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促进和保护所有人权——公民权利、政治权利、
经济、社会及文化权利，包括发展权

白化病患者享有人权问题独立专家访问莫桑比克的报告

秘书处的说明

白化病患者享有人权问题独立专家在其报告中，探讨了与莫桑比克白化病患者的权利有关的问题。根据她在访问前和访问期间收集的资料，独立专家侧重于最近袭击该国白化病患者的事件频发的情况下仍然存在的挑战。独立专家还讨论了影响白化病患者人权的问题，包括歧视、健康权和获得教育的机会。她强调了莫桑比克政府为解决其中一些问题所采取的重要步骤，并提出了一些建议，以期加强努力，缩小执行相关举措方面的差距，以及消除莫桑比克白化病患者在享有人权方面所面临的障碍。

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to Mozambique*

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* Circulated in the language of submission only.

I. Introduction

1. In accordance with her mandate under Human Rights Council resolution 28/6 and at the invitation of the Government of Mozambique, the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, conducted an official visit to Mozambique from 21 August to 3 September 2016. The objective of the visit was to make a full assessment of the human rights situation of persons with albinism throughout the country, with particular emphasis on the increasing reports of attacks against them.

2. The Independent Expert travelled to Maputo, Nampula and Beira. She met with the President of the Legislative Assembly, the Minister of Justice, Constitutional and Religious Affairs, the Minister of Foreign Affairs, the Vice-Minister of the Interior, the Deputy Attorney General, the President of the Supreme Court, the Ombudsman, the Chair of the National Human Rights Commission, the Permanent Secretary of the Ministry of Health, the Director of the Institute of Sociocultural Research (ARPAC), the Director of the Information Office (GABINFO), all members of the Multisectoral Commission mandated to address the issues faced by persons with albinism, provincial authorities in Nampula and Beira, and representatives of the police, judges and prosecutors overseeing cases of attacks against persons with albinism. The Independent Expert also had the opportunity to observe an ongoing trial concerning an attempt to sell the body parts of a person with albinism.

3. In addition, the Independent Expert met with various national and international civil society organizations in the field of human rights, as well as three civil society organizations dedicated to persons with albinism in Mozambique, Albimoz, Associação Defendendo os Nossos Direitos (ADoDs) and Amor e Vida. She also held several meetings with the National Association of Traditional Healers (AMETRAMO), various health practitioners at the Central Hospital of Maputo and teachers at the Josina Machel-Anchilo Inclusive Education Centre in Nampula.

4. The Independent Expert also held meetings with the United Nations country team in Mozambique, the heads of diplomatic resident missions in Mozambique and the donor community.

5. The Independent Expert expresses her sincere gratitude to the Government of Mozambique for its full cooperation. She is also grateful to all her interlocutors, especially persons with albinism who kindly shared their experiences and individual perspectives with her. She looks forward to fruitful and continued dialogue with the Government and other stakeholders on the implementation of the recommendations contained in the present report.

6. The visit of the Independent Expert was ably coordinated by the United Nations country team, in particular the Senior Human Rights Adviser, to whom the Independent Expert expresses her gratitude. She would also like to thank the Directorate of Human Rights and Citizenship of the Ministry of Justice, Constitutional and Religious Affairs for coordinating all official meetings.

II. Background

A. General overview

7. Mozambique stretches 12,470 km along Africa's south-east coast. Its neighbours are the United Republic of Tanzania to the north; Malawi, Zambia and Zimbabwe to the west; and South Africa and Swaziland to the south.

8. Mozambique gained its independence from Portugal on 25 June 1975 after 10 years of war. Its first President, Samora Machel, had been the head of the National Front for the Liberation of Mozambique (FRELIMO). Shortly after its independence, the country was plunged into a long and debilitating civil war between the Government, composed exclusively of FRELIMO, and the Mozambican National Resistance (RENAMO), which later became a political party. In 1992, two years after the adoption of a new Constitution, which guaranteed human rights, a ceasefire agreement was signed. That culminated in the country's first democratic elections in 1994, as a result of which RENAMO became the main opposition party. Recently, however, tensions resumed after RENAMO rejected the outcome of the 2014 legislative elections. Since September 2015, armed clashes between national security forces and members of RENAMO have been reported in various provinces including Tete, Sofala, Zambezia, Nampula, Niassa and Manica. Military operations were also conducted after RENAMO announced its intention to seize power in 6 of the country's 11 provinces. In this context, human rights violations and abuses, including cases of enforced disappearances and summary executions, have been reported.

9. Over 10,000 people have fled the insecurity and armed clashes in Mozambique. Since December 2015, Malawi has seen an increase in new arrivals from Mozambique, peaking at more than 250 people per day in early March 2016. According to the Office of the United Nations High Commissioner for Refugees, the numbers have since decreased significantly with many returnees settling into communities close to their area of origin.

10. While Mozambique had one of the world's highest economic growth rates in the late 1990s, its economic growth and performance have since decelerated. This is the result of several factors, including a drastic drop in the prices of natural resources on which the country depends. For example, in 2015, export prices for aluminium and coal decreased by 18 per cent and 12 per cent respectively. A decline in growth rates among the country's key trading partners also limited demand in export sectors at a time when low commodity prices were already causing a strain. Consequently, there has been a substantial decline in the growth of the extractive industry from 44 per cent in 2014 to 9 per cent in 2015. Further, according to the World Bank, in 2015, foreign direct investment fell by 24 per cent and exports declined by 14 per cent. Overall economic growth decreased from 6.3 per cent in 2015 to 3.7 per cent in 2016, the lowest since 2009.

