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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

对马达加斯加的访问

白化病患者享有人权问题独立专家穆卢卡·安妮·米蒂—德拉蒙德的
报告* **

概要

在本报告中，白化病患者享有人权问题独立专家介绍了她于 2022 年 9 月 20 日至 30 日对马达加斯加正式访问的结果。独立专家介绍了当局针对白化病人采取的积极举措，与此同时，当局也在应对各种挑战，包括攻击、持续的恐惧和不安全以及对数据和统计数字的需求。她还强调，必须开展强有力的宣传活动，打击各种迷思和危险观念，实施促进和实现健康权、受教育权和就业权的举措。独立专家针对这些问题提出了一系列建议。

* 因提交方无法控制的情况，经协议，本报告迟于标准发布日期发布。

** 本报告概要以所有正式语文分发。报告正文附于概要之后，仅以提交语文和法文分发。



Annex

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

I. Introduction

1. Pursuant to Human Rights Council resolution 46/12, the Independent Expert on the enjoyment of human rights by persons with albinism undertook a visit to Madagascar from 20 to 30 September 2022. The Independent Expert wishes to thank the Government for its timely response in granting her the invitation to visit.
2. The Independent Expert held meetings with stakeholders in Antananarivo, Fort-Dauphin, Ambovombe and Amboasary Sud. She met with authorities in the capital and in the southern region, including representatives from the Ministry of Foreign Affairs, the Ministry of Justice, the Ministry of Defence, the Ministry of the Interior and Decentralization, the Ministry of Public Security, the Ministry of Population, Social Protection and Advancement of Women, the Ministry of Education and the Ministry of Public Health, and the President of the first instance court and the prosecutor of Fort-Dauphin. She also met with representatives of the National Institute of Statistics, the High Council for the Defence of Democracy and Rule of Law, and the technical committee on albinism (see para. 68). She met with a range of stakeholders, including members of civil society organizations and persons with albinism and their families. She also held meetings with individuals imprisoned in the Maison Centrale de Taolagnaro who had been convicted of crimes related to persons with albinism.
3. The Independent Expert particularly thanks the Ministry of Foreign Affairs and the Ministry of Justice for their support as the key government focal points for the visit. She is also grateful to the staff of the Resident Coordinator and the Senior Human Rights Adviser and her team, colleagues at UNICEF and the United Nations country team for their valuable support, both before and during her visit. She sincerely thanks all interlocutors who made the time and effort to meet with her, in particular persons with albinism, some of whom travelled long distances to share their stories and experiences.

II. Context

A. Urgent appeal

4. At the end of 2021, the Independent Expert received reports of attacks on and killings of persons with albinism, mostly children, in Madagascar. Prior to that, Madagascar had not been considered a country of concern where attacks were commonly reported. The Independent Expert continued to receive similar reports into the beginning of 2022, which prompted her to send an urgent appeal to the Government on 11 February and to issue a press statement on 28 February calling for stronger protection for persons with albinism. She sent a visit request to the Government on 8 March and met with representatives of the authorities in Geneva in person, and with the authorities, virtually, in May, to discuss her concerns and the possibility of an official visit. An official acceptance of the dates for the visit was received from the Government on 24 August 2022. The Independent Expert commends the Government, as well as the Senior Human Rights Adviser and her team, for their proactive engagement, which made the visit a reality in a relatively short span of time.

B. Background

5. Madagascar gained independence from France in 1960 and has a population of around 28 million people.¹ Following independence, the country experienced political instability, including a series of coups, which has affected the economy negatively. The previous elections were held in 2019 and the next are planned for 2023.

6. Development prospects in Madagascar continue to be challenged by exposure to frequent, deep and persistent crises.² In 2020 the country experienced a recession that was said to be three times deeper than that in the rest of sub-Saharan Africa.³ The coronavirus disease (COVID-19) pandemic reversed more than a decade of gains in income per capita for people and pushed poverty to a record high. Madagascar is one of the African countries most severely affected by climate change impacts. An extreme food shortage in southern Madagascar has been caused by persistent underdevelopment, lack of infrastructure and basic services, high levels of insecurity and several years of drought.

7. This food insecurity is worsened during the pre-harvest “lean season”, which arrived early during September to October, compounding the ongoing situation of extreme poverty that the people in the south of Madagascar experience. As at the time of the visit, around 8.8 million people across the country were living with food insecurity, 1 million more than three months prior to the visit. Further deterioration was expected in the southern region between December 2022 and March 2023, when more than 2 million people would likely experience high levels of acute food insecurity.⁴ In 2021, the southern region of Madagascar experienced its worst drought in 40 years, with more than 1 million people on the brink of famine and over 14,000 people living in famine-like conditions.⁵ The severe drought in southern Madagascar had a devastating impact on a wide range of human rights, including the rights to life, health, food, water and sanitation. Poverty affected every area of life for those in the most vulnerable situations in this region, including persons with albinism.

C. International and regional standards and the normative framework

8. Madagascar has ratified several key human rights treaties, including the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Rights of Persons with Disabilities. It has also ratified the first Optional Protocol to the International Covenant on Civil and Political Rights, allowing individuals to submit complaints against the State alleging violations of the Covenant.

9. Madagascar is a member of the African Union and the South African Development Community, and has ratified the African Charter on Human and Peoples’ Rights and the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa.

D. National legislation and policy framework

10. The Constitution provides protection for civil and political rights (art 7.), including the right to life and a prohibition on torture, cruel, inhuman or degrading treatment (art. 8). Economic, social and cultural rights are also protected, including the right to health (art. 19)

¹ See <https://www.instat.mg/> (accessed on 19 January 2023).

² See <https://documents.worldbank.org/en/publication/documents-reports/documentdetail/099452505272217360/idu063da38be0ec1a043a60b77f0e8c615d431fb>.

³ Ibid.

⁴ See <https://www.worldbank.org/en/country/madagascar/overview>.

⁵ See <https://www.amnesty.org/en/location/africa/southern-africa/madagascar/report-madagascar/>.

the right to education (arts. 23–24) and the right to be free of discrimination in the context of employment (art. 28).

11. The Penal Code of 2005 covers a number of crimes, including murder, torture (art. 303), violence and assault against a person, including mutilation and amputation (art. 309), intentional assault and battery, and kidnapping and abduction. Under the Penal Code, it is considered an offence when people use sorcerers or the *ody*⁶(relating to personal amulets believed to protect and allocate powers to the wearer) to influence the population.

