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**Promoción y protección de todos los derechos humanos, civiles, políticos, económicos, sociales y culturales, incluido el derecho al desarrollo**

# Visita a Lesotho

## Informe de la Experta Independiente sobre el disfrute de los derechos humanos de las personas con albinismo, Muluka-Anne Miti-Drummond* **

*Resumen*

La Experta Independiente sobre el disfrute de los derechos humanos de las personas con albinismo, Muluka-Anne Miti-Drummond, realizó una visita oficial a Lesotho del 10 al 19 de abril de 2024. En el presente informe figuran sus conclusiones y una sinopsis de los problemas en materia de derechos humanos que experimentan las personas con albinismo en Lesotho, en particular los que afrontan en relación con el derecho a la salud, la educación y el empleo. Se evalúan otros obstáculos para que las personas con albinismo puedan hacer plenamente efectivos sus derechos humanos, como la estigmatización y la discriminación, y se describen ideas erróneas generalizadas sobre el albinismo. Además, se ponen de relieve los problemas socioeconómicos que experimentan muchas personas con albinismo, sobre todo en las zonas remotas y rurales del país, que requieren atención urgente. La Experta Independiente también ofrece recomendaciones para tratar de resolver los problemas mencionados.

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* Este informe se presentó a los servicios de conferencias para su tramitación fuera del plazo establecido a fin de incluir en él la información más reciente.

** El resumen del presente informe se distribuye en todos los idiomas oficiales. El informe propiamente dicho, que figura en el anexo, se distribuye únicamente en el idioma en que se presentó.

# Anexo

## Informe de la Experta Independiente sobre el disfrute de los derechos humanos de las personas con albinismo, Muluka-Anne Miti-Drummond

## I. Introduction

1. At the invitation of the Government of Lesotho, the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, undertook an official visit to the country from 10 to 19 April 2024. She sincerely thanks the Government for its cooperation in the preparation and conduct of her visit. She is especially grateful to the staff of the Ministry of Foreign Affairs and the Ministry of Justice, the key focal ministries supporting and facilitating her visit. She also extends her sincere gratitude to the United Nations Resident Coordinator, the United Nations country team and, in particular, the staff of the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the colleagues at the United Nations Development Programme (UNDP) who provided valuable support both before and during her visit.

2. The Independent Expert held meetings in Maseru and Thaba-Tseka. She met with representatives from the Ministry of Foreign Affairs, the Ministry of Law and Justice, the Ministry of Health, the Ministry of Education and Training, the Ministry of Gender, Youth and Social Development and the Lesotho College of Education, the President of the Court of Appeal, the Ombudsman, staff and students with albinism at Saint Catherine’s School and the Saint Bernadette Resource Centre for the Blind. She also met with State medical practitioners, including an ophthalmologist and an oncologist, the United Nations country team, representatives of civil society organizations working on various human rights and thematic issues and of organizations working specifically on albinism, persons with albinism and members of their families.

3. During her visit, the Independent Expert had the opportunity to participate in the forty-third ordinary session of the African Committee of Experts on the Rights and Welfare of the Child, which was held in Maseru from 15 to 25 April 2024. During the session, on 17 April, a specific “General Day of Discussion” took place, focusing on solutions to challenges faced by children with albinism. To take full advantage the day, which was an opportune event and an important milestone, the Independent Expert sat on various panels and met with persons with albinism and members of civil society organizations representing persons with albinism from the region. Many other stakeholders were involved in the discussions, including Government representatives and regional representatives.

4. The Independent Expert expresses her sincere gratitude to all those who made time to meet with her during her visit, particularly persons with albinism and their family members, who willingly shared their experiences, testimonies and life journeys, many of which have been marked by trauma, pain and extreme difficulty.

## II. Background

5. Lesotho is a landlocked country, surrounded by its larger neighbour, South Africa. It has population of around 2.3 million;[1] it is primarily a homogeneous country, with the Basotho people comprising the majority ethnic group. Lesotho was a British protectorate until the nation gained independence in October 1966. It is a constitutional monarchy, ruled by a King as Head of State and governed by a 33-member Senate and a 12-member National Assembly.[2] The current Government, which came into power in November 2022, is led by Prime Minister Samuel Ntsokoane Matekane.

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[1] World Health Organization (WHO), see https://data.who.int/countries/426.

[2] Ibid.

6. The economic landscape of Lesotho is a mixture of opportunities and challenges. In the aftermath of the coronavirus disease (COVID-19) pandemic, the country has been in recovery mode, although half of the population still lives beneath the poverty threshold.[3] Rising income inequality and unemployment continue to be challenges for the Government. Young people face a reported unemployment rate of 33.2 per cent, compared to the overall unemployment rate of 24 per cent[4] for the general population. However, with a per capita gross domestic product (GDP) of around $878.00 in 2023, Lesotho is classified as a lower-middle income country.[5] The country's economy relies heavily on remittances, especially from workers living abroad, including a large population in South Africa.

7. The population of Lesotho is around 49 per cent male and 51 per cent female, with life expectancy at around 58 years for females and 52 years for males. More than 60 per cent of the population resides in the rural areas. [6]

8. The main challenges that Lesotho faces, apart from economic vulnerabilities and inequalities, are climate change and related environmental risks and ensuring stability in political rule and governance.

### Albinism

9. Albinism is a relatively rare, non-contagious, genetically inherited group of conditions that affects people worldwide, regardless of ethnicity, sex or gender. It is the result of a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any or all of the skin, hair or eyes. Persons with albinism often appear pale in comparison to members of their family and community. In order for a person to be affected by albinism, both parents must carry the gene; in such a case, there is a 25 per cent chance that a child will be born with albinism.

10. The most common and visible type of albinism is oculocutaneous albinism, which affects the skin, hair and eyes. While a key physiological consequence of albinism includes vision impairment, the severity of impairment varies from person to person. The other key physiological consequence is vulnerability to skin cancer, which is fatal when left untreated. Skin cancer accounts for a significant number of early deaths of persons with albinism in climates with high ultraviolet (UV)indices.

11. Persons with albinism are commonly recognized as persons with disabilities. They have also been recognized as persons who face racial discrimination on the grounds of skin colour by the Committee on the Elimination of Racial Discrimination.[7] As such, persons with albinism endure multiple and intersecting discrimination within their immediate communities and in society at large.

