economic, Social and Cultural Rights the right to work is recognized, and in articles 7 and 11, the right of everyone to the enjoyment of just and favourable conditions of work and to an adequate standard of living, respectively, are guaranteed. These fundamental rights also include respect for the physical and mental integrity of workers in the exercise of their employment. The Convention on the Rights of Persons with Disabilities guarantees the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and a work environment that is open, inclusive and accessible. In addition, Sustainable Development Goal 8, target 5, of the 2030 Agenda is aimed at achieving full and productive employment and decent work for all, including for persons with disabilities, and equal pay for work of equal value. Access to employment and other income opportunities, such as land property and loans, is an essential aspect of participation in social life. In addition to being a source of material wealth, income-generating activities also confer social identity and acceptance.

35. Persons with albinism continue to be more vulnerable to unemployment and material deprivation. When they do gain access to employment, they are more likely to be in low-paying jobs, at lower occupational levels, with poor promotional prospects and working conditions. The fact that they are often engaged in the informal sector, without social protection, makes obtaining access to health services even more difficult, if not impossible. Furthermore, securing indoor employment, which is safer for persons with albinism, remains a major challenge for a significant number of persons with albinism, owing to the fact that they have not been able to obtain a suitable degree because of a lack of reasonable accommodation. Resorting to

agriculture and peddling, while often the only viable forms of self-employment, puts them at risk of contracting skin cancer.

36. The situation of the local labour market is an important environmental barrier, impeding access to employment and income opportunities for persons with albinism. In general, it is more difficult for groups that face discrimination to find a job in an environment marked by high unemployment and a shortage of decent work opportunities. Another major barrier is the denial of reasonable accommodation in the workplace. Employers are often reluctant to hire persons with disabilities, including persons with albinism, because they do not want to adapt the workplace to accommodate their needs.

37. Removing such barriers requires taking specific measures to promote the inclusion of persons with albinism in the job market (e.g., quotas, tax incentives and subsidies) and their access to non-salaried income-generating opportunities, such as loans and insurance schemes. It is also essential to ensure that persons with albinism have equal access to work and adequate vocational training in safe and healthy working conditions.

Other impacts

38. As noted by the Independent Expert, environmental barriers also affect access to justice for persons with albinism (A/HRC/40/62), including a lack of information, a lack of knowledge of one's rights and fear or mistrust of the justice system. In addition, legal and institutional frameworks do not always recognize or provide for procedural accommodations in the context of access to justice, and victims of attacks may be fearful of bringing complaints or may have lost confidence in the justice system as a result of failed attempts to obtain legal protection or judicial recourse for violations of bodily integrity or privacy. Moreover, the formal justice system is not always accessible, in particular for persons with albinism living in rural areas.

IV. Attitudinal barriers

A. Attitudinal discrimination faced by persons with albinism

39. Persons with albinism face attitudinal discrimination and stigma worldwide, which emanates from a lack of knowledge and widespread misconceptions about their condition. Exclusion from social interaction, negative attitudes, rejection and ostracism, in particular from close relatives, can have a strong and negative impact on their psychological and social well-being and may hinder their ability to participate fully in economic, social, political and cultural life.

40. Patterns of attitudinal discrimination faced by persons with albinism are context-specific and vary in intensity, depending on the social norms of the country, including the degree to which the human rights-based approach to disabilities has been embedded into national norms and practices, the perception of colour differences, historical experiences of racial discrimination and the level of public awareness of and accurate information on the condition. For instance, the stigma experienced by persons with albinism in the West, where this group is relatively less visible and the medical explanation for albinism is dominant, differs from the experience of persons with albinism living in regions in which they are hypervisible and mythical explanations about their condition continue to prevail.

Myths and beliefs

41. Numerous studies document the myths, beliefs and misbeliefs surrounding albinism.¹² Its cause often attributed to a range of fortune and misfortune. Persons with albinism may be considered supernatural beings, and their body parts may be seen as bringing power, wealth or success. Whether these spiritual attributions are seen in a positive light (for example, being sacred and inviolate or under divine protection) or negatively (being taunted as ghosts, witches or aliens), they have the same detrimental dehumanizing effect. This process results in the worst expressions of discrimination and makes possible the worst forms of violence, including mutilation and killings.

