



Independent Expert on the enjoyment of human rights by persons with albinism

Official visit to the Republic of Madagascar 20 to 30 September 2022

Preliminary findings

At the invitation of the Government of Madagascar, I undertook an official visit from 20 to 30 September 2022. I would like to thank the Government for the swift response in granting me the invitation to be here and the co-operation I have enjoyed throughout the preparation and execution of my visit. I particularly thank the Ministry of Foreign Affairs and Ministry of Justice for their support. I am also grateful to staff of the Resident Coordinator and the Senior Human Rights Adviser team., UNICEF, as well as the United Nations Country Team for their valuable support, both before and during my mission.

In my time in Madagascar, I held meetings in Antananarivo, Fort Dauphin, Ambovombe and Amboasary. I met with the authorities in capital and in the south region including representatives from the: Ministry of Foreign Affairs; Ministry of Justice; Ministry of Defence; Ministry of Interior; Ministry of Public Security; Ministry of Population, Social Protection and Women; Ministry of Education; Ministry of Health; President of the first instance court and Prosecutor of Fort Dauphin; National Institute of Statistics; High Council of the Defence of Democracy and Rule of Law; Technical Committee on albinism which include government representatives, UN Senior Human Rights Adviser, UNICEF, national human rights and associations of persons with albinism.

I wish to sincerely thank everyone that made time to meet with me. I particularly express my gratitude to persons with albinism who met with me in all the towns I visited, and bravely shared their stories and experiences.

Context

My visit to Madagascar comes at a time of great difficulties for persons with albinism in the country. I took up my appointment as Independent Expert on this mandate last August and soon after, began to receive reports of attacks against and abductions of persons with albinism, particularly in the south region. My visit was thus prompted by serious concerns that these attacks were increasing with each passing month. My mandate also requires me to assess the human rights situation of persons with albinism holistically, not only looking at the right to life but also the right to equality and

non-discrimination, the highest attainable standard of physical and mental health, education and work, among other issues.

I visited the south region of the country where attacks against persons with albinism have mostly been reported. Madagascar is one of the countries worse affected by climate change and I witnessed this first hand in the south. It has been reported that COVID-19 pushed the poverty rate in the country to a record high of 81%, which is compounded in the south by other adverse factors including drought, extreme food shortage and other natural disasters. In addition to poverty, the south is reported to have a high rate of illiteracy and lack of education among the population.

Challenges

Data and statistics

There is a dire need for data and statistics relating to persons with albinism to assist with formulating policies and assessing the support they would need to address the various challenges they face. The national census of 2018 did not sufficiently disaggregate data to enable an analysis of the population of persons with albinism in the country. However, I was informed that a household survey on persons with disabilities is being planned by the National Institute of Statistics (INSTAT) with partners which is an opportunity to include a variable on albinism to obtain concrete data on the albinism population.

Attacks

I was regularly informed that attacks against persons with albinism is a relatively new phenomenon in Madagascar and that the spikes in attacks have occurred in the last three years. However, I was also informed of prior incidents of attacks, including a case that occurred as far back as the 1990s and incidents in 2013 and 2017. It was also mentioned that there may have been other cases in the past, but the victims would have unlikely been identified as persons with albinism.

Information received from the gendarmerie show that in 2020 there were 10 reported cases of attacks; 8 cases reported in 2021 and 15 reported cases in 2022, almost double since the previous year. This week alone, I heard of another case of attack in Ampanihy in the Atismo Andrefana region. To date, there have been 33 cases of attacks recorded by the gendarmerie between 2020 and 2022, as well as 11 cases registered by the national police for 2021 and 2022 concerning mostly abductions targeting children. Records of attacks do not seem to be consolidated by the national police and gendarmerie. In one month alone this year, there were at least 4 attacks, confirming the spike of attacks. I want to stress that these are the reported cases and unreported cases are also possible especially as many occur in remote areas where access to information is also difficult.

Children are not the only victims of attacks. The youngest victim I am aware of is around 9 months old while the oldest is 72 years old. While most attacks were reported in the south, a 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 cases in the north in years preceding the attacks in the south.

Reasons for attacks

While attacks may be instigated for a number of reasons, the most common one reported is due to dangerous myths that the body parts of persons of albinism can bring wealth or luck. Poverty was also regularly cited as a root cause for the attacks.