## III. Context of the visit

12. The Independent Expert commends the Government of Lesotho for extending her an invitation to visit, even without a request. She highlights this as a good practice worthy of replication by States who engage with the special procedure's mechanisms of the Human Rights Council. The Government of Lesotho also provided prompt support to facilitate her visit. The Independent Expert further highlights that among the pledges made by Lesotho for the Human Rights 75 initiative[8] was the extension of standing invitations for country visits to the special procedures of the Human Rights Council and is appreciative that her mandate benefitted from this commitment.

13. The Independent Expert notes that Lesotho stands out among some of the countries in the region; she did not receive any information or allegations of killings concerning persons

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[3] United Nations, Lesotho Common Country Analysis Update 2023, p. 7.

[4] Ibid.

[5] See https://www.worldbank.org/en/country/lesotho/overview.

[6] United Nations Population Fund (UNFPA), Country programme document for Lesotho (2023) (DP/FPA/CPD/LSO/8).

[7] CERD/C/ZAF/CO/4-8, para. 20.

[8] See https://www.ohchr.org/en/human-rights-75/pledge/human-rights-75-pledges.

with albinism due to their albinism prior to or during her visit. With regard to the general understanding of albinism in Lesotho, the Independent Expert noted that, as in many other countries worldwide, it is seriously misunderstood, with many persistent misconceptions and myths about the condition. Her visit was intended to assist the Government in combatting such misconceptions and ensuring strengthened protections and support for the enjoyment of human rights for persons with albinism, including through country-wide awareness and education on the issue and through policymaking.

## IV. Relevant international and national frameworks

14. Lesotho has ratified many of the main international human rights instruments, including the Convention on the Rights of Persons with Disabilities, 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, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.

15. In addition, Lesotho has ratified the International Labour Organization (ILO) Discrimination (Employment and Occupation) Convention, 1968 (No. 111); the ILO Employment Policy Convention, 1964 (No. 122); and the ILO Equal Remuneration Convention, 1951 (No. 100).

16. In the regional sphere, Lesotho signed the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa in February 2024. It has also ratified the African Charter on Human and Peoples' Rights, the African Charter on the Rights and Welfare of the Child and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.

17. The Constitution of Lesotho (1993) includes provisions relating to a range of human rights, pertaining to both civil and political rights and to economic, social and cultural rights. The Constitution contains key clauses on human rights protection, including the right to life, equality before the law, freedom of expression and right to personal liberty (chap. II, sect. 4) and freedom from torture (chap. II, sect. 8). The Constitution also outlines the protection of individuals against discrimination on the grounds of race, sex, ethnic origin, colour, language, religion, political or other opinion, national or social origin, property, birth or other status (chap. II, sect. 18).

18. In 2021, Lesotho adopted the Persons with Disability Equity Act, which defines disability in line with the Convention on the Rights of Persons with Disabilities. However, in a typical medical-model approach, this Act provides eligibility for disability grants as limited to persons with a "severe disability." Furthermore, the Act does not fully articulate all the rights in the Convention on the Rights of Persons with Disabilities and has some provisions, particularly in relation to employment, that could be problematic if not interpreted and implemented in line with the spirit of the Convention.

19. In terms of other relevant policies, the second National Strategic Development Plan, which has been extended to 2027–2028, aims to, inter alia, address poverty, social exclusion, unemployment and healthcare. In its overall vision and objections, the plan focuses on reducing poverty and inequality and improving human development indicators, including education, health and employment. The plan is also intended to align with regional and international frameworks within the Southern African Development Community and the Sustainable Development Goals.

20. The National Social Protection Strategy (2021–2031) is aimed at improving the social protection system in the country and ensuring that vulnerable groups have access to a range of services and support. Among its targeted beneficiaries are children, older persons, persons with disabilities and those affected by HIV/AIDS. It also covers health and education support, gender and social inclusion, employment and livelihoods and climate change. In terms of disability issues, under the strategy a pro-poor disability grant was launched.

21. Lesotho has an Education Act (2010) and an inclusive education policy (2018). In terms of education, the Education Sector Investment Plan (2020–2030), which outlines the

commitment of the Government to inclusive education, is aimed at strengthening the capacity of teachers, delivering inclusive education and ensuring accessibility to education. The Lesotho National Disability and Rehabilitation Policy (2009), which is specifically intended for learners with disabilities, aims to integrate children with disabilities into mainstream schools while providing specialized support.

22. The implementation of the Sustainable Development Goals in Lesotho has been a multifaceted process that involves multiple stakeholders. The process is centralized through the second National Strategic Development Plan and is meant to have a people-centred approach to development. All of the 17 Sustainable Development Goals are priorities for Lesotho, although the following are key focuses: poverty reduction (Goal 1), zero hunger (Goal 2), health and well-being (Goal 3), and quality education (Goal 4). Gender equality (Goal 5), clean water and sanitation (Goal 6) as well as climate action (Goal 13).[9] Identified challenges to the implementation of the Sustainable Development Goals include limited financial resources, high unemployment and poverty rates, climate vulnerability, gender inequality, social exclusion and inadequate infrastructure and service delivery.[10]

# V. Positive initiatives

23. The Independent Expert recognized and commended a series of positive initiatives undertaken by Lesotho that strengthen human rights protection for persons with albinism. She commended the signing of the African Protocol on the Rights of Persons with Disabilities in 224 and encouraged the alignment of governmental policies and initiatives with the Convention on the Rights of Persons with Disabilities. She acknowledged the adoption of the National Strategic Development Plan and the National Social Protection Strategy, which provide a series of positive measure relevant to persons with albinism. During International Human Rights Day in December 2023, the Government provided sunscreen for persons with albinism in Thaba-Tseka, which provided much-needed sun protection for many who would otherwise have not been able to afford or access sunscreen.

24. In terms of human rights institutions, the Independent Expert noted the initiative to establish a national human rights commission to further support the work of the existing Ombudsman. This is a welcome initiative.

25. Other seemingly small but still important initiatives include the provision of sunscreen through local civil society organizations that are in partnership with overseas organizations that provide needed materials for persons with albinism.