Disability

42. Persons with albinism also face attitudinal discrimination on the ground of disability. Such discrimination usually stems from a focus on a person's impairment. Common forms of attitudinal discrimination related to albinism include the widely held view that the condition is contagious and the belief that it causes hearing impairment and affects intellectual abilities, as well as the idea that persons with albinism are inferior or second-class citizens.

Colour and appearance

43. Hypervisibility continues to be one of the root causes of the lack of acceptance and the stigmatization of persons with albinism. It makes them especially vulnerable to stigmatization in particular in countries where the majority of the population has more pigmentation.

Multiple and intersecting forms of attitudinal discrimination

44. Persons with albinism are subject to attitudinal discrimination on the multiple and intersecting grounds of disability and colour. These grounds are interlinked and intersect in ways that mutually reinforce and aggravate discrimination. This basic intersectionality, and the resulting, obvious, types of discrimination it entails, may be further aggravated by multiple layers of discrimination, including discrimination related to gender and age. Such aggravated forms of intersecting and multiple levels of discrimination may also affect the family members, in particular the mothers, of persons with albinism.

45. Women and girls are especially vulnerable to attitudinal discrimination owing to the gender dimension of some myths and misbeliefs. In some communities, they are subjected to rape and other sexual violence because of the belief that sexual intercourse with a woman or girl with albinism can cure health problems (CEDAW/C/TZA/CO/7-8, para. 18 (b)). Similarly, mothers of children with albinism may face rejection, ostracism and discrimination in communities where the birth of a child with albinism is considered to be a sign that she is guilty of misconduct, making them, and their children, particularly vulnerable to isolation, poverty and attacks (A/72/131, para. 23). Women with albinism are also highly vulnerable to exploitation and abuse in the workplace.

46. Children with albinism are at a higher risk of abandonment, stigmatization, marginalization and rejection. Infanticides of children with albinism have also been reported. Furthermore, some beliefs and misconceptions put children at a higher risk of attack. In sub-Saharan Africa, for instance, children with albinism in particular are

¹² Reimer-Kirkham and others, "Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights".

the targets of witchcraft-related attacks because of the belief that the innocence of the victim increases the potency of the witchcraft.

Lack of awareness

47. The attitudinal and environmental barriers faced by persons with albinism usually emanate from ignorance and misconceptions about the condition. For this reason, efforts to remove such barriers should be focused on raising awareness of the rights of persons with albinism and the fact that it is a genetic condition. Highlighting the achievements and capabilities of persons with albinism can contribute to promoting a positive image of them. Irresponsible reporting on and the misrepresentation of albinism in the media and the arts promote the stigmatization of and discrimination against persons with albinism by perpetuating belittling, negative and caricatured depictions of persons with albinism.

48. Awareness-raising measures should include targeted steps to increase the information and knowledge available to persons with albinism and their families. The measures should also be aimed at increasing the knowledge and awareness of health-care providers and education professionals. In addition, there is a need to raise public awareness of the condition through large-scale campaigns, in particular in countries where persons with albinism are subject to the worst forms of discrimination, attacks and violence.

B. Impact of attitudinal barriers on social inclusion

Impact on access to health

49. Stigma and stereotypes have a negative impact on access to health services. In some instances, persons with albinism are denied access to certain types of health care and services, including sexual and reproductive health care, owing to their condition. In some instances, doctors refuse to prescribe contraceptive pills to women with albinism because of their skin colour. This reveals the lack of knowledge among health professionals and the need to educate them.

50. The shame and stigma associated with albinism also deter persons with the condition and their families from seeking medical attention or rehabilitation. In some countries, persons with albinism who have HIV/AIDS are reluctant to make use of free and available antiretroviral therapy services because of the fear of being further stigmatized. The appearance of sun protective and optical devices, which may attract unwelcome public attention, can also deter persons with albinism from using them (A/HRC/37/57, para. 23).