What is 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 rooted in harmful practices and rituals have spread as rumours from one district to another, triggering new cases. Another very disturbing and dangerous myth include the idea that the eyes of persons with albinism contain diamonds.

Many interlocutors mentioned that persons with albinism were only targeted in the last 3 years but before this, there were attacks against twins due to misbelief that they were bad luck and attacks against pregnant women to extract their foetuses for rituals. These dangerous mystical rituals were said to be common among parts of the country. A number of interlocutors mentioned that such ritual attacks increase prior to elections.

The second most cited reason for attacks is poverty and many point to the incidences in the south, where poverty is acute, as an indicator that desperation for survival lead people to commit atrocities such as the attacks that have occurred.

Profile of attackers

Attackers are reported to include relatives of victims, community members, persons who travelled from other regions and *dahalos* or zebu raiders. Other information referred to the involvement of people in influential positions as a possibility, also due to false beliefs in rituals using body parts of persons with albinism which, according to wrong beliefs, help them attain power and stay in power. There are some who say that only the middleperson is often caught while the masterminds of these attacks remain unknown.

Ongoing fear and insecurity

Due to these attacks, persons with albinism live in persistent fear. Parents of children with albinism have resorted to taking their children to the local police and gendarmerie station, as well as boarding schools for the visually impaired in some regions and leaving them there for their protection. Some young people with albinism also move to live with relatives in areas that are deemed safer. In addition, a number of persons with albinism and authorities have requested to have designated safe areas or shelters where persons with albinism can seek protection for themselves.

In Amboasary, Ambovombe and Fort Dauphin, the cases I was aware of all involved abductions of children in an apparent attempt to sell them off to buyers. The majority of these children were either reportedly rescued by the authorities before a buyer could be found, or abandoned in remote places when buyers were not found. In some cases,

local community members have committed to and assisted the public security forces in protecting persons with albinism, but there are still grave concerns that these attacks will continue.

I was able to speak with children who were victims of attacks and can confirm that they still suffer from psychological trauma along with their family members and continue to need support.

Stigma and discrimination

Persons with albinism continue to suffer from stigma and discrimination. In the Malagasy language, persons with albinism are known as *varira* or *bobo*. They are often victims of social exclusion, bullying and marginalisation on a regular basis. Their hypervisibility in their communities have further exacerbated the stigma and discrimination they face. Derogatory names used for them include *sira* or salt (due to colouring), *sova* or burnt skin/burn scars and *rajako* or monkey. While *varira* appears to be a neutral term, a young girl with albinism voiced her desire to do without this terminology and be simply called by her first name. Stigma and discrimination perpetuates the dehumanization of persons with albinism. Dehumanisation coupled with dangerous false beliefs perpetuate 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.

In all my discussions the urgency to educate and raise awareness on albinism was highlighted as a priority. It was evident that misunderstanding of albinism was rife and that wrong beliefs were not only held by perpetrators but by some stakeholders as well who I met. 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.

Education

During my visit, local media covered the story of a student with albinism who was rejected by a private school in Talatamaty due to the school's belief that his presence would damage their reputation. According to reports, parents of students were also afraid that albinism was contagious. This case is a clear example of the many challenges learners with albinism face in trying to access education.

In the communities I visited many persons with albinism cannot attend school due to fear of attacks. Persons with albinism I met with indicated that in many cases schools allow them to sit in front of the class to access the board, but apart from that reasonable accommodation in schools is mostly non-existent. Many do not have access to proper glasses and had no knowledge of, let alone access to, even the most basic assistive devices such as magnifying glasses and monoculars. I met a single mother of a young girl with albinism who had to design a desk for her child out of her own costs to enable her child to better see the blackboard. The mother barely had the resources to do this.

I am aware that there are no particular policies in schools to assist learners with albinism, although I know that there are discussions around a policy for students with

disabilities within the Ministry of Education. I 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, the children were prevented from attending schools due to fear of attacks. Many also have to walk long distances to get to schools increasing their vulnerability to attacks, as well as sunburn and skin cancer. Teachers are also not properly trained on the special requirements that persons with albinism have including the provision of text in large font writing, sitting at the front of the classroom near the blackboard or away from the windows to avoid the harsh sunlight. These are easily achievable measures that can go a long way in providing learners with albinism better access to proper education.