26. The Independent Expert acknowledges the many efforts, including through partnerships between the Government and international and national organizations, to improve the development in the country, including through the Sustainable Development Goals, the 2030 Agenda for Sustainable Development and leave no one behind programmes.

# VI. Challenges

## A. Absence of data and statistics

27. Data on people with albinism are needed in order to appropriately implement relevant policies and assess their impact. Without data, particularly disaggregated data, there is no certainty on the progress or lack thereof on the situation of persons in vulnerable situations, including persons with disabilities and, by connection, persons with albinism. Disaggregated data on persons with albinism are therefore essential in order to understand their specific needs and to target the specific support and services that they require. Such data also allow previously overlooked human rights situations to be addressed, whether on non-discrimination, inclusion, the need to raise awareness about albinism or the need for the

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[9] Sustainable Development Goals – United Nations in Lesotho, accessible at https://lesotho.un.org/en/sdgs.

[10] Ibid.

targeted allocation of resources, including budgetary resources, towards initiatives that can provide solutions, where needed. Disaggregated data can also assist in ensuring that persons with albinism are not marginalized or excluded.

28. Throughout her visit, the Independent Expert noted the lack of data collected on persons with albinism within the governmental sectors she met with; she considers that the lack of data results from the fact that albinism is not well understood or prioritized. She notes the importance of undertaking a comprehensive situational analysis on persons with albinism to support data collection.

29. The last census in Lesotho was held in 2016. From the estimates received by the Independent Expert, an unverified number of around 8,798 persons with albinism were said to be living in the country, with 2,583 in Maseru. The forthcoming census in 2026 will provide an opportunity to include specific and updated disaggregated data and statistics on persons with albinism throughout the country. The presence of the United Nations Population Fund (UNFPA) is an added advantage to data collection for the 2026 census, and partnership between the relevant governmental authorities, in particular between the Bureau of Statistics and UNFPA, is encouraged. The Independent Expert requested that a specific question on persons with albinism be included in the surveys for the 2026 census. While she refers to the Washington Group short set of questions on functioning as a useful tool, she observes that it may not be sufficient to effectively collect data on persons with albinism and that the inclusion of specific questions related to albinism can be a reference point for the gathering of information and data.

## B. Stigma and discrimination

30. Throughout her visit, the Independent Expert observed a prevalent presumption by various stakeholders that persons with albinism are treated “well” and are “just like everyone else” in Lesotho. This position is supported by referencing the lack of reported cases of ritual attacks and killings. The Independent Expert explained at various meetings that, although the absence of data on attacks and killings is indeed a positive marker, the lived reality of persons with albinism in Lesotho is far from “equal”.

31. Most persons with albinism recounted stories and experiences of stigma and discrimination, mostly due to ignorance about albinism or due to false beliefs about the condition. Existing myths include the notion that persons with albinism do not die, rather they just “disappear”, and that persons with albinism turn into donkeys after death. Other myths hold that: persons with albinism are supernatural beings; their presence is an omen of good luck; shaking the hand of a person with albinism is lucky; persons with albinism may be instrumental in healing diseases; and employing someone with albinism incurs good luck for a business. While some of these myths may appear to be positive, it is important to note that they all attribute supernatural powers to persons with albinism or their body parts. They are thus dehumanizing and have the potential to lead to more harmful practices.

32. In many anecdotes told to the Independent Expert, it was clear that forms of stigma and discrimination against persons with albinism are not always overt, they include microaggressions and incidents of marginalization. Persons with albinism had experiences of “othering”, in which they were treated as having lesser potential, value or worth. The name given to a person with albinism in Sesotho, “*lesoefe*”, can be problematic. While some note that this is merely the word for the condition, others informed the Independent Expert that the term can be derogatory as it objectifies a person with albinism, focusing on the condition rather than the person. Some interlocutors pointed out that in Sesotho words referring to persons start with the suffix “*mo*” and the use of a word starting with “*le*” illustrated such objectification.

33. Another name given to persons with albinism was “*makhooa*”, which is a reference to a white person. While this is not on its own a dehumanizing term, in Lesotho, where the vast majority of persons with albinism are racially black, the term denies their ethnic identity and “others” them, rendering them outsiders in their own communities. The Independent Expert reiterates that the inappropriate naming of persons with albinism results in labelling

and dehumanization and can easily become the basis for human rights abuses, including prompting attacks or even killings, as witnessed in other countries in the region.

34. Misconceptions and false beliefs have also impacted the experiences of mothers with albinism. Some mothers with albinism experience depression upon discovering that their child has albinism. Several mothers reported that they were abandoned by their spouse/partner, who refused to accept fathering a child with albinism. The Independent Expert met a number of single mothers raising children with albinism, often without sufficient financial means.

35. In schools, children with albinism experience bullying, microaggressions and "othering", whereby they are made to feel excluded or marginalized by both teachers and peers. Few learners receive any form of reasonable accommodation in class. These factors have contributed to high dropout rates for learners with albinism, particularly in secondary and tertiary education.

36. The Independent Expert further noted that a number of children with albinism have been abandoned and left to be cared for by grandparents or community members. In Leribè, a safe house for orphans provides shelter for a number of children with albinism who have been abandoned by their parents and families. When asked about adoption possibilities, the Independent Expert was told that it is harder for children with albinism to find adoptive homes, most likely due to their condition.

37. The Independent Expert was informed that there is a significant cost to providing for persons with albinism, particularly children, who were often seen as "expensive" to raise and care for. As a result of their special health needs, which can include the need for sunscreen and medical check-ups for visual impairment, the costs of meeting the needs for children with albinism were high compared to those of children without albinism. The associated costs of providing for someone with albinism often results in the abandonment of a child with albinism or raising such a child without the provision of the special requirements needed to support them.

38. The Independent Expert is concerned about the significant number of testimonies she received from persons with albinism on how often they have been the subject of ridicule, prejudice and discrimination. She emphasizes that stigma and discrimination often underpin other forms of human rights abuses that persons with albinism suffer. They are also the basis for attitudinal barriers that need to be tackled effectively to ensure persons with albinism have an opportunity to live with dignity and equality.

39. Many persons with albinism stated that the cumulative effect of negative attitudes and the social exclusion they feel affects their mental health. The Independent Expert notes that Lesotho has the legislative framework to protect persons with albinism against stigma and discrimination, that concerted efforts need to be taken to empower people with albinism to know and use their rights under law and that significant education and awareness initiatives are necessary to combat misbeliefs, ignorance and false narratives about albinism.