11. Furthermore, the recently divulged scandal of secret loans undertaken by State-owned companies, combined with the impact of exchange rate depreciation, has led to a substantial increase in debt ratios, whereby the national debt constitutes about 86 per cent of the country's gross domestic product.

12. These causal factors have been exacerbated by natural disasters such as the 2015 flood in the southern districts followed by a countrywide drought, which seriously affected food security and potable water for thousands of people in the south and central regions of the country.

13. In addition, the country's rapid economic expansion over the past decades has had only a moderate impact on poverty reduction, and the geographical distribution of poverty remains largely unchanged by the economic growth spurts of the past decade. The 2015 Human Development Index puts the country near the bottom of its ranking (180th out of 188 countries and territories). The adult literacy rate is 56 per cent and average life expectancy at birth is 50.3 years. The 2016 Social Progress Index ranks Mozambique 117th and 127th regarding social progress and basic human needs respectively. Mozambique faces other challenges and malaria remains one of the most common causes of death. HIV prevalence, although decreasing, remains an issue of concern.

B. Persons with albinism

14. Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people worldwide regardless of ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in the skin, hair and eyes. Persons with albinism therefore often appear pale in comparison to members of their family and their communities. In order for a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance that a child will be born with albinism at each pregnancy. The frequency of albinism varies by region. In Europe and North America, the frequency reported is 1 in 17,000 to 1 in 20,000. The frequency in certain parts of the Pacific is reported to be 1 in 700. Among some indigenous groups in South America, the reported frequency is 1 in 70. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000 with prevalence rates of 1 in 1,000 for selected populations in southern Africa which encompasses Mozambique.

15. There are different types of albinism. The most common and visible type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type, subtypes reflect varying degrees of melanin deficiency in an individual. All human rights issues relating to albinism reported to date have been linked to its oculocutaneous form (which is also the most visible type of albinism). In the international human rights framework, persons with albinism have normative protection under the International Bill of Human Rights covering all their fundamental human rights including the rights to life, physical integrity, liberty and security, the highest attainable standard of physical and mental health and an adequate standard of living. Further protection can be found in the Convention on the Rights of Persons with Disabilities as well as the International Convention on the Elimination of All Forms of Racial Discrimination, which proscribes “racial discrimination” based on colour.

16. There is little information and data available on persons with albinism in Mozambique. In the absence of such data, civil society estimates that 20,000-30,000 persons with albinism live throughout the country.

III. Institutional and legal framework

17. Mozambique is a member of the United Nations, the African Union, the Commonwealth, the Southern Africa Development Community (SADC), the Community of Portuguese-speaking Countries and the Organization of Portuguese Speaking African Countries.

18. The Government of Mozambique is headed by President Filipe Nyusi. Administratively, the country is subdivided into 11 provinces. Each provincial government is headed by a governor and is charged with ensuring the implementation, at provincial level, of centrally defined government policies and the exercise of administrative supervision over local authorities. There are also elected provincial assemblies.

19. The legal system is based mainly on a civil law structure inherited from the Portuguese. However, legal pluralism also exists such that formal mechanisms of conflict resolution coexist with customary rules, provided that the latter do not contradict the values and principles enshrined in the Constitution. Regarding attacks against persons with albinism, however, the ordinary courts and tribunals are exclusively competent.

20. The Ministry of Justice, Constitutional and Religious Affairs is the main entity tasked with ensuring the enjoyment of human rights by persons with albinism. This is done through its Directorate of Human Rights and Citizenship. The Directorate is the driver of

initiatives to implement human rights in Mozambique. It does so through engagement with international organizations as well as by coordinating the Inter-Ministerial Working Group for Human Rights, which monitors and evaluates the implementation of recommendations of the universal periodical review. Despite its broad mandate, the Directorate is small and has few human and financial resources.

21. In addition, the Directorate coordinates the Multisectoral Commission whose main task is to ensure the full implementation of the Multisectoral Action Plan on Albinism, which was adopted on 24 November 2015 by the Council of Ministers. The Commission is composed of representatives of the Ministry of Justice, Constitutional and Religious Affairs, the Ministry of Health, the Ministry of Gender, Children and Social Action, the Ministry of Culture and Tourism, the Ministry of Internal Affairs, the Ministry of Education and Human Development, the Ministry of Science, Higher Education and Professional Training, the Ministry of Public Administration, the Ministry of Youth and Sports, Labour and Social Security, ARPAC, GABINFO, Eduardo Mondlane University, AMETRAMO and the three civil society associations Associação Defendendo os Nossos Direitos (ADoDs), Amor e Vida and Albimoz. Various members of the Commission have been active in implementing measures of the Action Plan. GABINFO, for example, has developed material, including community radio programmes, to raise awareness and share scientific information on albinism.

22. The judicial system has also been active in responding to the recent wave of attacks. The judiciary is headed by the Supreme Court, with national jurisdiction, composed of a president, a vice-president and a minimum of seven professional judges appointed by the President after consultation with the Superior Council of the Judiciary. The system comprises courts of appeal, provincial courts, and district courts.

23. Jurisdiction over attacks against persons with albinism lies mainly with the provincial courts. The judicial response of Mozambique to cases of attacks against persons with albinism is noteworthy, as Mozambique appears to have one of the highest number of cases on this matter that have been prosecuted in the region.