While my focus is on persons with albinism, I recognise that the overarching challenge in relation to education continues to be the provision of free primary education and ensuring access to this in remote regions. This is a concern which impacts all children, not only those with albinism, although those with albinism are disproportionately impacted in relation to lack of education. Ensuring access to education will help in empowering and helping many learners break out of the grips of poverty that is seen in many communities.

Health

Skin cancer is the highest cause of death among persons with albinism in countries that have tropical and hot climates. Access to proper sunscreen with the right SPF is lifesaving. However, accessing this is also difficult.

I met persons with albinism who had never used sunscreen as it was too expensive. One person said he was waiting to receive test results for a lesion he had due to sun exposure. I noted that many persons with albinism would be in the same situation.

I was informed that medical specialists such as dermatologists are not available in many districts particularly in rural areas. There are very few dermatologists in the whole country. Accessing skin cancer screening and specialist consultation were again, too costly for many to afford. A cost of a general check up can be 20,000 ariary (almost USD 5), and this is prohibitive to many in the albinism communities I visited. The need for ophthalmologists is equally important and persons with albinism in the south often have to travel to Antananarivo to see a specialist and get the correct lenses they need.

Employment and livelihood

I met with persons with albinism who had university degrees, including at postgraduate level, in fields such as law, medicine and management. I also met with persons with albinism who barely had a primary education. Access to education is non-existent for many in the rural areas resorting to a life of hard labour and an inability to have employment that can sufficiently provide a decent standard of living. Employment opportunities are also scarce in the south.

However, even the most educated persons with albinism face tremendous challenges in gaining employment. A doctor with albinism advertised his services with his photograph and received no contact from potential patients. When he re-advertised

without his photograph, he began to receive phone calls from interested patients. A young woman with albinism who completed a law degree was given employment but at a salary lower than her peers of the same position. She was bullied at work and was told that her presence was a liability for the company. She left the company due to the bullying. These are some of the reports I received from persons with albinism who have persevered and obtained education qualifications against near impossible odds, only to be overlooked or rejected when seeking employment.

I also heard that in some communities, parents cannot work because they need to remain at home and protect their children from potential attacks. I was pleased to see interest expressed by local labour unions who were willing to advocate for persons with albinism who are wrongfully turned away from gainful employment. More action is needed however to eliminate the barriers created by stigma and discrimination as well as economic barriers to education that prevent persons with albinism in later obtaining a sustainable livelihood. Many persons with albinism have to work labour jobs that require them in the fields or outside, exposing them to harsh sun rays that can lead to skin cancer. Furthermore, reasonable accommodation in the workplace are not commonly provided where persons with albinism have been employed. Such accommodations are necessary to level the professional playing field for person with albinism.

Access to justice

During my interactions with the authorities, I was given information on the number of arrests, detentions and prosecutions of cases related to attacks against persons with albinism. Most of the detentions and prosecutions relate to cases involving the abduction of children with albinism. No information was provided on convictions of perpetrators relating to the cases involving mutilations and murders of persons with albinism.

I have concerns about the capacity of police and gendarmerie to carry out effective investigations in such cases. While some authorities stated that they had sufficient forensic investigation skills and capacity, others highlighted a lack of a fingerprint database, forensic investigation laboratories and 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. I am concerned that confessions by accused persons is often relied on rather than evidence obtained through proper investigations. In turn, effective prosecutions appear to be hampered by lack of effective investigations.

While most interlocutors mentioned that the laws in Madagascar are sufficient to cover attacks against persons with albinism, few authorities were able to identify appropriate laws to be applied in these cases, including those related to trafficking. I am concerned that in the few cases that have been prosecuted, insufficient charges with very lenient sanctions have been applied. The cases mentioned to me involved the prosecution for abduction with sentences as low as 15 months suspended sentences and no higher than 30 months imprisonment being applied. Such sentences do not reflect the seriousness of attacks against persons with albinism.

I am further concerned about the lack of transparency in the processing and trials of the cases of attacks against persons with albinism. While I received information about a few trials, most interlocutors outside of the justice system were of the strong opinion that no single case had been brought to court, including the communities close to the courts and where attacks have occurred. Consequently, there is a growing perception that justice is not being done on behalf of the victims and the relevant communities. I was told, particularly in the south, that many families of victims prefer to seek reparations and sanctions through the *dina* or traditional justice system because they believed this would provide them with tangible results. Although the recourse to both the traditional and the formal justice system can simultaneously be used by victims, many preferred the former stating that they did not have faith in the latter.