12. Act No. 97-044 of 1998, on the rights of persons with disabilities, remains in force. A bill reforming the law is being drafted to bring the law into compliance with the Convention on the Rights of Persons with Disabilities. The National Disability Inclusion Plan (2015–2019) prompted activities to raise awareness about the rights of persons with disabilities.

13. Act No. 2007-023 of 2007 relates to the protection of the children and their rights. Act No. 2014-040 of 2015 was adopted to combat trafficking in persons and facilitated the establishment of a plan and a national office to combat trafficking.

14. Act No. 2014-007 of 2014 established the national human rights institution for the protection of human rights, which is also the national mechanism for the prevention of torture. Act No. 2015-001 of 2015 established the High Council for the Defence of Democracy and Rule of Law as an independent institution to monitor democracy, rule of law and the promotion and protection of human rights.

15. The National Strategy for Universal Health Coverage of 2015 is aimed at facilitating access to health services, alongside the national health-care solidarity fund, which helps provide members with basic health-care coverage.

16. The Education Sector Plan (2018–2022) is aimed at helping to increase access to education. The Plan has been extended for a further four years to help students access more years of compulsory education. Efforts have been made to provide free primary education under this plan.

17. The National Employment and Vocational Training Policy (2016) is focused on facilitating the development of skills among the population to help them find employment. The National Strategy for Social Protection is aimed at improving access for extremely poor or vulnerable members of the population to social services and benefits. The General State Policy (2019–2023) sets out development objectives covering 13 key areas, which include peace and security, combating corruption, education for all, health for all and decent work for all and food security.

E. Persons with albinism

18. Albinism is a relatively rare, non-contagious, genetically inherited group of conditions that affects people worldwide regardless of ethnicity or gender. It is the result of a significant deficit in the production of melanin and a consequent lack of pigmentation in the skin, hair and/or eyes. Most persons with albinism appear pale in comparison to members of their family or community. Albinism occurs in all racial and ethnic groups across the world, but the proportion of people affected by albinism in a given population varies by region. In Africa, the prevalence of albinism has been placed at ranging from 1 person in 5,000 to as low as 1 person in 15,000. However, recent population census data show that the prevalence has been severely underestimated in some cases. Data from a population census in one country in southern Africa suggested a prevalence as high as 1 in 130.⁷ Persons with albinism are also considered to be persons with disabilities, given their visual impairment and their susceptibility to skin cancer due to the lack of melanin.

⁶ Act No. 88-029 of 1988.

⁷ The 2018 population census of Malawi places the total population of persons with albinism at 134,636. With a total population of 17,563,749 in the country, this indicates that the incidence of albinism is about 1 in 130.

III. Main findings

A. Challenges

Data and statistics

19. The Independent Expert observed the absence of concrete data and statistics relating to persons with albinism. She was not able to obtain precise information on the population of persons with albinism nationwide, although she was able to receive some statistics on the number of persons with albinism in certain districts in the south where she visited. She highlighted the importance of gathering data to formulate policies and obtaining reliable information on the situation of persons with albinism and their needs. The 2018 national census did not sufficiently disaggregate data to enable an analysis of the population of persons with albinism in the country. However, in her meeting with the National Institute of Statistics, she was informed that a household survey on persons with disabilities was being planned, which is an opportunity to include a variable on albinism to obtain concrete data on the population of persons with albinism in the country.

Stigmatization and discrimination

20. Persons with albinism continue to suffer from stigmatization and discrimination in their communities, both in rural and urban settings. In the Malagasy language, persons with albinism are known as *varira* or *bobo*. They are often victims of social exclusion, bullying and marginalization. Their hypervisibility in their communities exacerbates the stigmatization and discrimination they face. Derogatory names used for them include *sira* (salt), due to colouring, *sova* (burned skin/burn scars) and *rajako* (monkey). While *varira* appears to be a neutral term, a young girl with albinism voiced her desire to do without that term and simply be called by her first name. Stigmatization and discrimination perpetuates the dehumanization of persons with albinism. Dehumanization, coupled with dangerous false beliefs, perpetuates harmful practices, including attacks. It is always easier to kill or mistreat a person if you believe they are not human, and persons with albinism are often victims of this perception.

21. A number of persons with albinism recounted to the Independent Expert their experiences in their family life, at school and at work, with a majority having suffered from prejudice or discrimination. In some cases, mothers who had given birth to children with albinism were abandoned by their partners in the misbelief that the mothers had been unfaithful. A number of persons with albinism find it difficult to have long-term romantic relationships due to stigmatization and a lack of understanding of albinism by partners/suitors.

Attacks

22. The Independent Expert was repeatedly informed that attacks against persons with albinism was a relatively new phenomenon in Madagascar, and that spikes in attacks had occurred only in the previous three years. She was also informed of prior incidents, including a case dating back to the 1990s, and incidents in 2013 and 2017. There may have been other cases in the past, but it is unlikely the victims would have been identified as persons with albinism.

23. Prior to the visit, the Independent Expert had seen reports of at least 25 cases of attacks against persons with albinism between February 2020 and the first week of September 2022. Information received from the gendarmerie indicates that in 2020 there were 10 reported attacks and 8 cases were reported in 2021. Between January and August 2022, 15 attacks were reported – almost double the total of the entire previous year. The majority of the attacks that were reported were in the southern region, where poverty is particularly acute. During her visit, the Independent Expert received reports of attacks in Ampanihy in the Atismo-Andrefana Region. While most attacks were reported in the south, one case was also reported in the north, in the Diana Region, giving rise to concerns of a replication of attacks in other parts of the country. However, it is noteworthy that some individuals indicated they were

aware of attacks having been perpetrated in the north in the years preceding the attacks in the south.

24. During the visit, the Independent Expert was also informed about 11 cases registered by the national police between 2021 and the end of March 2022, concerning mostly abductions targeting children. In one month alone in 2022, there were at least four attacks, further confirming the spike in attacks. It is possible that there are unreported cases, especially since many violations occur in remote areas where access to information is difficult. The Independent Expert obtained separate statistics from the gendarmerie and the national police, which the authorities stated did not overlap. The information provided did not include sufficient data to help the Independent Expert identify which cases related to information she had received prior to her visit. She underlines the need to better collate and track data on attacks against persons with albinism.