## C. Health

40. The National Health Strategic Plan (2017–2022)[11] included key health priorities and services for the country, including goals for universal health coverage, the provision of resources and services for marginalized and rural populations, maternal and child health, health education and promotion, mental health, non-communicable diseases, partnerships and international cooperation. All of these issues are relevant and important for the provision of much needed healthcare and support for persons with albinism.

41. With regard to non-communicable diseases, which include cancer, the overall health policy aims to prevent, control and manage non-communicable diseases through early detection and focus on lifestyle modifications. The policy is also used as a tool for implementing the Sustainable Development Goals, particularly Goal 3 on good health and

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[11] See https://www.childrenandaids.org/sites/default/files/2018-05/Lesotho_Nat%20Health%20Strat%20Plan_2017-2022.pdf.

well-being. Along with existing initiatives to help alleviate health challenges in the country, the needs and situation of persons with albinism remain invisible, although arguably they would be easy to address through the provision of sunscreen and regular screening and through education and awareness among health practitioners and service providers about albinism.

42. Many persons with albinism and their relatives consistently highlighted health challenges as being one of the most critical areas for persons with albinism. The risk of skin cancer is extremely high for persons with albinism, and the lack of access to visual aids, including spectacles, can seriously limit their quality of life. Skin cancer is the primary cause of death for persons with albinism in the region, rendering sunscreen an essential medicine, not a cosmetic product. The Independent Expert was informed, however, that the public health system in Lesotho does not provide sunscreen to prevent skin cancer. Rather, the provision of sunscreen is mainly done through the initiatives of civil society organizations who partner with overseas non-governmental organizations to obtain and distribute sunscreen, albeit to a limited number of persons with albinism throughout the country. In this regard, there are logistical challenges and resource constraints. Oftentimes, the distribution of sunscreen does not reach the most remote rural areas and the absence of data and statistics on persons with albinism do not allow for the distribution of sunscreen to reach those most in need. In general, the few civil society organizations that work on albinism have to collate their own data and information on persons with albinism and attempt to provide them with sunscreen, proving that a nationwide effort, centralized under the Ministry of Health, is needed to ensure better distribution and access. During her visit to Thaba-Tseka, the Independent Expert had to leave her vehicle and to walk up a mountain to reach a family consisting of two adult children with albinism and their mother. This was illustrative of the remote location of some persons with albinism. The family was unaware of the benefits of sunscreen and had never used it.

43. The Independent Expert has been informed that skin cancer in persons with albinism, although treatable, is often detected late for and can thus result in death. She highlighted that the provision of sunscreen is essential, not only to address a public health concern that affects a group of people in a vulnerable situation, but also from an economic standpoint. To provide sunscreen as an essential medicine and as a preventative means to stem skin cancer is a much cheaper and less financially onerous method of dealing with the disease, as opposed to the provision of specialist treatment (often overseas due to lack of specialization in country), including ongoing medical treatments and follow-up.

44. In her discussion with representatives from the Ministry of Health, the Independent Expert noted the need to include sunscreen, in particular to protect against ultraviolet A (UVA) and ultraviolet B (UVB) radiation and with a sun protection factor above 50 (SPF50+), in the national essential medicine list in order to facilitate the adequate supply and dissemination of this life-saving product to persons with albinism.

45. The lack of specialists for persons with albinism is a key concern. The Independent Expert was informed of the difficulties faced by persons with albinism who have to travel from all over the country to Maseru, where most specialists reside. The most needed specialists for persons with albinism are ophthalmologists, oncologists and dermatologists. The Independent Expert was informed that, as part of the public health services in Lesotho, there is only one ophthalmologist, no dermatologist and one oncologist for the whole country. There is clearly a need for more training and specialists working in these areas.

46. As a result of the lack of specialized services, many persons with albinism have few avenues to resort to when they require health services in the public sector. Almost all of those interviewed by the Independent Expert noted that they themselves have to come up with funds to get the assistance and resources they need. This includes access to specialized visual aid and obtaining spectacles. The Independent Expert is aware that, with the availability of only one ophthalmologist in the public health system, the services provided are generally to provide persons with albinism with needed prescriptions. Persons with albinism must obtain the spectacles they need from an optometrist, using their own funds. This almost always requires a referral for specialized assistance abroad, which, in the majority of cases, takes place in South Africa, which has an agreement with the Government to provide services to people from Lesotho.

47. Access to visual aids, including spectacles, is difficult due to high costs and the lack of specialists. The cost of spectacles can range from 3,500 rand to 14,000 rand (roughly $190 to $760), which is unaffordable for many. Many of those interviewed reported that they needed to factor in costs such as transport if they lived outside of Maseru and that, owing to severe visual impairment stemming from albinism, they special lenses are often required, the cost of which can be exorbitant.

48. The Independent Expert met with several individuals with albinism who seemed in need of medical assistance. She was deeply saddened to meet a person with albinism who suffered from a deformity on her face due to a reconstruction procedure in Bloemfontein following skin cancer that went wrong, leaving her in a painful state. She had received treatment for skin cancer on her face and subsequently required reconstructive surgery, which left her with a deformity. For seven years she has struggled to find out what caused the deformity and even at the time of her meeting with the Independent Expert, she was still waiting to obtain follow-up support to remove the swelling and the underlying cause of the large growth on her face. The individual in question was a widowed mother with albinism from Thaba-Tseka who was unemployed and heavily dependent on her sister, who was a domestic worker, to help provide for her. She was deeply depressed by the deformity; she is often ostracized or stared at in public spaces.

49. The impact of stigma and discrimination has led to psychosocial issues for persons with albinism. It is evident that there is a need to provide support for the mental health of persons with albinism as many experience depression and trauma due to discrimination and mistreatment. Some interlocutors expressed the need for counselling and highlighted that persons with albinism, particularly children and youth, are often lacking in self-esteem and confidence. The Independent Expert was not aware of specific psychosocial care being provided for persons with albinism although it was mentioned that such services exist in the health sector. The degree to which persons with albinism have access to such services, or to be aware of them, is likely to be very limited. As a result, many persons with albinism carry the burden of skin ailments, visual impairments and trauma. Depression was often cited as commonplace, not only for persons with albinism but also for their family members and caregivers.