24. The police have also been instrumental in investigating such cases. The police forces have the role, in accordance with article 254 of the Constitution, of guaranteeing law and order and safeguarding the security of people and property, public peace, respect for the rule of democratic law and strict observance of the rights and freedoms of citizens. The police forces include the Protection Police, the Criminal Investigation Police and the Rapid Intervention Force. In addition, and as a means to increase good relationships with communities, community policing councils have been established across the country. The police in Mozambique are part of the Southern African Regional Police Chiefs Cooperation Organization.

25. The National Commission on Human Rights of Mozambique was established by law on 22 December 2009 and became operational in September 2012. It is headed by 11 commissioners. The National Commission on Human Rights is also the National Mechanism for the Prevention of Torture. It can receive individual complaints and release public statements. Despite the extent of its mandate, the Commission has been unable to conduct missions to evaluate the human rights situation of persons with albinism outside of Maputo, owing to limited resources. The Commission has, however, conducted an awareness-raising campaign and subsequently received complaints from persons with albinism regarding discrimination in access to education and in everyday life.

26. The Ombudsman was elected by the parliament in May 2012. His main duty is to ensure the protection and promotion of citizens' rights in the action of public servants and institutions. The Ombudsman receives funds from the State budget and human resource support is seconded to him from other government departments. He hears complaints and

receives petitions and makes specific recommendations to the department against which the complaints were made. However, as those departments are not bound by the recommendations of the Ombudsman, the impact of this mechanism remains weak.

27. The use of existing mechanisms serving vulnerable groups to address attacks against persons with albinism is to be commended. Of particular note is the use of reference groups. Reference groups were formed a few years ago at the provincial level to fight trafficking in persons, organs and body parts. Membership includes provincial entities, traditional authorities and members of civil society. With the increase in reports of attacks against persons with albinism, reference groups promptly incorporated the issue of kidnapping and trafficking of body parts of persons with albinism in their operations. Their method of work includes rapid information-sharing across their networks, alert systems and coordinated action. Further, reference groups make frequent use of media, particularly community radio, as a means of spreading useful information to the country's mostly rural population.

IV. Main findings and challenges

A. Attacks

Situation

28. Physical attacks against persons with albinism, including kidnapping and trafficking in body parts, have been reported in the majority of the provinces of Mozambique, although Zambezia seems particularly affected. Children seem to be the majority of victims of attacks, although adults are also targeted. Even after their death persons with albinism cannot rest in peace as their graves are pillaged and their bones stolen. Persons with albinism are therefore hunted from cradle to grave.

29. Cases have been reported in both rural and urban areas. It is also remarkable that while some cases may have a cross-border dimension, in the vast majority of cases reported there is no indication of an international dimension to the crimes committed. However, it should be noted that complete information on the overall chain of command for the commission of these crimes, including patterns of crime, actual amounts paid, details on end users and the masterminds behind them, remains lacking. Therefore, any conclusions drawn concerning this matter are at best a reasonable probability and not a certitude.

30. According to authorities, there was a sudden surge of physical attacks against persons with albinism, including kidnapping and trafficking in persons, at the end of 2014, which intensified until mid-2015. The Supreme Court reported that judicial action has been taken for 65 cases. At the peak of the attacks in 2015, the Independent Expert received reports from civil society of over a hundred attacks during this period. Yet there remains the possibility that the number is even higher, as there is no systematic mechanism to facilitate the monitoring and reporting of such cases. While 2016 has seen a relative decline in the number of reported attacks, the issue remains urgent as attacks have not ceased.

31. Reporting of cases is hampered by the remoteness of certain rural areas where attacks tend to occur. In addition, these are communities where discrimination against persons with albinism also tends to be relatively high owing to lack of knowledge about the condition and relatively low levels of education in general. The reporting of attacks is also hampered by the involvement of family members, friends and neighbours of victims. The secrecy that often surrounds the witchcraft practices that spur attacks and organized crimes of this nature are also barriers to reporting. Further, the remoteness of some communities from the provincial capital further complicates the reporting of cases, their investigation

and the implementation of protection measures for persons with albinism living in those areas. These challenges to adequate reporting remain issues of high concern for the Independent Expert and Mozambicans with albinism.

32. Real fear exists among persons with albinism across the country. The situation is aggravated by the fact that persons with albinism are ultimately unable to trust even those who are supposed to care for and protect them. In addition, given that persons with albinism are a relatively small group, an attack on one person in the community constitutes an attack on all. Further, victims of attacks and their families are deeply traumatized and in dire need of assistance in rebuilding their lives and restoring their dignity, including through access to judicial, psychosocial and socioeconomic assistance.

Multisectoral Action Plan

33. The government's response to the recent wave of attacks has been commendable. In particular, the Action Plan adopted on 24 November 2015 responds to the attacks with concrete, time-bound measures to be carried out in the short, medium and long terms. The Action Plan also identifies the actors responsible for each measure as well as a clear overall timetable for its implementation.

34. The Action Plan was established taking into account a preliminary socioanthropological study on albinism conducted by ARPAC. Its multisectoral structure involves nine ministries and two national institutes as well as various actors from both academia and civil society. The Action Plan seeks to promote education, information and awareness on albinism among families and communities; guarantee protection and social assistance to persons with albinism; ensure prevention of attacks, provision of legal assistance, procedural celerity and the sharing of information on judicial decisions; and conduct research such as socioanthropological studies to support evidence-based policy-making.

35. Further, the Action Plan incorporates a dual approach to the issue that is likely to be effective if fully implemented. The dual approach includes, on the one hand, an emergency and priority response in the area of protection and prevention regarding attacks and, on the other hand, aims to address, through policy, discrimination in the enjoyment of socioeconomic rights, disability rights, health rights and other human rights issues outside the context of attacks.