I was informed that there have been only two convictions out of all the cases out of the 11 cases registered by the police and the 33 cases registered by the gendarmerie. The majority of the cases therefore remain unprosecuted throughout the country. I spoke to persons accused of crimes related to albinism and noted that many were held in pre-trial 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. I urge that due process procedures be followed and that cases on albinism be properly investigated to facilitate the identification and prosecution of masterminds 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. I also emphasise the need to communicate the outcomes of these trials to the victims and their families, and the general public as this can assist in avoiding mob justice. The recent violence in Ikongo where a child with albinism was abducted and killed leading to members of the community confronting the local gendarmerie has been widely reported locally and internationally. The resulting tragedy and eruption of violence resulted in around 30 individuals being killed. I highlight the Ikongo tragedy to further emphasise that “justice must not only be done, but must also be seen to be done.”

Representation

Addressing stigma and discrimination require not only awareness raising but also ensuring that persons with albinism are given positions of influence and visibility to create more positive role models, particularly for youths and children to look up to. Aside from a young singer with albinism who was known in the country, there is still very few persons with albinism who occupy positions of influence whether in the State institutions, private sector or in the public domain. Commemorating 13 June, the IAAD annually and bringing together persons with albinism provides an opportunity to highlight persons with albinism as a way to inspire and also tackle wrongful myths about the condition.

Positive initiatives

Having highlighted the challenges of persons with albinism, I would like to stress that there have also been positive initiatives taken by Government and stakeholders to address these issues. Among the most notable is the step taken to form a Technical Committee on albinism comprised of representatives from the UN (Senior Human Rights Adviser, UNICEF) the Ministry of Justice, Ministry of Population, Social

Protection and Women, Ministry of National Defence, Gendarmerie, National Human Rights Institution, Ombudsman and associations of persons with albinism with a likelihood to include other pertinent stakeholders such as Ministry of Health and the Ministry of Education. The Committee is a multi-sectorial group that is looking into a possible national policy on persons with albinism, which can address the myriad of challenges in the country. I would like to note the existence of the African Union Plan of Action on albinism (2021 – 2031) which provides important goals and priority areas that could assist in tackling many of the human rights challenges persons with albinism face.

I understand that the Committee along with important support from UNICEF and the Senior Human Rights Adviser will also conduct a situational analysis on albinism that will help extract information in three regions: Anosy, Androy and Atsimo Andrefana.

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.

I am personally pleased to see that many people are aware of the challenges persons with albinism face, including in communities where members have stepped up to become protectors and guardians of persons with albinism. Community mobilisation and cooperation will further support the protection measures that are expected from the state security agents, particularly in rural and remote areas.

I also heard of initiatives by the OMC (*Organisme Mixte de Conception* or Security Taskforce) in Ambovombe and Fort Dauphin to protect persons with albinism including through a mapping of households with persons with albinism, the provision of contact details of the authorities directly to these households, providing a hotline for reporting attacks, as well as 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 protection of persons with albinism.

The celebration of 13 June in Tolagnaro (Fort Dauphin) this year brought together many persons with albinism in the South to commemorate and share their experiences as a community. Regularly holding this event will go a long way in humanising and removing stigma associated with albinism. 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.

With regard to legislative framework, it is noteworthy that Madagascar has ratified the ICCPR, CRC, CAT, CERD, CEDAW, CRPD and has a law on the protection of the rights of children. Steps to domesticate the provisions of the CRPD into Madagascar's laws are also welcome.

Preliminary Recommendations

These recommendations are addressed primarily to the authorities while recognising the need to have the support of important stakeholders including the UN and

international organizations, regional organizations, civil society organizations and persons with albinism to ensure their effective implementation.