50. In terms of neonatal and maternal care, it is evident that all health practitioners who meet persons with albinism need to be educated and to be fully aware of the scientific and biological cause and aspects of the condition. In several interviews, the Independent Expert was informed of the stigma and discrimination experienced by mothers of children with albinism after they delivered their babies. Healthcare providers often avoided assisting the mother and child. However, the Independent Expert was told of a number of positive experiences at Saint James hospital in Thaba-Tseka, where healthcare providers explained to mothers why their baby had albinism and encouraged them to provide maternal care and support to their babies. This is an essential practice; from the moment of the birth of a child with albinism, required immediate care should be provided, including ample information for parents and relatives to help them to understand the genetic source of albinism. With the provision of such treatment, from the outset, misconceptions about the condition can be dispelled and attention can be focused on support and care for the wellness of both mother and child. There have been various cases where psychosocial stress was exacerbated by the action of healthcare providers at the birth of a child with albinism; such negative actions need to be effectively addressed.

## D. Education

51. The inclusive education policy of Lesotho provides a good framework for the fulfilment of the right to education for persons with albinism. The overall policy was developed to ensure access to quality education in an inclusive environment for all learners, regardless of their abilities, background or disabilities. The key objective of the policy includes promotion of equity and inclusion, improving access to education, support for teachers, provision of resources (including assistive technologies and learning materials) and collaboration and partnerships pertaining to governmental departments, civil society organizations, communities and families to create a supportive network for education.

52. While these are noble aspirations, they are challenging to implement in Lesotho owing to several issues. The Independent Expert is aware that there are numerous challenges relating to inadequate resources and infrastructure; limited skilled and trained teachers; cultural attitudes and stigma in the sense of how communities view learners with disabilities; financial constraints, both for education institutions and for families of learners; limited awareness and advocacy for the needs and rights of learners; geographical barriers; and inadequate inclusive education services – all of which play a role in the inability of many learners with albinism to access and fully achieve an adequate education. These challenges worsen as learners enter secondary and tertiary education.

53. The Independent Expert met with senior officials of the Ministry of Education and the Lesotho College of Education who reported that there is a specific Special Education Unit within the Ministry of Education. However, even among representatives of that unit, there was not a lack of available data on learners with albinism. Furthermore, many of the interlocutors the Independent Expert spoke to were of the view that albinism is not a disability and therefore had not considered reasonable accommodations or assistive devices for those learners.

54. Access to education is extremely challenging for persons with albinism. There is a great need for reasonable accommodation for learners with albinism in schools, including the provision of assistive devices, large print documents, the placement of persons with albinism at the front of the classrooms and the provision of extra time for sitting exams. These accommodations are fairly easy to implement but are still not available in many cases, particularly in rural communities where teachers do not have an understanding of albinism. The Independent Expert was also concerned by reports that teachers also discriminate against persons with albinism, along with other students. She met persons with albinism who recounted stories of stigmatization by teachers in school. She also met many whose educational prospects were hindered by a lack of financial means or reasonable accommodation.

55. The Independent Expert visited two schools with learners with albinism, Saint Catherine’s School and the Saint Bernadette Resource Centre for the Blind. She spoke with learners with albinism at Saint Catherine’s school and was able to invite them to participate in the General Day of Discussion held at the forty-third ordinary session of the African Committee of Experts on the Rights and Welfare of the Child. While learners at the Saint Bernadette Resource Centre have access to assistive devices, including a magnifying machine for reading documents, which is not the case for the majority of students with albinism throughout the country, the students at the school still experienced challenges. Families of students with albinism at the school relied heavily on support in the form of education grants for low-income families provided by the Ministry of Social Development, which are meant to help subsidize educational costs for low-income families. The Independent Expert was told that one learner with albinism at Saint Catherine’s School was not in attendance owing to lack or late payment of school fees. Furthermore, access to sunscreen remained a challenge for learners at the school. One student informed the Independent Expert that she learned about the need for sunscreen from a television commercial and realized she needed sunscreen with SPF50+. She had concerns about skin lesions on her face due to lack of sun protection. She also mentioned she had not seen an ophthalmologist to address the type of visual aid she needed owing both to cost issues and a lack of awareness of how to access such a service by herself.

56. Learners with albinism often live in remote rural areas but need to travel to Maseru to attend better educational facilities involving financial costs for transport and travel. In other cases, the Independent Expert was told that parents of students with albinism often need to resort to private schools, in spite of high costs, in order to obtain proper support for their children. In various institutions, teachers were not fully trained to deal with learners with albinism and thus simple accommodations, such as placing students with albinism at the front of the classroom, were not implemented. In addition, teachers were not trained to address incidents of bullying and harassment against learners with albinism and, often, were also guilty of perpetuating the same discriminatory treatment to students with albinism.

57. There is a serious need to address holistically the educational needs of persons with albinism within the objectives outlined in the inclusive education policy. Resources need to

be allocated to ensure implementation of the policy under conditions where learners with albinism can also benefit.

58. The Independent Expert noticed that persons with albinism often rejected being identified as persons with a disability, stating that they were just as capable as anyone else and sought to disassociate themselves with the negative perception of disability. There is a need to combat the stigma associated with disability, in line with the provisions of the Convention on the Rights of Persons with Disabilities. This would require moving away from highly medical approaches to disability and embracing the human rights-based approach, using which focus and attention is placed on removing barriers that hinder persons from accessing services and rights on an equal basis with others. This is essential not only in education but in all spheres where the situation of persons with albinism are assessed.

## E. Employment

59. The inability of persons with albinism to finish their education results in difficulties in accessing adequate employment. The majority of persons with albinism who the Independent Expert met with were either self-employed or unemployed. They did not receive any government financial assistance and were often reliant on relatives and others for support. Poverty, which is often a reality for persons with albinism, affects their ability to access sunscreen, visual devices and much needed health services.

60. The Independent Expert notes that lack of access to employment was also due to employers discriminating against persons with albinism. In one case, a qualified person with albinism was asked whether her qualifications were indeed hers, implying that she was not capable of obtaining the credentials she had acquired at the time of her interview.