36. However, some aspects of the Action Plan should be strengthened to ensure its full implementation. A key issue in this regard is the absence of a specific budget. Currently, each sectoral entity has to allocate part of its budget to implement its designated role in the Action Plan. Consequently, the Action Plan competes with the other priorities of these entities. This is a serious issue that puts the full implementation of the Action Plan at stake in a context where immediate implementation is needed as a matter of urgency.

37. Another challenge to the effectiveness of the Action Plan is an apparent lack of collaborative engagement between the Multisectoral Commission and key human rights mechanisms such as the National Commission on Human Rights and the Office of the Ombudsman. It is also important to ensure that civil society, particularly organizations of persons with albinism, are encouraged to take part fully in the meetings of the Multisectoral Commission and in the implementation of measures. Similarly, the Action Plan would benefit from being closely associated, through mutual information and coordination, with the reference groups established at provincial level.

38. It is also important to ensure the wide dissemination of the Action Plan among State institutions and civil society organizations because, as the Independent Expert observed, authorities at the provincial level as well as key human rights organizations were sometimes unaware of it.

Judicial response

39. In 2014 the Government adopted the new Penal Code, replacing the previous code of 16 September 1886. The new Code provides the police and the judiciary with adequate tools to deal with the specificities of cases of attacks against persons with albinism. For example, the Code includes not only trafficking in persons and organs, usually included in trafficking laws, but also trafficking of body parts, often not directly covered by such legal frameworks. This enables the prosecution of cases of trafficking of body parts such as limbs, hair and skin which would not, *stricto sensu*, match the definition of organs but which are often hacked off, trafficked and sold in cases of attacks against persons with albinism. The Code also contains other relevant offences such as kidnapping, murder and grave tampering. It prescribes sentences that are generally viewed as proportionate to these crimes and judges have discretion to weigh in aggravating circumstances upon sentencing.

40. According to the Supreme Court, since 2014, 65 criminal cases have been initiated by district and provincial courts: 36 in the Province of Zambezia, 15 in Nampula, 4 in Tete, 4 in Cape Delgado, 3 in Sofala, 2 in Niassa and 1 in Inhambane. This is a relatively high number when compared with other States with similar situations. While more can be done to increase this number, the effort is commendable. The systematic prioritization of cases of attacks as recommended by guidelines from the Supreme Court, combined with proportionate sentencing and the publicity surrounding these cases, can reasonably be linked to the recent decline in the number of reported attacks.

Other challenges

41. Despite the successes achieved in Mozambique, the security of persons with albinism remains precarious owing to the underlying causes of attacks, which have yet to be fully uprooted. These include, first, the inability to find and arrest the masterminds who, authorities believe, operate in a secretive but powerful cross-border network akin to that of drug barons. To date, none of these people have been caught or prosecuted and perceived networks have yet to be identified. While there is a belief that the masterminds are from outside Mozambique, there are insufficient elements to support this assertion and until then, care should be taken in making such inferences so that xenophobia is not stoked, as the country welcomes refugees and migrants.

42. Identifying and addressing root causes of attacks remains a challenge. ARPAC confirmed that the findings of its preliminary socioanthropological study on albinism (yet to be shared with the Independent Expert) constitute only a first step in the process of understanding the situation, and that other complementary, in-depth research must be undertaken to fully understand all aspects of the phenomenon.

43. In her recent report to the General Assembly (A/71/255), the Independent Expert cited witchcraft as one of the root causes of attacks. She stated that attacks against persons with albinism were linked to the witchcraft-related belief that the body parts of persons with albinism could produce wealth and good luck when used in witchcraft potions, or could bring success in particular endeavours such as artisanal mining and fishing. It was for that reason that the remains of victims were often dismembered and body parts stolen, including limbs, genitals and hair, among others. In addition, it is reported in Mozambique that their faeces are collected to be used or sold for witchcraft rituals.

44. In theory, belief in witchcraft can be described as belief in a negative, malevolent force that can be used by people to explain misfortune, apportion blame and dialogue with real or perceived spirits to bring about harm in the physical realm. In practice, it is difficult to distinguish between the trade of witchcraft practitioners or witchdoctors, on the one hand, and the work of traditional healers, on the other. Despite the efforts of AMETRAMO to screen its members and ensure that they are traditional healers and that they do not

practise witchcraft, it appears that many practitioners of traditional medicine are not registered with the Association and that the organization lacks concrete mechanisms to ensure systematic follow-up and monitoring of its members. Further, it is clear — and AMETRAMO concurs — that advertisements in newspapers and radio purportedly posted by traditional healers that offer to make people richer, cure incurable diseases, get people out of prison and other apparently unreasonable goals pointing to witchcraft are not part of traditional medicine; such assertions should not be made by any registered traditional healer.

45. General poverty in society is another root cause. Poverty seriously threatens the progress made by the Government on this issue. With body parts of persons with albinism allegedly priced at millions to billions of meticaís, it is logical that the gullible would be attracted to attempt this macabre trade. It should, however, be stressed that the Independent Expert has never come across concrete evidence or a single case where money for body parts changed hands. It could therefore be the merely hypothetical possibility of earning money that leads some people to commit such attacks. However, as mentioned earlier, the exact structure of these crimes, including details of the profile of participants as well as details on financial incentives, are not fully understood.

46. The poverty of persons with albinism renders them extremely vulnerable to attacks. They tend to live in insecure homes and often cannot afford basic items for their protection such as mobile phones, which are particularly important as persons with albinism can use text messages to indicate their whereabouts. Similarly, owing to lack of resources, the graves of persons with albinism are often very simple, leaving them vulnerable to exhumation of bodies and theft of body parts.