51. The discrimination and stigma faced by persons with albinism has far-reaching psychosocial consequences. Several studies highlight the mental health issues faced by persons with albinism, such as loss of self-esteem, depression, isolation and suicide.¹³

52. Removing attitudinal barriers to the right to health requires raising awareness and training health professionals about albinism, for instance, through the inclusion of the condition in the curricula of medical schools in a manner centred on human rights and social inclusion.¹⁴ It also requires that persons with albinism and their families receive more, and more up-to-date, information about their condition, preventive measures and available treatment.

¹³ Reimer-Kirkham and others, “Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights”.

¹⁴ See, for example, the work done by the organization Positive Exposure (<https://positiveexposure.org>).

Impact on access to inclusive education

53. Attitudinal discrimination is a major barrier to the realization of the right to education for persons with albinism. Pupils with albinism experience discrimination, social stigma and verbal and physical abuse from school staff and students alike. Ignorance and misconceptions may lead to the exclusion of children with albinism from schools, and some parents even keep their children away from mainstream schools to protect them from violence. There are also instances in which school authorities are reluctant to enrol children with albinism owing to the fear of contagion, pressure from parents of other children and the fear of school authorities of not being able to protect pupils with albinism from attacks.

54. Even when teachers, parents and students are supportive of pupils with albinism, expectations may be low and little attention may be given to their education. Some parents keep their children away from school or discourage them from pursuing higher education because they do not believe in their capacity to learn, while other families believe that special schools are better suited to the education of their children with albinism.

55. Removing such barriers requires raising the awareness of and training families, teachers, school authorities and other education personnel in mainstream education institutions about albinism, including through teacher-training programmes. Providing reasonable accommodation and supporting students with albinism are further measures that can be taken in this regard.

Employment and income-generating activities

56. Misconceptions and beliefs surrounding albinism seriously impede the ability of persons with the condition to obtain access to employment and other income-generating activities. For example, the widespread belief that persons with albinism are less productive and have intellectual disabilities may deter employers from hiring them. Such beliefs are further reinforced by the fact that persons with albinism are often not given the chance to complete their higher education. The colouring of persons with albinism and the fear of contagion are also used as bases on which to deny them employment on the ground that they would drive clients away.

57. The Independent Expert reported that, in countries with records of attacks against persons with albinism, the absence of work in a secure environment produces endemic fear and has an impact on livelihood, given that such insecurity often results in a decrease in the number of hours that they are able or willing to risk working away from home ([A/72/131](#), para. 63). It also affects the right to work of family members and caregivers of persons with albinism.

58. Persons with albinism may also be denied access to loans. For example, in 2017 the Association of Persons with Albinism in Malawi reported that this population was labelled as a risk group by loan institutions and small village loan and savings groups.

Other impacts

59. Stigma and discrimination have a negative impact on the right to adequate housing of persons with albinism. That right is firmly anchored in international human rights law, which recognizes the right of everyone to an adequate standard of living for themselves and their family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. Several instances have been reported in which landlords refused to rent their accommodations to persons with albinism because they feared that they would be implicated in possible attacks, that a

tenant with albinism would run away overnight, leaving their bills unpaid, or would bring them bad luck.¹⁵

60. Persons with albinism also experience exclusion from marital and family life. In the testimonies of people in several countries, the difficulty in finding a spouse and being accepted by in-laws was stressed. The difficulty of having a marital life is particularly devastating in societies in which marital status is a key determinant of social status, social inclusion and access to various rights.

61. As noted by the Independent Expert, societal exclusion and stigmatization are significant barriers to obtaining access to justice because they inhibit an understanding of and access to the justice system (A/HRC/40/62, paras. 31–34). Social stigma within society also predisposes key stakeholders in the justice system to be biased against persons with albinism. Hence, the prejudices of key actors in the system undermine a safe and enabling environment for persons with albinism, as well as their access to justice.

62. In regions where prejudice against persons with albinism is prevalent, this population seldom participates actively in politics because it faces and fears discrimination. Name-calling, mockery and threats against politicians with albinism in Ghana, Kenya and the United Republic of Tanzania have reinforced such fear. Nevertheless, persons with albinism have often succeeded in their political quests, overcoming serious prejudices and becoming living proof of a summit of social inclusion.