61. The Independent Expert was equally concerned that many persons with albinism have never had any ophthalmological care owing to financial constraints. Lack of ophthalmological care can be a critical determinant in whether a person with albinism can be successful in education, their ability to access gainful employment and other critical aspects of their life. As such, the provision of reasonable accommodation is essential to ensuring persons with albinism thrive in their workplace. The Independent Expert was informed of some positive cases where management was supportive of persons with albinism, and reasonable accommodation and support were given, allowing employees to perform well at their tasks. Such good practices need to be replicated in other workplace situations through education and employer awareness.

62. While the Persons with Disability Equity Act (2021) provides for equal opportunities in accessing employment for persons with disabilities, it prohibits discrimination in relation to recruitment processes and retention of employment and requires the provision of reasonable accommodation in the workplace. However, the Independent Expert noted with concern that the provision that effectively requires persons with disabilities to perform their “duties and responsibilities as competently as other employees” does not clarify how the assessment of competency is to be made and does not clearly link such an assessment to the requirement for employers to provide reasonable accommodation. The Independent Expert is concerned that such a provision could be detrimental to the rights of employees with disabilities if not interpreted and implemented in line with the spirit of the Convention on the Rights of Persons with Disabilities.

63. The Independent Expert notes that, under the second National Strategic Development Plan, access to employment opportunities is set specifically out for persons with disabilities. Reasonable accommodation is therefore encouraged where it refers to encouraging measures to make workplaces more accessible for those with disabilities so that they can fully participate in society.

## F. Social protection

64. The second National Strategic Development Plan provides the framework for social protection benefits, including for persons in vulnerable situations, including persons with

disabilities and albinism. There are provisions for pro-poor disability grants and the establishment of minimum quotas for the hiring of person with disabilities and a host of other programmes aimed at providing assistance to those deemed to be in vulnerable groups. The Ministry of Social Development is the key department overseeing the issue of social protection benefits.

65. In discussions with persons with albinism, it was clear to the Independent Expert that social protection benefits were generally inaccessible for persons with albinism. When assessing the various grants that could be provided to them, including due to visual impairment, which is also a disability, the Independent Expert found that many persons with albinism were ineligible to receive such support. Many were not aware that such support existed while others, who were aware, said they would receive the grants although sometimes inconsistently due to late or non-payment by the concerned ministry.

66. As in other parts of the world, the Independent Expert noted the existing common misunderstanding by stakeholders that persons with albinism are not considered to be persons with disabilities. As such, many would have not felt that they were eligible to request social protection benefits or other forms of benefits provided for persons with albinism. The Independent Expert explained that interaction between visual impairment and extreme susceptibility to skin cancer, combined with attitudinal and environmental barriers, can render a person as having a disability and therefore eligible to obtain social support. She again emphasized the need to move away from the medical approach to disability that can be a hindrance in obtaining much needed governmental benefits and subsidies. She also noted that mothers and grandmothers providing care for children with albinism are among those who are in dire need of government support and encouraged information sharing and awareness to be raised by the Ministry of Social Development in this regard.

67. Although the Independent Expert commends the adoption of the Persons with Disability Equity Act (2021), she notes that provisions for the eligibility for disability grants are based on persons having severe disabilities. This requirement, which renders many persons with albinism as ineligible to receive disability grants, is therefore of concern. The Act consists of other aspects that need to be revisited in order to bring them into better alignment with the Convention on the Rights of Persons with Disabilities.

68. The Independent Expert also notes the concerns about the establishment of the Disability Advisory Council, its composition and functions and the need to ensure that equal consideration is given to representatives of persons with disabilities, including those with albinism. She understands that, since the adoption of the Act, the Advisory Council has yet to meet, raising concerns that it is not ready to discuss and address certain issues relating to the Act.

## G. Remote rural areas

69. In her field visit to Thaba-Tseka, the Independent Expert experienced one of the most profound realizations concerning the vulnerability and invisibility experienced by persons with albinism in remote rural areas. She visited the village of Liponchong in the high mountainous terrain of Thaba-Tseka. The drive from Maseru to Thaba-Tseka took around three hours and, in order to reach Liponchong, the delegation needed to climb over a mountain on foot for around an hour. The village could not be reached by car and there were no public services in the village. In the home that the Independent Expert visited, the family relied on selling of a few agricultural goods and snacks for their livelihood.

70. The Independent Expert learned about the struggle of persons with albinism in Liponchong. Exclusion, marginalization and stigma were common in the village, as albinism was not understood in the community. The Independent Expert noted the importance of having a dialogue with the village leaders in order to ensure that they understood albinism and to encourage the full inclusion of persons with albinism.

71. Persons with albinism in remote areas do not have access to sunscreen and have never seen sunscreen products. Despite the distribution of sunscreen during Human Rights Day in 2023, the supply did not reach Liponchong. The Independent Expert noted the effects of sun

damage on the skin that were present in persons with albinism she spoke to, including apparent actinic keratosis, photoaging and precancerous skin lesions, as well as the absence of means to treat them. The nearest hospital was over an hour away, by foot, and many families lacked the funds to take public transport. Moreover, the nearest access point for public transport was far from the village. A young lady with albinism, who was pregnant, reported that she needed to walk by foot for two hours to get to nearest medical facility for her prenatal check-up.

72. In speaking to a group of mothers of children with albinism in Thaba-Tseka, the extreme difficulties of providing and maintain their livelihoods were emphasized repeatedly. Several of the mothers had been abandoned by their partners, who had left to work abroad in South Africa. Children with albinism, as young as six years old, particularly in rural areas, walked to school for an hour, risking both their personal safety and their health in the harsh sun. Some children had sunscreen protection while others could not afford to it. To access healthcare facilities required long travel. At school, there is severe lack of understanding about albinism and students with albinism often dropped out of school to work in outdoor jobs or became unemployed.

73. What the Independent Expert witnessed in Thaba-Tseka confirms that persons with albinism, particularly in rural areas, are among those furthest left behind. The marginalization experienced by people with albinism in Maseru was exacerbated in rural areas. In fact, while poverty seemed to affect many persons with albinism in Maseru owing to unemployment, poverty was more evident in rural communities where the risk of being forgotten is the harsh reality faced by persons with albinism. The Independent Expert urged the Government to ensure that persons with albinism in remote and rural areas obtain the support they need to live a more meaningful life.