Profile of victims and perpetrators

25. The majority of attacks against persons with albinism were against children. Among the cases the Independent Expert is aware of, the youngest victim was around 9 months old while the oldest was 72 years old. Much of the information received contained references to children being targeted for their eyes. Some children had been abducted and kept alive while perpetrators searched for a “buyer”. Some children had been killed, and perpetrators had mutilated or dismembered their body with the intention of selling body parts to buyers.

26. In Amboasary Sud, which many interlocutors referred to as a hotspot for attacks against persons with albinism in the south, the Independent Expert was informed of three cases of attempted abductions of children. She also received information about two other cases in Ambovombe. A father of a daughter with albinism recounted how attackers had come in the night with knives and had taken his daughter. Similar stories were shared about attacks in the night where children had been taken; some had been found and returned safely to their families. Most victims were from very poor socioeconomic backgrounds and were living in remote areas in houses that were not properly secured. Both boys and girls have been targeted, as the main focus for perpetrators is the albinism. One case involved a young man who did not have oculocutaneous albinism (pale skin, eyes and hair), but rather ocular albinism, which mainly affects the eyes.

27. Profiles of reported attackers vary, and include relatives of victims, community members, persons who travelled from other regions, and *dahalos* (cattle raiders). Reports also highlight the involvement of people in influential positions as a possibility. Most perpetrators are acting with the intent of selling body parts or exploiting a person with albinism for financial means. In many cases, only the middleperson is caught, while the masterminds of the attacks remain unknown.

Root causes of attacks

Harmful practices related to false beliefs and superstition

28. Superstition and dangerous myths are central in the belief systems of many Malagasy. Harmful practices have included the killing of twins, who were seen as curses or as bringing bad luck to a family. In the same vein, persons with albinism, primarily children, are being targeted due to a severe lack of understanding about albinism as a condition.

29. One common dangerous belief is that the eyes of persons with albinism are powerful and can help in locating precious stones. Other beliefs include that the eyes of children with albinism are diamonds or sapphires. The Independent Expert met with a person supporting a child with albinism whose eyes had been extracted and taken by her attackers. Though she survived, she is severely affected psychologically and requires support.

30. The gendarmerie noted that attacks against persons with albinism often occurred in regions where there was a high rate of cattle theft and acts of banditry, mainly perpetrated by *dahalos*, and other crime. It was reported that some believed that the use of eyes of persons with albinism could help them evade detection. Such harmful practices and false beliefs provide fertile ground for attacks and inhumane treatment of persons with albinism. These myths have reportedly led to the trafficking of body parts and organs, not only of persons

with albinism but of others as well. Some reported that human sacrifice, prior to a new mining endeavour or a new project, was commonly used as a way of obtaining luck or good fortune.

31. Unique to Madagascar is that most attacks have focused on the extraction of the eyes of persons with albinism due to false beliefs that they can bring in money and also cause someone to be invisible. These false beliefs have spread dangerously as rumours from one district to another, triggering new cases. A number of interlocutors mentioned that such ritual attacks increased prior to elections, thus implying that those with influence or seeking influence are also engaged in these attacks.

Poverty, aggravated by climate change and lack of education

32. Poverty and lack of education were commonly cited as causes of attacks. A lack of education worsens the ignorance and misunderstanding around albinism. Poverty, particularly in the context of hunger and famine, can also fuel attacks. Many people who are desperate to survive resort to desperate means, including committing atrocities under the false belief that it will result in financial gain. Superstitious rumours about ways to obtain fortune are rife and have led to what some have called copycat attacks. Others mentioned that ideas spreading through social media from other parts of Africa have fuelled wrong beliefs about the body parts of persons with albinism as a source of financial gain. In the region where attacks occurred, the literacy rate is low and absenteeism from school high. Many adults there have not received primary education, let alone further studies. Combating harmful practices and dangerous myths thus requires a series of measures that also address the dire socioeconomic situation of the communities where attacks are reported.

Ongoing fear and insecurity

Shelters

33. Due to the increase in attacks, persons with albinism live in persistent fear. In some regions, parents of children with albinism have taken their children to boarding schools for the visually impaired and left them there for their protection. In one of the schools, the number of children with albinism seeking shelter increased over the past year to around 24, and gendarmerie agents were required to guard the school.

34. Some parents have been so worried about the safety of their children that they have chosen to leave them with the gendarmerie rather than take them home, where they were more vulnerable to attacks. The Independent Expert was aware of a shelter in the District of Betroka where the gendarmerie was sheltering six children with albinism. In some cases, wives of police and gendarmerie officers became the caregivers for children with albinism in shelters. A number of persons with albinism have requested the establishment of designated safe areas or shelters where persons with albinism can seek protection. The practice of seeking shelter with the local security forces was increasing, and one child with albinism was under the care of the governor of the region. Some young persons with albinism move to live with relatives in areas that are deemed safer.

35. In some cases, local community members have committed to protecting persons with albinism and have assisted the public security forces in that regard, but there are still grave concerns that these attacks will continue. The Independent Expert met with families and child survivors, and noted that they continued to suffer from psychological trauma and that they continued to need support.

New reports of attacks

36. During the preparation of the present report, the Independent Expert continued to receive alarming reports of attacks, including an attempted abduction of an infant with albinism in November in the Menabe Region. The kidnappers were confronted by the gendarmerie and the child is safe. Another incident, in Melaky Region, involved the kidnapping of a child with albinism near a mining quarry, raising concerns that the victim was to be used for human sacrifice. In another case, two men were arrested in the city of Morondava, also in Menabe Region, in possession of 30 eyes that had been extracted, representing at least 15 victims. Although the police report does not specify whether the

victims were persons with albinism, it is indicative of ritual attacks resulting from harmful myths. Also concerning is that those cases were in the west of the country, indicating that attacks are now happening in other parts of the country. The Independent Expert continues to highlight to the authorities the urgency of preventing such attacks.