B. Discrimination

47. The wave of attacks against persons with albinism highlights a pre-existing context of discrimination in the country. Discrimination against persons with albinism, even in its most extreme forms, is widespread and, far from being a new phenomenon, seems to be deeply rooted in a prevalent misunderstanding of albinism, which often takes the form of myths. According to these myths, people with albinism do not die but simply disappear; the birth of a child with albinism is a curse on the family or on the community; and the most dangerous: that their body parts can produce wealth and good luck when used in witchcraft potions. These myths also influence social behaviour towards persons with albinism and their family, in particular mothers of children born with albinism. Common behaviour includes spitting on the floor after seeing a person with albinism to avoid having children with albinism and refusing to shake hands with or touch persons with albinism to avoid perceived contagion. This illustrates the social exclusion that persons with albinism face every day. It was also reported to the Independent Expert during her visit that children with albinism, and their mothers, were frequently abandoned.

48. Persons with albinism are referred to as *fortuna*, *bolada* (lump sum, jackpot), or *riqueza*, in direct reference to the alleged value of their body parts. Discrimination also exposes persons with albinism to attack as they tend to consign themselves to self-isolation including by living far away from the community to protect themselves from abuse and mistreatment.

49. Discrimination affects persons with albinism throughout their lives and in all areas, including education, as well as access to opportunities in general. Mozambicans with albinism reported general difficulty in finding employment and the particular strain this has caused in the current economic context. From various parts of the country, they reported that although they were often called for employment interviews based on their applications, after a face-to-face meeting with the employer they were often not recommended for the

post. Mechanisms, including those of the National Human Rights Commission and the Office of the Ombudsman, should be promoted to ensure that such decisions are not taken on the basis of the appearance of persons with albinism. Efforts to raise awareness about these mechanisms among persons with albinism are also needed. Similarly, awareness must be raised about the quota established by labour laws, which state that 5 per cent of public sector employees should be persons with disabilities.

50. Persons with albinism are also among the poorest and are in dire need of support. They have been generally neglected and left out of human rights discourses and the services provided to various social groups. Even though the Action Plan is expected to rectify this situation, at the time of the visit the implementation of the Action Plan was generally still too weak and services appeared not to reach those who needed them the most.

51. While training to counter discrimination is necessary for all stakeholders working on this issue, including State actors, civil society organizations and the media, empowerment of persons with albinism is key. As persons with albinism stressed at a meeting with the Independent Expert, it is fundamental that they be able to “fully affirm their identity in society” without being belittled. The promotion of persons with albinism as role models is also particularly important to ensure their full integration.

52. Similarly, it is particularly important for the mothers of children with albinism to be empowered as they are the first line of defence for their child. While relatives of persons with albinism, including fathers, have been implicated in attacks, there are no reported cases involving the birth mothers of persons with albinism in Mozambique. Given the immense amount of familial pressure on mothers to abandon their children with albinism at birth, there is a need to support those mothers who have overcome this hurdle and continue to protect their children. Proactive awareness-raising targeting women in general to prepare them for the possibility of having a child with albinism could be a further measure of protection in this regard.

C. Health

53. The right to the enjoyment of the highest attainable standard of physical and mental health has been recognized in such instruments as the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights. This right encompasses specific entitlements including the right to an adequate system of health protection, the right to care in the prevention and treatment of illnesses, the right to access essential medicines and the provision of health-related education and information, as well as the participation of those concerned in health-related decisions.

54. Owing to the lack of melanin in persons with albinism, they are particularly vulnerable to skin cancer. In Mozambique, as in various countries of the region, skin cancer is a life-threatening condition for persons with albinism because there are few facilities for adequate medical interventions. Although no specific figures are available for Mozambique, statistics from other parts of Africa indicate that persons with albinism die early from skin cancer, specifically between the ages of 30 and 40. This means that cancer is likely to be the leading cause of death for persons with albinism.

55. In Mozambique, the health system is composed of public, for-profit private and non-profit private actors. The public sector is the main provider of services but the network covers only about 60 per cent of the population. The three regional central hospitals, in Maputo, Beira and Nampula, provide free dermatological and ophthalmological services. The health system also includes provincial hospitals, district hospitals, with limited access to surgery services, and local health centres.

56. The efforts made by the Government to ensure access to adequate and affordable health services for persons with albinism, including through free access to dermatological and ophthalmological services, constitute good practice. However, regional centres are not readily accessible, in terms of both cost and distance, to people living in rural and remote areas. It also appears that there is a lack of awareness of the existence of such services among persons with albinism, including organizations representing them. To improve service delivery, awareness-raising on the availability of services is key. Further, the use of mobile clinics to ensure that persons with albinism in remote areas can be screened on a regular basis for skin cancer is a best practice established in the region.

57. The addition of sunscreen to the list of essential medicines was a key step taken by the Government. The provision of such items of first necessity should be systematic and constant and should reach, through the existing health structure, all the local health centres at no cost to clients. Supply should be based on a needs assessment, and awareness-raising on this service should target persons with albinism and parents of children with albinism.

58. Lack of melanin in the eyes of persons with albinism results in high sensitivity to bright light and significant vision impairment. Vision impairment varies in severity from one person with albinism to another, often but not necessarily in proportion to the level of residual pigment. Free consultations with ophthalmologists, provided in Mozambique, are commendable. However, it is important to ensure that prescription glasses as well as low-vision devices are also made available at little or no cost to persons with albinism.