## H. Raising awareness and representation

74. The Independent Expert underscores that albinism is still profoundly misunderstood in Lesotho and that the lack of knowledge about the condition has contributed to the myriad challenges and struggles that many persons with albinism experience. She emphasized the importance of establishing a robust nationwide programme to debunk myths and to educate and raise awareness about persons with albinism in order to effectively combat stigma, prejudice and discrimination. Such a programme could be in the form of a national action plan; in this regard, the Government and stakeholders can refer to countries in the region[12] that have adopted such policies as a means to tackle, holistically, the various challenges that persons with albinism face. Such awareness-raising programmes need to tackle ongoing issues until albinism is well understood and the marginalization and exclusion of persons with albinism are effectively addressed.

75. As part of a national action plan, the Government, in partnership with relevant stakeholders, including persons with albinism, should focus on nationwide campaigns and awareness-raising initiatives on albinism. Use of the human rights-based approach to providing solutions for persons with albinism can be aided through reference to the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2011–2031).

76. Commemoration of International Albinism Awareness Day (13 June) at the national, provincial and community level, which is important among albinism communities, will also help in eliminating misbeliefs and ignorance about albinism.

77. The Independent Expert was pleased to note that there are a number of high-profile and influential persons with albinism in Lesotho who have overcome extraordinary hurdles to succeed in various areas of influence. Among these are State representatives, members of the judiciary, academics and leaders of civil society organizations. While the presence of such high-profile individuals helps to demystify albinism, the Independent Expert is concerned that the challenges they have faced have been downplayed and their successes have been used to minimize the need for reasonable accommodation for persons with

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[12] Angola, Malawi, Mozambique, Uganda and the United Republic of Tanzania.

albinism in places of learning and workplaces. She was happy to have had an audience with the President of the Court of Appeal, Kananelo E. Mosito, a person with albinism himself, who recalled his challenges in his personal and professional journey. The Independent Expert emphasized the need for greater representation of persons with albinism in all spheres of society, not only to help in eliminating stigma and discrimination but to also increase awareness of albinism and the specific measures that must be taken to ensure an equal playing field in life for those with albinism. Many persons with albinism are extremely gifted, with great potential to excel in life, but their aspirations are cut short by discrimination and a lack of resources and support.

## I. Empowerment and capacity-building

78. The Independent Expert notes that there are three civil society organizations working on albinism, which are severely underresourced and mostly volunteer based. The Independent Expert emphasizes the importance of the provision of necessary resources by authorities, international organizations, donors and development partners, whether financial, technical or material, to the relevant civil service organizations that have the potential to make positive changes to the lives of persons with albinism in Lesotho. For such a relatively small population, any help and support provided by donors can go a long way to saving and improving the lives of people with albinism, in particular in remote and acutely vulnerable communities such as those in Thaba-Tseka. She further notes that persons with albinism can also directly benefit from the support given to programmes for persons with disabilities, including in the context of work carried out by the United Nations in Lesotho.

79. The Independent Expert stressed the importance of empowering, equipping and building the capacity of the above organizations, which provide key services to persons with albinism. She welcomes efforts by the Government, entities of the United Nations, development partners and the private sector to provide support, both in capacity-building and in resources, to these organizations as they are essential links to persons with albinism in the country.

80. The Independent Expert stands ready to provide support, including technical assistance, to address the various human rights challenges of persons with albinism in Lesotho.

## J. General Day of Discussion for children with albinism

81. The General Day of Discussion for children with albinism was held on 17 April 2024, during the forty-third ordinary session of the African Committee of Experts on the Rights and Welfare of the Child. The Independent Expert engaged in various panels and discussions to highlight the plight and human rights challenges of children with albinism. Participants were moved to tears when survivors of attacks in the United Republic of Tanzania spoke about their difficult and painful journey and the need for stronger accountability in the region with regard to grave human rights violations perpetrated against children with albinism.

82. An outcome statement[13] was issued at the end of the event, which acknowledged, at the outset, that children with albinism faced unique health, social and safety challenges that require urgent and tailored responses to ensure the full enjoyment of their human rights. Reference was made to, inter alia, the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031) policy and the Pan-African guidelines on the elimination of harmful practices related to accusations of witchcraft and ritual attacks; two key documents developed under the mandate of the Independent Expert.

83. The calls espoused in the outcome document of the forty-third ordinary session of the African Committee of Experts on the Rights and Welfare of the Child are relevant to the needs and assessment for persons with albinism in Lesotho, including the need to: develop

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[13] See https://www.acerwc.africa/en/article/activity/day-general-discussion-solutions-challenges-faced-children-albinism.

and implement comprehensive national strategies and action plans on albinism; allocate resources and funding to support programmes and initiatives on albinism, particularly with regard to access to healthcare, education and social services; and the need for further research and data collection on persons with albinism to better understand root causes to discrimination and violence.

84. The Independent Expert was able to invite and bring together children and young people with albinism from Maseru and from neighbouring African countries to participate in the event. The Independent Expert extends her gratitude to the African Albinism Network and the Piere Fabre Foundation for facilitating the participation of albinism leaders from across the continent at the Day of General Discussion.

## VII. Conclusion and recommendations

85. **Persons with albinism in Lesotho, in particular those living in remote rural areas, are among the most marginalized persons in society. While the Independent Expert commends the commitments made by the authorities under the international human rights treaties and agreements it has ratified, and the fact that she has not received cases of attacks and killings of persons with albinism in the country, she nonetheless, highlights the need to address the numerous challenges that exist for albinism communities.**

86. **Given the numerous challenges outlined by the Independent Expert in the present report, and the need to ensure that the authorities take specific steps to eliminate discrimination and strengthen human rights protection for persons with albinism, the Independent Expert makes the following recommendations:**

(a) **Legislation and policy**

(i) **Review and amend the Disability Equity Act (2021) to ensure that it aligns with the Convention on the Rights of Persons with Disabilities, including on the provisions of eligibility of persons with disabilities to the disability grant and other benefits and ensure it is interpreted and implemented in line with the spirit of the Convention;**

(ii) **Pass the law establishing a national human rights commission as a means to enforce the enjoyment of human rights for all, including persons with albinism;**