Access to justice

Formal justice system

37. The authorities provided the Independent Expert with information on the number of arrests, detentions and prosecutions in cases related to attacks against persons with albinism. Most of the cases involved the abduction of children with albinism, possibly due to their increased vulnerability, although all persons with albinism are at risk. No information was provided on convictions of perpetrators in the cases involving mutilations and murders of persons with albinism. Case information provided by the authorities prior to the visit included the following:

(a) Four persons allegedly responsible for the attempted abduction and transfer of a minor child and an adult with albinism in the Districts of Ambovombe and Amboasary Sud had been arrested and the cases were being investigated by the Court of First Instance of Fort-Dauphin;

(b) Five people accused of an attempted transaction involving the transfer of a child with albinism to another person in the District of Fort-Dauphin on 1 November 2021 were tried on 1 February 2022. As a result of the trial, two people were sentenced to prison and a fine;

(c) Eight people involved in a case of an abduction of a child with albinism in the District of Amboasary Sud on 5 January 2021 were all placed under a committal order and tried on 10 August 2021; five were sentenced to a prison term, three were released;

(d) One person involved in a case of abduction of a child with albinism under 15 years of age in the district of Amboasary Sud in September 2021 had been arrested; the trial was under way;

(e) Four persons were involved in the abduction of a child with albinism under 15 years of age in the District of Fort-Dauphin on 30 October 2021; one person had been arrested and a search for the others was ongoing.

38. The Independent Expert also received the following information from officials in Fort-Dauphin:

(a) Five people allegedly responsible for the attempted abduction of a minor child with albinism under 15 years of age, and the attempted sale of an infant child with albinism and an adult with albinism, in November 2021 in the Maroalipoty in Ambovombe had been arrested and the cases were being investigated;

(b) Five people accused of an attempted transaction involving the transfer of a child with albinism to another person in the District of Taolagnaro on 1 November 2021 had been tried on 1 February 2022; as a result of the trial, two people were sentenced to prison and a fine;

(c) Eight people involved in a case of attempted abduction of a child with albinism in the District of Amboasary Sud on 5 January 2021 were all placed under a committal order and then tried on 10 August 2021; three were sentenced to 30 months of imprisonment, two were sentenced to 15 months of imprisonment and three were released;

(d) Two people, accused of the abduction of, and complicity to abduct, a child with albinism under 15 years of age in Manambaro in the District of Taolagnaro on 16 April 2022, had been arrested and were awaiting trial;

(e) Nine people, accused of the abduction of, and complicity to abduct, a child with albinism under 15 years of age in Sampona in the District of Amboasary Sud on 7 July 2022, had been arrested and were awaiting trial.

39. While two of the above cases appear to overlap, with slightly different details, three of the cases referred to by local authorities appear to be in addition to those referred to by the Government prior to the visit. The Independent Expert was unable to clarify the overlap of cases or obtain further information on the three cases reported by the Government prior to the visit that do not appear to have been included in the information she was given by local authorities during her visit.

40. The police and gendarmerie have been the key agents responding to attacks against persons with albinism. While the Independent Expert recognizes the efforts that security agents have made in the protection of persons with albinism and arrest of perpetrators, she is concerned that local communities often do not trust authorities to deal promptly and efficiently with their complaints.

41. The Independent Expert noted that the police and gendarmerie required more capacity and equipment in order to carry out effective investigations in such cases. While some officials stated that there was sufficient forensic investigation skills and capacity, others highlighted the lack of a fingerprint database, of forensic investigation laboratories and of qualified forensic pathologists in the country as obstacles. Many indicated that they relied on footprint tracking and catching individuals in the act to ensure convictions. One government official lamented that investigations were harder when suspects refused to confess. The Independent Expert is thus concerned about a reliance on confessions by accused persons rather than evidence obtained through proper investigations. In turn, prosecutions appear to be hampered by a lack of effective investigations.

42. While most interlocutors mentioned that the laws in Madagascar were sufficient to cover attacks against persons with albinism, few officials were able to identify the appropriate laws to be applied in such cases, including those related to trafficking. The Independent Expert is concerned that in the few cases that have been prosecuted, insufficient charges were laid, and lenient sanctions were imposed. The level of punishment in cases brought to her attention was as low as a 15-month suspended sentence and no higher than 30 months of imprisonment. Such sentences do not reflect the seriousness of attacks against persons with albinism.

43. The Independent Expert is further concerned about the lack of transparency in the processing of, and trials on, the cases of attacks against persons with albinism. While she received information about some trials, including in the aforementioned cases, most interlocutors outside of the justice system were of the strong opinion that very few cases brought to court had resulted in a satisfactory outcome. Consequently, there is a growing perception that justice is not being done on behalf of the victims and the relevant communities.

44. The Independent Expert was informed that there have been convictions in only 2 of the 11 cases registered by the police and the 33 cases registered by the gendarmerie. The accused in the majority of the cases throughout the country therefore remain unprosecuted. The Independent Expert spoke to persons accused of crimes related to albinism and noted that many were being held in pretrial detention and did not appear to be fully aware of the charges brought against them. Most stated that they had not seen a lawyer since their detention and did not recall if they had one. Due process procedures must be followed and cases properly investigated to facilitate the identification and prosecution of the authors of the attacks. A failure to ensure due process may result in the wrong persons being prosecuted, while the actual perpetrators continue to carry out attacks. The Independent Expert also cautioned against the use of social media by some authorities to announce the arrest and capture of “perpetrators”, which can undermine the justice process, particularly the presumption of innocence for those arrested. She emphasized the need to communicate the outcomes of trials to the victims and their families, and the general public, which can help in avoiding mob justice.

Traditional justice system

45. The Independent Expert was also told that, particularly in the south, many families of victims preferred to seek reparations and sanctions through the *dina* (traditional justice system) because they believed doing so would provide them with tangible results. Although

victims can have recourse to both the traditional and the formal justice systems simultaneously, many preferred the former, stating that they did not have faith in the latter.

46. The Independent Expert notes that the *dina* process must be approved by the court before the conditions can be enforced. There are concerns that community leaders within the *dina* are not trained in or aware of human rights principles and thus can implement decisions that may be arbitrary or unjust. A *dina* process that has not been carried out in accordance with principles of human rights can fuel or lead to mob justice. Cooperation between the formal justice system and the *dina* needs to be strengthened, and the latter process should ideally be applied only to civil cases, leaving criminal cases to be addressed primarily within the formal justice system.