59. The Ministry of Health has a traditional medicine department that works closely with AMETRAMO. This department ensures the mutual exchange of knowledge between medical practitioners by documenting the practices of traditional healers, on the one hand, and training the Association's staff on basic medicine, on the other. Such training also seeks to facilitate referrals to hospitals where needed.

D. Education

60. The Committee on the Rights of Persons with Disabilities, in its general comment No. 4 (2016) on the right to inclusive education, stresses that the right to inclusive education encompasses a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to remove the barriers that impede that possibility. It involves strengthening the capacity of the education system to reach out to all learners. It focuses on the full and effective participation, accessibility, attendance and achievement of all students, especially those who, for different reasons, are excluded or at risk of being marginalized. Inclusion involves access to and progress in high-quality formal and informal education without discrimination. It seeks to enable communities, systems and structures to combat discrimination, including harmful stereotypes, recognize diversity, promote participation and overcome barriers to learning and participation for all by focusing on the well-being and success of students with disabilities.

61. Mozambique started its inclusive education programme in 1998 in five provinces, and a policy of inclusive education has also been included in subsequent strategic plans of education. However, the number of children with disability having access to inclusive education within the formal system is still limited. Consequently, in 2011, the Government decided to create three inclusive education centres, whose mission is to ensure access to education for diverse children, including those with special educational needs.

62. The Independent Expert welcomes the three inclusive education centres in Mozambique that can accommodate students, including students with special education

needs, in their boarding school facilities. She notes, however, that in Nampula, for example, the school is far from being at full capacity. Persons with albinism and the organizations working towards the realization of their rights seem for the most part to be unaware of the existence of the centres.

63. In addition, the implementation of the inclusive education programme faces major challenges throughout the country, among them lack of training among teachers on the concept of inclusive education, including on the special education needs of students with albinism. This is a major barrier because inclusive education goes beyond the establishment of specialized centres; it requires an in-depth transformation of the education system in legislation and policy, and also with regard to the mechanisms for the financing, administration, design, delivery and monitoring of education.

E. Participation

64. For initiatives to contribute effectively to the implementation of the rights of persons with albinism, all measures, including legislative initiatives, programmes and policies, must create space for the effective and meaningful participation of persons with albinism. From a human rights perspective, this is not only desirable in terms of ownership and sustainability, but is in itself a human right: the right to take part in public affairs.

65. It is important that in all actions and interventions on this issue, Government and all stakeholders should uphold the principle of “nothing about us without us” and involve organizations of persons with albinism at every step, where the process cannot be led directly by them. In this regard, the capacity of the three organizations working specifically on the rights of persons with albinism — Albimoz, Associação Defendendo os Nossos Direitos (ADoDs) and Amor e Vida — needs to be strengthened and adequately supported, at both the financial and the technical level. However, it is also important for these organizations, each having its own focus, to work together, as they did during the celebration of International Albinism Awareness Day on 13 June 2016 in Maputo.

66. In addition, persons with albinism and civil society organizations working on the rights of persons with albinism need to be informed in order to participate and benefit from ongoing initiatives. Meaningful participation can only take place if clear and comprehensive information on the different initiatives has been provided to the stakeholders. Similarly, once adopted, an initiative designed specifically for persons with albinism only becomes significant when it is used by those for whom it was designed, and this can happen only if information on the initiative is being systematically shared with the stakeholders.

F. International community

67. While the primary responsibility to promote and protect the rights of persons with albinism lies with the Government, a coordinated response requires the support of the international community, including development partners and civil society, which must integrate the issue into existing programmes while also developing particular measures.

68. The Independent Expert calls upon regional and subregional bodies to intensify cooperation to address attacks against persons with albinism and in particular to address possible cross-border elements of these attacks, including trafficking in persons and in body parts as well as extradition of alleged perpetrators. In this regard, it is worthy of note that Mozambique is a signatory to the SADC Protocol on Mutual Legal Assistance in Criminal Matters and various bilateral treaties. Mozambican police cooperate with the police forces of other countries, either directly or through the International Criminal Police Organization

(INTERPOL); border services agents also cooperate with the corresponding forces of Mozambique's six neighbouring countries. The Extradition Act 17/2011 may also be a tool for facilitating transnational efforts and cooperation.

69. The issue of attacks against persons with albinism is a regional issue, and it is therefore vital that States of the region cooperate intensively to share best practices, find the root causes and work closely on investigations of cases both within and across their borders.

V. Conclusion and recommendations

70. The situation of persons with albinism in Mozambique requires urgent and immediate attention. The response of the Government of Mozambique to the issue will be a real test of its commitment to the principle of leaving no one behind — starting with the furthest behind first — that underlies the 2030 Agenda for Sustainable Development and the Sustainable Development Goals, to which Mozambique committed. The cycle of violence, attacks and discrimination must be broken.

71. The initiatives taken by the Government to date are to be commended because they provide concrete measures on the issues faced by persons with albinism. It is however important to strengthen efforts, including by providing adequate resources, both human and financial, for the full implementation of the Multisectoral Action Plan and other ongoing measures in the fields of health services, prosecution, research and policy development. The momentum achieved by Mozambique should continue, even in the face of economic and political challenges. Given the relatively small number of Mozambicans with albinism, estimated to be in the tens of thousands, cost cannot be used as an excuse.