(iii) **Establish a task force comprising the key actors and entities identified to ensure coordination and cohesion in the work of the various ministries and departments for enhancing the realization of human rights for persons with albinism, including the right to health, education, employment and non-discrimination;**

(iv) **Support the aforementioned task force in the preparation and adoption of a national strategy or action plan on albinism, with reference to existing examples from countries in the region, including the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa as guidance on key areas of focus;**

(v) **Mainstream albinism into relevant national policies in line with the efforts to achieve the 2030 Agenda for Sustainable Development and the Sustainable Development Goals;**

(b) **Data**

(i) **Ensure the systematic collection of disaggregated data and include a question on albinism in the forthcoming census for 2026, in partnership with UNFPA;**

(ii) **Ensure appropriate information about persons with albinism in all data collected for persons with disabilities, which should be disaggregated;**

(iii) **Undertake a situational analysis to better understand the human rights challenges faced by persons with albinism, in particular in Lesotho, particularly in rural areas and among socioeconomically disadvantaged communities;**

(c) **Awareness-raising**

(i) **Carry out awareness-raising programmes on albinism throughout the country, in particular at the local and rural community levels; such programmes should include community initiatives and involve organizations representing persons with albinism and their family members at all stages of planning and implementation processes;**

(ii) **In collaboration with United Nations agencies, funds and programmes, as well as civil society organizations, use events such as International Albinism Awareness Day, on 13 June, Human Rights Day, on 10 December, and the International Day of Persons with Disabilities, on 3 December, to highlight the rights of persons with albinism and their family members;**

(d) **Health**

(i) **Ensure that sunscreen is included on the national list of essential medicines that are available and accessible;**

(ii) **Provide sunscreen through the public health system to ensure nation-wide distribution, particularly to remote rural areas;**

(iii) **Make quality health services available, affordable and accessible, including through sufficient numbers of specialized doctors, such as ophthalmologists, dermatologists, oncologists, paediatricians and psychologists, for rural areas;**

(iii) **Incorporate modules on persons with albinism, in particular in the fields of poor vision, skin cancer prevention and treatment, and psychosocial support, both for persons with albinism themselves and their family members, into training courses for healthcare professionals;**

(iv) **Ensure community outreach activities, including early intervention and preventative measures relating to skin cancer, for persons with albinism in local communities, in particular in rural areas and remote areas;**

(v) **Ensure access for low-income persons with albinism to government subsidies and financial support for visual devices;**

(vi) **Ensure sustainable and continuous support for all of the above-mentioned services;**

(e) **Education**

(i) **Integrate provisions for learners with albinism into inclusive education programmes to ensure that learners with albinism are well integrated in mainstream schools, in particular through the provision of reasonable accommodation, including assistive devices, including relevant training for educators;**

(ii) **Undertake a situational analysis and comprehensive mapping exercise of the experience of learners with albinism, including those who have dropped out of school, and take the necessary measures to ensure their reintegration into the formal school system;**

(iii) **Ensure that all schools, particularly in remote areas, are provided with reasonable accommodation and appropriate adaptive and assistive devices, such as monocular lenses and magnifiers, in order to accommodate the educational needs of all students with disabilities, including those with albinism;**

(iv) **Establish and implement policy guidelines for educators through a consultative process with learners with albinism, their guardians and representative organizations to ensure access to appropriate and timely**

**reasonable accommodations at places of learning for both the visual and skincare requirements of learners with albinism;**

(v) **Ensure that measures are established in learning institutions to prevent stigma, prejudice and bullying against learners with albinism and ensure that teachers address such behaviour;**

(vi) **Include albinism in education curricula, including subjects such as life skills, as way of raising awareness and enhancing the understating of albinism;**

(vii) **Carry out research into the assistive technology available in the region for persons with albinism, with a view to ensuring accessibility to such technology at all levels of education;**

(viii) **Equip and train teachers within the Special Education Unit in the implementation of their mandate and the provision of necessary support to students with albinism;**

(f) **Employment**

(i) **Ensure that all complaints of discrimination and unfair treatment of persons with albinism are investigated and that appropriate sanctions are administered;**

(ii) **Ensure that persons with albinism are provided with adaptive and assistive devices to facilitate their functioning in the workplace;**

(iii) **Ensure that the 2 per cent quota for the hiring of persons with disabilities in larger companies takes into account persons with albinism in positions that are suitable for them or for which they are competent;**

(iv) **Conduct widespread training on reasonable accommodation in the public and the private sectors, including for persons with albinism;**

(g) **Participation and representation**

(i) **Support the inclusion of persons with albinism and their representative organizations in relevant decision-making processes at all levels of government, including in public debates, including in the development of legislation, policy and programmes;**

(ii) **Provide support to initiatives and programmes on albinism organized by civil society organizations;**

(iii) **Strengthen public institutions responsible for formulating, implementing and assessing public policies from a human rights perspective, especially those seeking to protect the rights of the most marginalized groups and those in vulnerable situations;**

(iv) **Create an enabling environment for civil society organizations, including by ensuring their continued participation in forums, including in government settings;**

(h) **Accountability**

(i) **Support and strengthen the work of the Ombudsman's office in the protection of the rights of persons with disabilities, including persons with albinism;**

(ii) **Ensure albinism is covered in stakeholder reports to the international and regional human rights mechanisms, including treaty bodies and the universal periodic review process;**

(i) **Human rights mechanisms: implement all relevant recommendations made by United Nations human rights mechanisms, including by the Committee on the Rights of Persons with Disabilities, regarding the implementation of policies to address the multiple forms of discrimination against persons with albinism.**

87. **The Independent Expert recommends that the United Nations and the international community:**

(a) **Support and provide capacity-building and technical assistance for human rights work on albinism;**

(b) **Contribute to the development of research programmes and activities on albinism, in close coordination with local and international partners;**

(c) **Integrate support for persons with albinism into development and human rights programmes for persons with disabilities and other vulnerable and marginalized groups, as well as programmes for women and children where appropriate; such programmes should also seek to integrate support for parents, in particular mothers, of children with albinism;**

(d) **In line with the central pledge of the 2030 Agenda for Sustainable Development, namely to leave no one behind, reaching the furthest behind first, fully integrate the responses to issues faced by persons with albinism into United Nations programming through coordination with various United Nations agencies and programmes.**