Violence in Ikongo

47. The Independent Expert's visit almost coincided with the outbreak of violence related to the abduction and murder of a child with albinism in the town of Ikongo in the southeast of the country. Community members, including relatives of the victim, confronted the local gendarmerie in their quest to find answers, which led to violence – over 20 community members were killed. The individuals had apparently tried to enter the premises where the accused men were being held, and the gendarmerie had fired at the crowd. The tragedy further highlighted the principle that justice must not only be done but must also be seen to be done, as family members of victims often take matters into their hands. Clear communication must be adopted by security authorities to engage with the public or with local communities to address their concerns, as such communication can deter mob justice.

48. The incident also highlighted the difficult relationship communities sometimes have with the authorities, particularly in the gendarmerie, which is primarily responsible for security in the rural areas. The Independent Expert notes that commendable efforts have been made by both the gendarmerie and the police in providing protection to persons with albinism, for example by keeping a record of their presence in order to facilitate a quick response should they require assistance. Many officers are working together with community members to support and protect those with albinism in their communities. However, there have been reports of abuse and ill-treatment at the hands of gendarmerie officers, and a lack of effective responses to requests for help. The relationship between gendarmerie and the police can also be strained at times, thus hampering efforts to bring perpetrators to justice. The Independent Expert notes the need for more coherence between these two departments in their work, and also notes the important role the Ministry of the Interior plays in coordinating the cooperation of these agents, particularly within the Organisme Mixte de Conception (security taskforce), which include representatives from the Ministry of Defence, the Ministry of the Interior and Decentralization, the Ministry of Public Security, and the State Secretary of the National Gendarmerie. The Independent Expert remains interested in being informed of the findings of the investigation on Ikongo, particularly regarding the child victim and the follow-up to the case.

Persons with disabilities

49. The National Disability Inclusion Plan of 2015 sets out development goals for persons with disabilities in the country. The Ministry of Population, Social Protection and Advancement of Women is the key focal point for disability in the Government. According to information received by the Independent Expert, resources are still needed to support activities under the Plan.

50. By law, persons with disabilities are entitled to receive health care, education and access to training and employment on an equal basis with others, although in practice these services are limited. The Independent Expert was informed that efforts were being made to bring laws on disabilities into line with the Convention on the Rights of Persons with Disabilities, which would positively affect the rights of persons with albinism.

Education

51. The Constitution provides for tuition-free public education for all children who are citizens, and makes education until the age of 16 compulsory. Educational institutions should

be encouraged to make the infrastructure adjustments necessary to accommodate students with disabilities. The law also specifies that the State must facilitate, to the extent possible, access to its facilities, public spaces and public transportation to accommodate persons with disabilities. However, access to quality education is still a challenge in Madagascar, and persons with disabilities continue to be among those who do not have such access. Access to education for persons with disabilities was limited due to a lack of adequate infrastructure, specialized institutions and personnel. Few schools had staff with the skills and training to accommodate learners with disabilities, a matter that was raised in May during a workshop organized by a non-governmental organization working in the area of the rights of persons with disabilities.

52. The limited, or absence of, access to quality education is most evident in the south of the country, where the Independent Expert visited and where the illiteracy rate was said to be among the highest in the country. Some villages were three to four hours' walking distance from the next village. It was generally known that absenteeism in schools was common among the general population and that the rate was even higher among children with disabilities.

53. In the communities the Independent Expert visited, many persons with albinism cannot attend school due to fear of attacks. Persons with albinism indicated that in many cases schools allowed them to sit in the front of the class to see the blackboard. Apart from that, reasonable accommodation in schools is mostly non-existent. Many are not able to obtain proper glasses and had no knowledge of, let alone access to, even the most basic assistive devices, such as magnifying glasses and monocular glasses. The Independent Expert met a single mother of a young girl with albinism in Ambovombe who had to have a desk built at her own cost, to enable her child to see the blackboard better. The mother barely had the resources to do this.

54. In both rural and urban settings, learners with albinism faced discrimination regularly. During the visit, local media covered the story of a student with albinism who had been rejected by a private school in Talatamaty owing to the school officials' belief that his presence would damage the school's reputation. In addition, according to reports, parents of students at the school were afraid that albinism was contagious. This case is a clear example of the many challenges learners with albinism face in trying to access education. Through advocacy, including from the association of persons with albinism in the country, the rejected student was able to attend another school.

55. The Independent Expert notes that there are no specific policies in schools to assist learners with albinism, although she is aware of the discussions around a policy for students with disabilities within the Ministry of Education. She met parents of children with albinism who were desperately asking for assistance to educate their children, as they could not afford to do so. In other cases, where parents could afford an education, children had been prevented from attending school owing to fear of attacks. Many must walk long distances to get to school, increasing their vulnerability to attacks, sunburn and skin cancer. Teachers were not properly trained in fulfilling the special requirements of persons with albinism, such as by providing text in large fonts, seating them near the blackboard, or away from the windows to avoid the harsh sunlight, and allowing students with albinism to wear hats and sunglasses. These are easily achievable measures that can go a long way in providing learners with albinism better access to proper education.

56. While the Independent Expert's focus is on persons with albinism, she recognizes that the overarching challenge in relation to education continues to be the provision of free primary education and ensuring access thereto in remote regions. This situation affects all children in those areas, although children with albinism are disproportionately affected. Ensuring access to education will help to empower many learners and help them to break out of the grip of poverty that is seen in many communities. Socioeconomic inequalities in the country are closely linked to inequality in education. Persons with albinism, as constituents of persons with disabilities, should be guaranteed effective access to free education in accordance with the Constitution and without discrimination.

57. The Independent Expert met with persons with albinism in the capital who had been able to successfully complete postgraduate degrees in various fields, but not without many

challenges. They cited the support of family members as crucial in providing them with the motivation and assistance necessary to get through the various stages of their education.