1. Competing priorities and the urgency of the human rights situation of Mozambicans with albinism

72. Mozambique is currently confronted by various challenging and pressing issues in the socioeconomic and political realms. In such a context, the issue of violent attacks and discrimination against persons with albinism faces a real risk of being ignored. Therefore, the Independent Expert strongly urges the Government to continue to make concerted efforts to ensure that this does not become the case. Efforts made by the Government after the attacks have started to bear fruit; interrupting them, including by delay or failing to allocate sufficient budgetary resources for the Action Plan, could lead to a resurgence of attacks, as the situation remains volatile. Further, the ongoing economic situation could encourage a resort to witchcraft, including the use of body parts of persons with albinism, and thereby increase the possibility of a resurgence of attacks.

2. Data collection

73. The availability of relevant data is fundamental to the building of effective policy and strategies to address the enjoyment of human rights by persons with albinism. In this regard, and given the current lack of data, the Independent Expert recommends that the Government of Mozambique:

- (a) Insert the variable of persons with albinism in the national census scheduled for 2017;
- (b) Ensure that all data collected relating to the situation of persons with albinism are disaggregated, at a minimum, by sex and age.

3. Research

74. The Independent Expert welcomes the decision to conduct a preliminary socioanthropological study on albinism, as well as further studies scheduled in the Action Plan. Investigative research is necessary to fully understand the phenomenon of attacks and its root causes. Such research would also benefit from a regional approach. The Independent Expert particularly stresses the importance of conducting research on patterns of trafficking of body parts, to determine whether there are international networks and to identify the masterminds at the root of the demand. She recommends that such research be undertaken urgently, and provided with adequate financial and human resources.

4. Multisectoral Action Plan

75. The Independent Expert commends the comprehensive Action Plan, particularly its substantive time-bound feature, its multisectoral strategy and its participatory approach. She also commends the dual approach of the Action Plan, which is designed to produce, on the one hand, an emergency and priority response to the attacks and, on the other hand, anticipates the development of policy to address the other human rights issues faced by persons with albinism.

76. The Independent Expert notes however that a major risk factor challenging the progress made by Mozambique on the issue of attacks against persons with albinism is the failure to fully implement the Action Plan. The Independent Expert therefore recommends that the Government:

- (a) Continue prioritizing the implementation of the Action Plan;
- (b) Ensure that a specific budget is earmarked for the implementation of the Action Plan, either within each of the participating entities, or directly attached to the Action Plan;
- (c) Increase the human and financial resources of the entity coordinating the Action Plan, including for building a monitoring, tracking and accountability mechanism, as well as for increasing the visibility of actions taken;
- (d) Ensure the participation of key human rights mechanisms in the implementation of the Action Plan such as the Office of the Ombudsman and the National Commission on Human Rights;
- (e) Facilitate the participation of civil society organizations of persons with albinism in the commission implementing the Action Plan. Given the long-term disenfranchisement of persons with albinism, the relative newness of their representative organizations and the need to build their capacity, there is a need for creative outreach to ensure their participation. Means such as WhatsApp groups and frequent SMS text messaging updates can prove helpful in this regard.

5. Strengthen other mechanism

77. Reference groups at provincial level have proven to be very useful in fighting attacks. The Independent Expert recommends that the Government strengthen such groups, and that they be involved in the implementation of the Action Plan.

78. The complaint mechanisms of the National Human Rights Commission and of the Ombudsman should be promoted to ensure that cases of discrimination against persons with albinism are reported and that adequate action is taken promptly.

79. The Government should also ensure that the National Human Rights Commission has the financial, human and material resources required to fully execute

its mandate effectively, on a fully independent basis and in accordance with the principles relating to the status of national institutions for the promotion and protection of human rights (the Paris Principles).

6. Cooperation and coordination

80. The Independent Expert was particularly surprised by the lack of awareness of the existing programmes and initiatives undertaken. The many initiatives taken at national and provincial level appear to be generally unknown among Mozambican authorities, including members of the Multisectoral Commission and the reference groups. For example, the reference groups and the member of the Multisectoral Commission whom the Independent Expert met had little knowledge of each other's efforts. Similarly, there appeared to be a lack of awareness of the services provided by regional hospitals. The Independent Expert stresses the importance of enhanced cooperation, coordination and information-sharing between the different entities to ensure complementarity. This includes the sharing of best practices for the strengthening of service delivery through simple technologies such as an e-mail listserv of all groups working for the promotion and protection of human rights of persons with albinism.

81. It is similarly and particularly important to ensure that persons with albinism and civil society organizations are aware of these initiatives, including with regard to attacks, health and education, where they are not directly involved in their implementation. The Independent Expert therefore recommends an active sharing of information on the different existing initiatives with persons with albinism, including through the use of community radio and TV broadcasts and basic technologies such as WhatsApp groups and SMS text messaging.

7. Witchcraft

82. The confusion between traditional healers and witchcraft practitioners is a factor that should be addressed because lack of clarity leaves witchcraft practice unchecked and exposes persons with albinism to attacks. Despite the efforts of AMETRAMO to dissuade its members from practising witchcraft, it is still difficult to distinguish between the practices of traditional healers and witchcraft practitioners in a significant number of cases. The Independent Expert therefore recommends ensuring enhanced oversight of traditional medicine practitioners by, for example, regulating their practice with legislation and a licensing regime, to ensure that their practice can be clearly differentiated from witchcraft. Such a Government-led monitoring mechanism should also include sanctions for non-registered practitioners. Given the existing cooperation between the Association and the Ministry of Health, such an oversight mechanism could be based within the Ministry.