Technical Committee on Albinism

- Support the work of the technical committee on albinism and the inclusion and active participation persons with albinism in the development and implementation of a national action plan on albinism and ensure the necessary resources to carry out their work and recommendations;
- Support the work on a situational analysis on persons with albinism which will assist in providing concrete actions necessary to improve the lives of persons with albinism

Data

- Ensure data collection on numbers of persons with albinism in the in the forthcoming household survey for persons with disabilities disaggregated at a minimum by gender, age, health status and rural/urban prevalence
- Collect disaggregated data on the employment of persons with disabilities, including persons with albinism
- Ensure albinism is included in the collection of data for the forthcoming census (likely in 2028)

Participation and representation

- Promote persons with albinism as role models, champions to combat myths that dehumanize them;
- Collaborate with persons with albinism and organizations representing them to ensure their inclusion in public debates relevant to them and consult with them in the development of legislation, policy, programs and services for them;
- Assist organizations representing persons with albinism in strategic advocacy to integrate their issues into larger related public debates including on the right to life, health, education and employment;
- Consider persons with albinism in future state party reports to human rights bodies including treaty bodies and UPR
- Involve persons with albinism in all decisions and measures taken for the full implementation and enjoyment of their rights

Awareness raising

- Carry out intensive continuous awareness-raising about albinism across the country, particularly at the local and rural community levels where attacks have been widely reported to demystify albinism and counter erroneous beliefs and superstition
- Mobilise relevant stakeholders, such as community and religious leaders, the OMC, health workers, the education sector and extractive industries to tackle myths about albinism and other vulnerable groups who have been victims of ritual attacks
- Use events such as International Albinism Awareness Day on June 13, and other relevant days such as International Human Rights Day on December 10,

and International Day of Persons with Disabilities on December 3, to highlight and give visibility to the rights of persons with albinism and their family members

Education

- Provide access to education for persons with albinism particularly in the remote parts of the country, including in the deep south;
- Immediately improve security infrastructure at schools where children with albinism attend;
- Increase resources to help in providing reasonable accommodation for learners with albinism, including the training of personnel on the practical implementation of reasonable accommodation and purchase of assistive devices;
- Ensure that adaptive devices such as monocular and specialized glasses are provided to learners with albinism, free of charge, on an ongoing basis after proper ophthalmological assessment
- Train teachers to be attentive to stigma, prejudice and bullying, encourage preventative measures

Health

- Make quality health care and services available, affordable and accessible, particularly regarding skin cancer prevention and treatment;
- Ensure sunscreen is available as an essential medicine, and made accessible through the use of regional health centres, mobile clinics;
- Provide transportation to and from sunscreen distribution points, particularly in remote communities;
- Ensure availability and accessibility to specialized doctors, such as dermatologists and ophthalmologists and health care workers to better understand and provide for the needs of persons with albinism

Employment and Standard of Living

- Adopt measures to address poverty in the light of Agenda 2030 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;
- Combat discrimination and stigma that have prevented persons with albinism from accessing the labour market, both in the public and private sectors
- Ensure complaints of discrimination in the labour market by persons with albinism are addressed in the relevant tribunal including by the Ombudsman and the National Human Rights Institution.

Protection from attacks

- Strengthen protection of persons with albinism particularly in remote areas where they are attacked; including through 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 by ensuring that they have doors and locks
- Ensure that if shelters are used, the authorities take the lead in this initiative with support from the international community and are accompanied by an appropriate exit strategy to ensure such shelters are temporary
 - Put into place effective measures to ensure any shelters established or used for persons with albinism appropriately take into account the best interest of the child and the right to a family and community environment, respect the principle of informed consent in relation to admittance into the shelters, provide holistic support

Access to justice

- Ensure robust investigations are carried out and concluded in an expedited manner to ensure perpetrators of crimes against persons with albinism are prosecuted;
- Inform the public of the conclusions of trials relating to persons with albinism, including information on the outcome of the Ikongo tragedy;
- Ensure respect for due process in investigations relating to crimes against persons with albinism;
- Provide technical capacity assistance to police, gendarmerie and judicial officers, particularly in the regions where attacks are common, to ensure investigations, prosecutions and judicial processing are carried out effectively
- Carry out a review of legislation to identify legal gaps in relation to the prosecution of such cases and ensure the justice system is capacitated to apply appropriate laws and sentences
- Ensure fair and adequate reparations for victims of attacks and their family members, including medical, psychosocial and other forms of rehabilitation

Crosscutting issues

- Ensure the law on disability aligns with the CRPD
- Refer to AU Plan of Action on albinism (2021-2031) to assist in the implementation of policies on albinism
- Ratify the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa
- 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)