Health

58. Although the Government has taken some steps to provide health care, including free health care for children under the age of 5 and persons over the age of 65, access to quality health care and facilities is still a challenge for persons with albinism. Over 60 per cent of the population is said to live more than 5 kilometres from a health centre, often in remote and difficult-to-reach areas without roads or communications.⁸ Unequal distribution and lack of quality health infrastructure were also common challenges, especially in remote areas. In her discussion with representatives of the Ministry of Health, the Independent Expert noted the need for the Ministry to ensure that more information about albinism is disseminated within the Ministry, among health-care workers and through media and awareness-raising programmes. Educating the public on the science around albinism will help dispel the myths about it being a supernatural condition. As was done in campaigns that debunked myths and combated stigmatization around HIV/AIDS, the Ministry of Health needs to work closely with key partners to regularly combat the wrong beliefs about albinism while raising awareness about the need for sunscreen and providing this product as an essential medicine. Education on albinism can also be a focus in postnatal services from the moment a child with albinism is born, and in support given to mothers and families who need to understand the genetic origin of the condition.

59. Skin cancer is the most common cause of death among persons with albinism in countries that have tropical and hot climates. Access to proper sunscreen with the right sun protection factor is life-saving. However, such access is difficult for persons with albinism in the country. The Independent Expert met with persons with albinism in the south who had never used sunscreen, as it was too expensive. One person stated that he was waiting to receive test results for a lesion he had due to sun exposure. Many persons with albinism are likely in the same situation.

60. The Independent Expert was informed that medical specialists, such as dermatologists, were not available in many districts, particularly in rural areas. She was informed that there were around three specialists in dermatology servicing the whole country. Accessing screening for skin cancer and specialist consultations were also too costly for many. A general check-up can cost 20,000 ariary (almost \$5) – prohibitively expensive for many people with albinism in the communities visited. Access to ophthalmologists is equally important, and persons with albinism in the south often have to travel to Antananarivo to see a specialist and obtain the lenses they need.

61. In terms of psychological support, the Independent Expert noted the lack of services provided for persons with albinism. Many persons with albinism described their struggles, and their need for mental health support owing to discrimination and a persistent fear of attacks and violence. Provision of this support is essential, particularly for survivors of attacks and those trying to overcome trauma, but access continues to be a challenge.

Employment and livelihood

62. The National Strategy for Social Protection is aimed at providing support to the most vulnerable groups, including those in extreme poverty. The Independent Expert however notes that such support is yet to be the reality for many, including persons with albinism.

63. The Independent Expert met with persons with albinism with a diverse range of educational backgrounds. Some had university degrees, including at the postgraduate level, in fields such as law, medicine and management, while others barely had a primary education. However, regardless of their educational background, all still faced considerable obstacles in accessing gainful employment that could provide a decent standard of living. Employment opportunities are particularly scarce in the south. The Independent Expert further notes that

⁸ See <https://www.usaid.gov/madagascar/global-health>.

in some communities, parents of children with albinism cannot work because they need to remain at home and protect their children from potential attacks.

64. The most educated persons with albinism face tremendous challenges in gaining employment. A doctor with albinism recalled how when he advertised his services with his photograph, no potential patients contacted him. When he re-advertised without his photograph, he received phone calls from interested patients. A young woman with albinism who had completed a law degree described how she had been given employment, but at a salary lower than that of her peers in the same position. She was bullied at work and told that her presence was a liability for the company. She later left the company due to the bullying. The Independent Expert is aware of a number of persons with albinism who have persevered and obtained education qualifications against near impossible odds, only to be overlooked or rejected when seeking employment.

65. During her interaction with civil society members, the Independent Expert was pleased to see interest expressed by local labour unions that were willing to advocate for persons with albinism who were wrongfully turned away from gainful employment. More action is needed, however, to eliminate the barriers created by stigmatization and discrimination, as well as economic barriers to education that prevent persons with albinism from securing a sustainable livelihood. Many persons with albinism must take jobs that require them to labour outside, exposing them to harsh sun rays that can lead to skin cancer. Furthermore, reasonable accommodation in the workplace is not commonly provided where persons with albinism have been employed. Such accommodations are necessary to level the professional playing field. Measures should be taken to encourage the recruitment of persons with disabilities in the public and private sectors.

Representation, and the need for ongoing public awareness and education

66. Addressing stigmatization and discrimination requires not only awareness-raising, but also ensuring that persons with albinism are given positions of influence and visibility to ensure more positive role models, particularly for young people and children to look up to. Aside from a young singer with albinism who is known in the country, few persons with albinism occupy positions of influence in State institutions, in the private sector or as public figures. Commemorating International Albinism Awareness Day (13 June) annually, bringing together persons with albinism, provides an opportunity to highlight persons with albinism as a way to inspire others and tackle harmful myths about the condition.

67. In the discussions held by the Independent Expert with stakeholders, she noted with urgency that education and awareness-raising on albinism, involving all stakeholders in society, needed to be a priority. It was evident that misunderstanding of albinism was rife and that wrong beliefs were held not only by perpetrators but by some stakeholders with whom she met, including civil society organizations. Increasing understanding of albinism and sharing correct information on the condition is a responsibility for all stakeholders and can lead to the changing and shifting of mindsets.

B. Positive initiatives

68. Having highlighted the challenges of persons with albinism, the Independent Expert notes that a number of positive initiatives have been undertaken by the Government and stakeholders. Among the most notable is the steps taken to form a technical committee on albinism, comprising representatives from the United Nations (the Senior Human Rights Adviser in Madagascar and the United Nations Children's Fund (UNICEF)), the Ministry of Justice, the Ministry of Population, Social Protection and Advancement of Women, the Ministry of Defence, the gendarmerie, the national human rights institution, the office of the ombudsman and associations of persons with albinism, and which will likely include other pertinent stakeholders, such as the Ministry of Health and the Ministry of Education. The technical committee is a multisectoral group that is looking into a possible national action plan on persons with albinism, with a view to addressing the myriad of challenges in the country.

69. The Independent Expert would like to highlight, for the benefit of the work of the technical committee, the existence of the African Union plan of action on albinism (2021–2031),⁹ which sets out important goals and priority areas and which could be of assistance in tackling many of the human rights challenges persons with albinism face. She also highlights the recently adopted Pan-African Parliament guidelines regarding accusations of witchcraft and ritual attacks.¹⁰

70. Towards the end of the visit, the technical committee, along with significant support from UNICEF and the Senior Human Rights Adviser, commenced a situational analysis on albinism that will help extract information in three regions: Anosy, Androy and Atsimo Andrefana. The situational analysis is a much-needed assessment of the challenges and needs of persons with albinism in those regions and can contribute to an overall national action plan on albinism.