83. Certain advertisements in newspapers and on the radio are obviously misleading and can also contribute to witchcraft and related practices. The Independent Expert recommends the regulation of obviously misleading advertisements in newspapers that promote witchcraft. She also recommends that AMETRAMO continue its awareness-raising activities by publicly denouncing practices that do not fall within the normal practice of traditional medicine and healing.

8. Poverty

84. General poverty in Mozambique, the attraction of the alleged market value of body parts of persons with albinism and the grinding poverty faced by most

Mozambicans with albinism renders them extremely vulnerable to attacks. The Independent Expert therefore urges the Government to:

(a) Continue to adopt measures to address poverty in the light of Agenda 2030 and to ensure that Mozambicans with albinism have full access to social welfare programmes and are included in all poverty reduction programmes;

(b) Ensure that the houses of persons with albinism are safe by providing community-based protection measures that should include structural reinforcement of their homes through the provision of doors and locks, as well as the provision of other basic security items such as mobile phones, torches and whistles.

9. Victim support

85. The Independent Expert recommends that the Government ensure the provision of psychosocial, medical and legal assistance to persons with albinism who are victims of attacks as well as to their families.

10. Discrimination

86. Discrimination against persons with albinism is a deep-rooted phenomenon in Mozambican society that affects them at every stage and in every aspect of their lives. The Independent Expert therefore recommends that the Government:

(a) Raise awareness on albinism to fight the rampant myths that result in discrimination and exclusion. Such a programme must be sustained for at least two years and must be wide-reaching, including rural and remote communities;

(b) Promote persons with albinism as role models. The Independent Expert would encourage the nomination of a person with albinism to a high-level position in Government;

(c) Consider the adoption of special measures, such as affirmative action measures in the field of employment, beginning with the implementation of the existing quota of 5 per cent of posts within the public sector reserved for persons with disabilities.

11. Health

87. The Independent Expert welcomes access to free dermatological and ophthalmological services provided by regional hospitals. However, she notes a lack of awareness of the existence of such services among persons with albinism as well as barriers to access to these services, particularly for persons with albinism in rural and remote areas. The Independent Expert recommends the use of models such as mobile clinics to ensure that persons with albinism in remote rural areas can be screened for skin cancer and vision needs on a regular basis.

88. The Independent Expert reiterates the importance of systematic and constant provision of items of first necessity such as sun protective clothing and sunscreen. She recommends that a permanent supply of sunscreen be made available, as it is already regarded as an essential medicine, and distributed throughout the country through existing networks of health services.

89. Further, the independent Expert recommends that prescription glasses as well as low-vision and adaptive devices be made available at little or no cost to persons with albinism in both urban and rural areas.

12. Education

90. The Independent Expert welcomes the policy of ensuring that schools are fully inclusive. She notes, however, that there are still challenges to its full implementation, and recommends an assessment of the current situation taking into account international standards, including general comment No. 4 (2016) of the Committee on the Rights of Persons with Disabilities. There remains a significant gap between truly inclusive education and the current situation in Mozambique, and a thorough transformation of the education system has yet to take place through full implementation of existing policies, adequate financing, the design of education material and training of teachers.

91. The Independent Expert recommends that the Government:

- (a) Ensure that information on existing education centres and inclusive education policies is widely disseminated;
- (b) Fully implements the inclusive education policy by providing adequate training and regular support to teachers on special education needs, including for children with albinism, who have been historically left out;
- (c) Ensure that low-vision devices and large print material are made available in all schools where they are needed.

13. Training and awareness-raising

92. The dissemination of accurate information on albinism, including existing initiatives and mechanisms for protection and enjoyment of human rights by persons with albinism, is fundamental to ending myths, witchcraft beliefs and practices, attacks and discrimination. To this end, the Independent Expert recommends that the Government:

- (a) Engage in widespread and strategic public awareness campaigns on albinism for a minimum of two years, engaging people at community level by using creative awareness-raising methodologies and relying on regional best practices such as the use of community radio, mobile cinema and village gatherings. The provision of resources to associations serving persons with albinism and other human rights organizations is necessary in this regard;
- (b) Train public officials at the national, regional and local levels, including members of law enforcement agencies, community police, the judiciary and the legislature, as well as traditional leaders and healers on the rights of persons with albinism;
- (c) Train health-care workers, community leaders and, in particular, persons with albinism themselves on the scientific explanations of albinism and their rights as citizens;
- (d) Train women in general as potential mothers of children with albinism. Such trainings should be integrated into ongoing programmes targeting women or through other specific programming.

14. Participation

93. Persons with albinism, as well as the three organizations working specifically on the rights of persons with albinism, should be involved in all initiatives on the principle of “nothing about us without us”. The Independent Expert recommends that the Government, and the international community in Mozambique, ensure the full participation of persons with albinism in all decisions and measures taken. In this

regard, the capacity of the organizations of persons with albinism in Mozambique needs to be strengthened and adequately supported, both at the financial and the technical level.

94. Similarly, the Independent Expert stresses the importance of complementarity among civil society organizations working for the protection and promotion of the human rights of persons with albinism, as they are working towards the same goals.

15. International cooperation

95. Many of the issues that Mozambique faces regarding persons with albinism are regional. Transnational cooperation, joint action and exchanges of best practices are therefore fundamental. The Independent Expert recommends strengthening international cooperation and collaboration to address the human rights challenges faced by persons with albinism, including by putting the issue on the agenda of regional and subregional meetings.

96. In addition, international development partners should support the efforts of the Government of Mozambique in addressing this urgent situation, including through financial and technical assistance for the full implementation of the Multisectoral Action Plan and other initiatives.