V. Policies and measures addressing social development challenges faced by persons with albinism

A. International

63. At the international level, the situation of persons with albinism continues to garner increased attention. Since 2013, five resolutions addressing the subject of albinism have been presented before the Human Rights Council and three before the General Assembly. Moreover, since her appointment, in June 2015, and pursuant to her mandate (Human Rights Council resolution 37/5), the Independent Expert has worked to promote the realization of the enjoyment of human rights by persons with albinism throughout the world, including by reporting on the challenges and obstacles they face, as well as raising awareness and facilitating the collection, exchange and promotion of information and good practices. International Albinism Awareness Day continues to be celebrated annually on 13 June by the United Nations (General Assembly resolution 69/170), as well as in scores of countries. In Uganda, the Office of the United Nations High Commissioner for Human Rights has provided technical support to the Equal Opportunities Commission to carry out a study on the situation of persons with albinism.

B. Regional

64. Following the endorsement, in May 2017, by the African Commission on Human and Peoples' Rights of the Regional Action Plan on Albinism in Africa (2017–2021),¹⁶ it was endorsed in May 2018 by the Pan-African Parliament.¹⁷ The plan is

¹⁵ A/HRC/34/58/Add.2, para. 28, and A/72/131, para. 60.

¹⁶ Resolution on the Regional Action Plan on Albinism in Africa (2017–2021) (see www.achpr.org/sessions/resolutions?id=415).

¹⁷ Resolution on persons with albinism in Africa (see www.chr.up.ac.za/images/centrenews/2018/files/2018_pap_resolution_on_persons_with_albinism.pdf).

reflected in the national plans on persons with albinism of several countries, including Kenya, Malawi and Mozambique. Promoted by the Independent Expert, the Regional Plan is a compendium of specific measures that chart a road map for national Governments to ensure that persons with albinism are not left behind with regard to efforts to achieve the Sustainable Development Goals. It includes measures, targets and indicators, in line with the Goals.

C. National

65. With regard to institutional barriers, several States have adopted targeted national policies on albinism that rely on a multisectoral approach. In the United Republic of Tanzania, for instance, the Deputy Prime Minister's Office has convened a task force, composed of representatives of the Government, civil society organizations and United Nations agencies, to develop a multisectoral and coordinated policy response to ensure the protection and well-being of persons with albinism (A/HRC/37/57/Add.1, para. 38). In a similar vein, the Fiji Albinism Project is governed through multisectoral coordination among the ministries responsible for health, education and women's issues (A/HRC/40/62/Add.1). The modalities of work include the sharing of information, measures to enhance individual care and the appointment of dedicated staff. In Guatemala, the National Council for Persons with Disabilities and a programme aimed at persons with disabilities and older adults of the Ministry of Public Health and Social Assistance consider persons with albinism as persons with disabilities owing to their hereditary genetic condition, encompassing the visual impairment and sensitivity to solar exposure often associated with the condition.

66. With regard to the collection of disaggregated data, the Independent Expert noted the methodology created by the Washington Group on Disability Questions, in the United States of America, as a basis for universalizing the collection of data on persons with albinism worldwide through the national census (A/73/181, para. 76). The national censuses of Namibia and the United Republic of Tanzania are two examples of good practices of collecting data on persons with albinism using that methodology. In Nigeria, the Albino Foundation, with the support of the European Union, began a baseline survey on persons with albinism, and in 2018, the International Organization for Migration launched a situation analysis on the human rights and protection of persons with albinism in Mozambique (A/73/181, para. 86).

67. Measures taken to remove barriers faced by persons with albinism to public services, in particular education and health, continue to be prominently informed by a specialized approach that consists of providing specific services for this population. In Malawi and the United Republic of Tanzania, for instance, mobile clinics attending specifically to persons with albinism who live in non-urban centres have had a highly positive results in terms of skin cancer prevention and treatment, as well as on reasonable accommodation for visual impairment (A/HRC/37/57/Add.1, paras. 48–51). In the United Republic of Tanzania, the Medical Stores Department has designated sunscreen a priority medicine for persons with albinism. Moreover, the sunscreen distributed through mobile clinics is locally made and formulated for general use, with specific attention paid to the needs of persons with albinism. Local production is particularly important to ensure constant availability. In Kenya and Nigeria, the Government has initiated programmes for the prevention and treatment of skin cancer. In both countries, however, challenges persist for persons with albinism living in rural and remote areas in terms of accessibility, availability and affordability.