71. The existence of the association of persons with albinism and its plan to have similar groups in other regions is a positive sign that this community is empowered to ensure their voices are heard and that decisions made on their behalf will also take into account their views. The Independent Expert met with members of the association and was encouraged to see their advocacy, often in the local national media, on the issue of persons with albinism. She notes the importance of continued engagement with civil society organizations working on albinism in not only having their voices heard but involving them in the decisions that have a direct impact on their lives.

72. The celebration of International Albinism Awareness Day in Taolagnaro in 2022 brought together many persons with albinism in the south to commemorate and share their experiences as a community. Regularly holding events to commemorate the day will go a long way in humanizing persons with albinism and removing the associated stigma. It is also an opportunity to bring together stakeholders to strengthen cooperation and underscore the need to effectively and collectively address the challenges persons with albinism face.

73. The Independent Expert was pleased to see that many people are aware of the challenges persons with albinism face. During her meetings with civil society organizations, for example, she noted that members of the communities had accompanied persons with albinism as guardians and protectors, in their travel to meet with the Independent Expert, given the distance and threat of attacks. Community mobilization and cooperation will further support the protection measures that are expected from State security agents, particularly in rural and remote areas.

74. The Independent Expert notes that the Organisme Mixte de Conception in Ambovombe and Fort-Dauphin has established several initiatives to better protect persons with albinism, including a mapping of households with persons with albinism, the provision of authorities' contact details directly to those households, a hotline for reporting attacks, and increased patrols in the relevant neighbourhoods. These measures, with appropriate safeguards, such as data protection measures, reliable mobile networks and effective rapid response, can strengthen the protection of persons with albinism.

75. In terms of support from the United Nations, the Independent Expert is pleased to see the work done by the United Nations country team, particularly through the Resident Coordinator, in his strong support for addressing the challenges faced by persons with albinism; the Senior Human Rights Adviser and her team, in their coordination, capacity-building and advocacy on the human rights of persons with albinism; UNICEF, through its programmes on child protection and through the support it provided for the visit of the Independent Expert; the United Nations Population Fund (UNFPA), through its support to the National Institute of Statistics in obtaining data and its partnership with UNICEF in a conference in June on a possible national action plan; and many other members of the country team who are potential key partners. Multisectoral coordination and the fostering of partnerships will ensure a more effective approach to tackling the challenges faced by persons

⁹ See <https://www.ohchr.org/sites/default/files/2021-11/AU-Plan-of-Action-EN.pdf>.

¹⁰ See <https://www.ohchr.org/en/documents/tools-and-resources/pan-african-parliament-guidelines-accusations-witchcraft-and-ritual>.

with albinism. The Independent Expert looks forward to further joint efforts with the authorities, civil society and regional and international partners in this regard.

IV. Conclusions and recommendations

76. The Independent Expert acknowledges the various issues faced by the authorities and their partners in addressing the human rights challenges faced by persons with albinism. She is deeply encouraged by the work that has been done thus far and the willingness of stakeholders, particularly through the technical committee on albinism, to tackle these challenges head on. At the same time, she emphasizes the urgent need to enforce stronger protection measures for persons with albinism in the light of ongoing attacks and threats, and to bring perpetrators to justice, as attacks are now being reported in other regions of the country. Persons with albinism remain some of the most marginalized persons, particularly in the south. Under the Sustainable Development Goals, persons with albinism, by nature a minority group, can be classified as among those furthest left behind, thus requiring particular support and action. The rights of persons with albinism therefore need to be at the heart of human rights discussions, particularly in the light of ongoing stigmatization and discrimination but also because of the atrocious attacks perpetrated against them. The work of the technical committee and various partners is crucial, and measures taken to protect persons with albinism and support them in the realization of their human rights should be included in long-term development initiatives, all the while ensuring that they are also represented and engaged in the decisions that affect them.

77. The Independent Expert puts forward the recommendations listed below.

Technical committee on albinism

78. The authorities should:

- (a) Support the work of the technical committee on albinism and the inclusion and active participation of persons with albinism in the development and implementation of a national action plan on albinism, and ensure the resources necessary to carry out the work and recommendations of the Committee;
- (b) Support the work on developing a situational analysis regarding persons with albinism, which will assist in implementing the concrete actions necessary to improve the lives of persons with albinism.

Data

79. The authorities should:

- (a) Ensure that data on the number of persons with albinism collected by the National Institute of Statistics through the upcoming household survey for persons with disabilities are disaggregated, at a minimum, by gender, age, health status and rural/urban prevalence;
- (b) Collect disaggregated data on the employment of persons with disabilities, including persons with albinism;
- (c) Ensure that albinism is included in the collection of data for the next general census (likely to be conducted in 2028);
- (d) Provide strong and adequate safeguards for all data collected on persons with albinism to prevent misuse for attacks, discrimination and other illicit acts.

Participation and representation

80. The authorities should:

- (a) Promote persons with albinism as role models and champions to combat myths that dehumanize them;

(b) Collaborate with persons with albinism and organizations representing them to ensure their inclusion and consultation in public debates, as well as in the development of legislation, policy, programmes and services for them;

(c) Help organizations representing persons with albinism in strategic advocacy to integrate their issues into larger related public debates, including on the rights to life, health, education and employment;

(d) Consider persons with albinism in future State party reports to human rights bodies, including treaty bodies and under the universal periodic review mechanism;

(e) Involve persons with albinism in all decisions and measures taken for the full implementation and enjoyment of their rights.

Awareness-raising

81. The authorities should:

(a) Carry out intensive ongoing awareness-raising about albinism to demystify albinism and counter erroneous beliefs and superstitions across the country, particularly at the local and rural community levels, where attacks have been widely reported;

(b) Mobilize relevant stakeholders, such as community and religious leaders, the Organisme Mixte de Conception, health workers, the education sector and extractive industries, to tackle myths about persons with albinism and other vulnerable groups who have been victims of ritual attacks;

(c) Use the commemoration of International Albinism Awareness Day (13 June) and of other relevant days, such as Human Rights Day (10 December) and the International Day of Persons with Disabilities (3 December), to highlight and give visibility to the rights of persons with albinism and their family members;

(d) Organize workshops to raise awareness about the human rights of person with albinism and combat myths.

Capacity-building

82. The authorities should:

(a) Carry out training on the human rights of persons with albinism among stakeholders, including authorities, civil society organizations and partners;

(b) Carry out capacity-building for local communities, including members in the *dina* and other community leaders.

Education

83. The authorities should:

(a) Develop a comprehensive policy on disability inclusion for the whole education system, and ensure it is implemented;

(b) Provide budgetary support for inclusive education measures under the national education plan and ensure that persons with albinism are included as beneficiaries of those measures;

(c) Provide access to education for persons with albinism, particularly in the remote parts of the country, including in the far south;

(d) Immediately improve security infrastructure at schools where children with albinism attend;

(e) Increase resources to help in providing reasonable accommodation for learners with albinism, including for the training of personnel on the practical implementation of reasonable accommodation and for the purchase of assistive devices;

(f) Ensure that assistive devices, such as monocular and specialized glasses, are provided to learners with albinism, free of charge, on an ongoing basis after proper ophthalmological assessment;

(g) Ensure that teachers are trained on disability inclusion and the human rights-based approach as part of their training curriculum as educators and to also empower learners with disabilities;

(h) Train teachers to be aware of the stigmatization of, prejudice against and bullying of students with albinism, and on taking preventative measures.

Health

84. The authorities should:

(a) Ensure that quality health care and services are available, affordable and accessible, particularly in the area of skin cancer prevention and treatment;

(b) Ensure that sunscreen is available as an essential medicine, and make it accessible through regional health centres, mobile clinics and the provision of transportation to and from sunscreen distribution points, particularly in remote communities;

(c) Ensure the availability and accessibility of specialized doctors, such as dermatologists and ophthalmologists, and build the capacity of health-care workers to enable them to better understand and provide for the needs of persons with albinism;

(d) Ensure that sufficient budget is allocated for the implementation of the national health policy, particularly where it relates to persons with disabilities and therefore persons with albinism.

Employment and standard of living

85. The authorities should:

(a) Adopt measures to address poverty, in the light of the 2030 Agenda for Sustainable Development, to ensure that persons with albinism are not left behind, that they have full access to employment and social welfare programmes and that they are included in all poverty-reduction programmes;

(b) Combat discrimination and stigmatization that have prevented persons with albinism from accessing the labour market, in both the public and private sectors;

(c) Ensure that complaints made by persons with albinism about discrimination in the labour market are addressed in the relevant tribunal and bodies, including by the ombudsman and the national human rights institution.

Protection from attacks

86. The authorities should:

(a) Strengthen the protection of persons with albinism, particularly in remote areas where they are attacked, including by enhancing cooperation with security committees at the district and community levels, increasing street lighting and patrols in hotspots, and providing support, such as social grants, for the reinforcement of unsecured homes;

(b) Facilitate the effective collaboration of the Organisme Mixte de Conception in the protection of persons with albinism, including through the sharing of information and provision of speedy responses to news of attacks;

(c) Ensure that if shelters are used, the authorities take the lead, with support from the international community, and that the approach is accompanied by an appropriate exit strategy to ensure that such shelters are temporary;

(d) Put in place effective measures to ensure that when shelters are established or used for persons with albinism, the best interests of the child and the

right to a family and community environment are appropriately taken into account, the principle of informed consent is respected in relation to admittance into the shelters, and holistic support is provided;

(e) Facilitate the safe return and reintegration of those living in shelters to their families and ensure that stronger protection is provided in their communities.

Access to justice

87. The authorities should:

(a) Ensure that robust investigations are carried out and concluded in an expedited manner to ensure that perpetrators of crimes against persons with albinism are prosecuted;

(b) Inform the public of the conclusions of trials relating to persons with albinism, including information on the outcome of investigations into the Ikongo tragedy;

(c) Ensure respect for due process in investigations relating to crimes against persons with albinism, including respect for the presumption of innocence of those arrested or suspected of involvement;

(d) Provide technical capacity assistance to police, gendarmerie and judicial officers, particularly in the regions where attacks are common, to ensure that investigations, prosecutions and judicial processing are carried out effectively;

(e) Provide the equipment and resources necessary to assist with forensic investigations of cases, including an effective fingerprint database, forensic laboratories and qualified forensic experts;

(f) Carry out a review of legislation to identify legal gaps in relation to the prosecution of such cases and ensure that justice system officials are trained to apply appropriate laws and sentences;

(g) Ensure fair and adequate reparations for victims of attacks and their family members, including medical, psychosocial and other forms of rehabilitation.

Cross-cutting issues

88. The authorities should:

(a) Ensure that the law on disability aligns with the Convention on the Rights of Persons with Disabilities;

(b) Engage and support the United Nations country team in its initiatives to address the challenges of persons with albinism;

(c) Refer to the African Union plan of action on albinism (2021–2031), to help inform the implementation of policies on albinism, as well as to the Pan-African Parliament guidelines on accusations of witchcraft and ritual attacks;

(d) Engage with regional mechanisms, including the Southern African Development Community, to tackle cross-border crimes, including through the Southern African Regional Police Chiefs Cooperation Organization;

(e) Cooperate and share best practices with other countries in the region dealing with attacks against persons with albinism and encourage a forum of engagement among key stakeholders;

(f) Ratify the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa;

(g) Support the work of the ombudsman in receiving potential complaints from persons with albinism, and the High Council for Defence of Democracy and Rule of Law in its advocacy for the rights of persons with albinism;

(h) Ensure the independence of the national human rights institution in accordance with the principles relating to the status of national institutions for the promotion and protection of human rights (the Paris Principles).

International cooperation

89. The authorities should:

(a) Implement all recommendations made by treaty bodies in relation to the promotion, protection and fulfilment of the rights of persons with albinism, particularly those made by the Human Rights Committee, the Committee on the Rights of Persons with Disabilities, the Committee on the Rights of the Child, the Committee against Torture and the Committee on the Elimination of Discrimination against Women;

(b) Include persons with albinism in the preparation of future State party reports to treaty bodies and the national report under the universal periodic review;

(c) Support civil society groups representing persons with albinism in the form of human rights training and capacity development;

(d) Implement the national action plan on persons with albinism, once it has been developed.

90. The Independent Expert calls on the international community to provide the Government of Madagascar with financial and technical assistance to support the development and implementation of measures to ensure the full enjoyment of rights by persons with albinism in the country.