68. In many countries, a lack of resources continues to be a major challenge to the implementation of the inclusive approach promoted through the Convention on the

Rights of Persons with Disabilities, which is aimed at making mainstream services available and accessible to all, including persons with albinism. In countries that have adopted inclusive education strategies, such as Guatemala, Ukraine and the United Republic of Tanzania, students with albinism will only benefit from these strategies if provided with the necessary reasonable accommodation ([A/HRC/37/57/Add.1](#)).

69. Several countries have launched campaigns to raise awareness among targeted audiences and the general public of albinism. The Independent Expert reported a good example of such an awareness-raising initiative in the United Republic of Tanzania, where the United Nations Educational, Scientific and Cultural Organization carried out a pilot project from 2015 to 2016 on community awareness. The project made use of community radio stations and took a sociocultural approach by empowering key community stakeholders and family members of persons with albinism to mobilize their communities to protect and promote the well-being and rights of persons with albinism.

70. Promoting the political participation of persons with albinism is also important for combating attitudinal and environmental barriers. In the United Republic of Tanzania, a person with albinism was appointed to the position of Deputy Minister responsible for labour, youth, employment and disability affairs during the period from 2015 to 2017 ([A/HRC/37/57/Add.1](#), paras. 34–38). The appointment led to the prioritization of albinism and fruitful initiatives advancing the promotion and protection of the rights of persons with the condition. In 2008, the President of the National Assembly nominated the first member of parliament with albinism, Al-Shaymaa Kwegyir, who served two full terms.

D. Responses by civil society organizations

71. Recent studies confirm that civil society organizations representing persons with albinism exist in most countries.¹⁸ The type and range of activities undertaken by them depend largely on the situation of persons with albinism in their respective countries and the capacity of the State to provide the required support, including raising public awareness, providing health and social services, lobbying and advocacy and conducting research.

72. The media and creative artists, such as film-makers, have an important role to play in combating attitudinal barriers by disseminating accurate and relevant information about the condition of albinism, promoting a positive image and highlighting the contributions of persons with albinism to various fields, including politics and human rights.

VI. Conclusions and recommendations

73. Persons with albinism continue to face environmental and attitudinal barriers that prevent them from participating fully in economic, social, political and cultural life. The degree and impact of such barriers are higher in low-income countries, which also tend to be areas where the frequency of albinism is higher. Specific measures continue to be critical in order to improve the terms of participation of persons with albinism in society. Such measures will ensure that this population is not left behind and deprived of the enjoyment of human rights,

¹⁸ Jean Burke, Theresa Kaijage and Johannes John-Langba, “Media analysis of albino killings in Tanzania: a social work and human rights perspective”, *Ethics and Social Welfare*, vol. 8, No. 2 (2014).

social inclusion and well-being. For the realization of those goals, the following five pillars of action are critical:

(a) Recognizing and addressing the multiple and intersecting forms of discrimination faced by persons with albinism, notably on the primordial grounds of disability and colour, as well as gender, race and age, and taking steps to combat them;

(b) Disseminating information, raising awareness of human diversity and the rights of persons with albinism and combating the stereotyping and derogatory characterization of this population in the mass media;

(c) Taking specific measures, such as national action plans, policies and legislation, to promote the human rights and enhance the social and economic inclusion of persons with albinism, including access to public health services, inclusive education, employment, justice, social protection and poverty reduction programmes;

(d) Ensuring the participation of persons with albinism in social, political, civic and cultural life, as well as their consultation and active involvement in the design, implementation and evaluation of laws, policies, campaigns and training programmes;

(e) Collecting, compiling and disseminating data on persons with albinism in order to identify patterns of discrimination and better formulate laws and policies.

VII. Observations and views on follow-up

74. States should consider streamlining their reporting on the social development challenges faced by persons with albinism with a view to avoiding any overlap with work carried out under the mandate of the Independent Expert. Additional resources are needed for consistent monitoring and meaningful research in order to advance and accelerate progress towards protecting the rights of persons with albinism.
