



Ministry of Justice, Constitutional and Religious Affairs



United Nations Educational, Scientific and Cultural Organization

Organização das Nações Unidas para a Educação, a Ciência e a Cultura

## Report of the “PALOP” Conference and Training on Albinism: Progress, Challenges and Way Forward

Maputo, 27-29 December 2019



Seating from left to right: Ms. Andrea Wojnar, UNFPA Rep. to Mozambique, Mr. Albachir, National Director of Human Rights, Ms. Ikponwosa Ero, UN Independent Expert on Albinism, Mr. Lucas Mangrassa, the Vice - Minister of Gender Children and Social Action, Mr. Paul Gomis, UNESCO Rep. to Mozambique, Mr. Marcoluigi Corsi, UNRC a.i. and UNICEF Rep. to Mozambique, and some participants.



UNITED NATIONS  
INDEPENDENT EXPERT  
PERSONS WITH ALBINISM

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**Publisher :**

United Nations Education, Scientific and Cultural Organisation

204, Frente de Libertação de Moçambique road

Maputo, Mozambique

Tel . : +258 21481700

Webiste : <https://en.unesco.org/fieldoffice/maputo>

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# Map of Mozambique



Source: Moçambique: evolução da Toponímia e da Divisão Territorial 1974 - 1987

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## Acknowledgements

UNESCO, the Ministry of Justice, Constitutional and Religious Affairs (MJCR), in partnership with the Open Society Initiative for Southern Africa (OSISA), the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (IE), Ms. Ikponwosa Ero, Ford Foundation, the Office of the High Commissioner for Human Rights (OHCHR), The United Nations Fund for Population (UNFPA) and the International Organisation for Migration (IOM) would like to thank the many individuals, Civil Society Organisations (CSOs), members of PALOP governments, as well as representatives of UN agencies in Mozambique, the medias and NGOs who successfully participated in the conference and training and contributed to this report. They provided their presentations during the conference, notes, comments and constructive critics that are reflected here. The organizers would like to acknowledge the contributions that came from the report of the Ministry of Justice Constitutional and Religious Affairs. Moreover, UNESCO, the MJCR and the United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (IE) are most grateful to all persons with albinism who sacrificed their time and shared their experiences and opinions during the Conference and Training. Their contributions were key in understanding albinism and to the writing of this report. Finally, UNESCO would like to express its gratitude to government staff, the UN colleagues for the time and efforts they invested in facilitating the logistics and for the writing of this report.

## Executive summary

The sharing of ideas and experience throughout the Conference and Training emphasized that despite significant progress achieved at policy level, persons with albinism (PWA) continue to face developmental challenges, as well as human rights issues throughout Africa, and



*Figure 1: H.E. Mr Lucas Magrassé, the Vice-Minister of Gender Children and Social Action, in the middle*

within the Portuguese-speaking African Countries (PALOP) in particular. Their exclusion from development processes is often caused by cultural misbeliefs, inequitable access to education, healthcare and economic opportunities, which are not sufficiently adapted to their specific needs.

The three days PALOP Conference and Training on Albinism, which brought together diverse stakeholders, shared grounded experiences and good practices, revealed progress achieved so far, remaining challenges and made recommendations on strategies to address the pressing developmental and human rights issues affecting PWA. The remaining obstacles cannot be addressed in an isolated manner. Stakeholders should structure, position themselves, act in a way that makes the most out of their capacity, and be champions of the cause globally, and amongst the PALOP in particular, said Mr. Paul Gomis, the Representative of UNESCO to Mozambique. He further stressed the vital and urgent need to adopt an inclusive approach to address the multidimensional nature of albinism. Access to ‘competitive inclusive quality education’ and healthcare, but also protection and human rights, changes in cultural beliefs and improvement of the global governance are paramount for the required transformative change that will enable PWAs and persons with disability (PWD) to take charge of their lives and fully participate in the sustainable development of their communities. Capacity building and development of stakeholders, in-depth research and gender-based data collection, resource mobilisation and advocacy at all levels and awareness-raising campaigns are among key recommendations that resulted from the Conference and

Training. Gender relations and cultural practices, ideology, behaviour and attitudes toward PWA are decisive in effecting change. The global south's CSOs must take the lead in voicing the concerns of PWA to shape decision-making processes. Governments should be proactive in ensuring that legal framework are in place and enforced, and that policy and legislation complies with international and regional human rights instruments. This conference was a milestone toward a more systematic and integrated intervention to advance the human rights of PWA. As a crucial head start, PALOP member states should adopt an action plan on albinism inspired by the Regional Action Plan, 2017-2021, and build a network to mobilise more resources for coordinated and collective action.

## Acronyms and Abbreviations

- AAAA:** Angolan Association of Person with Albinism
- ADRA:** Adventist Development and Relief Agency
- AU:** African Union
- CRPD:** Convention on the Rights of Persons with Disability
- CSOs:** Civil Society Organisations
- CWA:** Children with Albinism
- EAF:** Edelmiro Antonio Foundation
- FAO:** Food and Agricultural Organisation of the United Nations
- IE:** United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism
- INGO:** International Non-Governmental Organisations
- IOM:** International Organisation for Migration
- MJCR:** Ministry of Justice, Constitutional and Religious Affairs
- NAP:** National Action Plan on Albinism
- NGO:** Non-Governmental Organisation
- OHCHR:** Office of the United Nations High Commissioner for Human Rights
- OSISA:** Open Society Initiative for Southern Africa
- PALOP:** Portuguese- speaking African Countries (Países Africanos de Língua Oficial Portuguesa)
- PWA:** Persons with Albinism
- PWD:** Persons with Disability
- RAP:** Regional Action Plan on Albinism
- SDG:** Sustainable Development Goals
- UN:** United Nations
- UNDP:** United Nations Development Program
- UNESCO:** United Nations Educational, Scientific and Cultural Organisation
- UNFPA:** United Nations Population Fund
- UNHRC:** United Nations Human Rights Council
- UNICEF:** United Nations Children's Fund
- UPR:** Universal Periodic Review
- UTSS:** Under the Same Sun

Under the leadership of the UNESCO Mozambique, and in cooperation with the Ministry of Justice, Constitutional and Religious Affairs (MJCR), the Open Society Initiative for Southern Africa (OSISA), the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (IE), Ms. Ikponwosa Ero, Ford Foundation, the Office of the High Commissioner for Human



*Figure 2: Mr. Paul Gomis, The UNESCO Representative to Mozambique, opening the Conference and Training.*

Rights (OHCHR), the United Nations Population Fund (UNFPA) and the International Organization for Migration (IOM), the Portuguese-speaking African Countries (PALOP)<sup>1</sup> Conference and Training on Albinism took place in Maputo, from 27<sup>th</sup> to 29<sup>th</sup> of November 2019. It resulted from a UNESCO two-year project on protection and promotion of the human rights of PWAs in Mozambique funded by UNESCO, OSISA and later the Ford Foundation, in support to the Mozambique's Multisectoral Plan on Albinism.

The Conference and Training opened by Her Excellency Mr. Lucas Mangrassa, the Vice-Minister of Gender, Children, and Social Action, the Representative of the UN Resident and Humanitarian Coordinator ad interim, Mr. Marcoluigi Corsi (also UNICEF Representative to Mozambique), Ms. Ikponwosa Ero, the IE and Paul Gomis, gathered approximately 120 participants. They came from across the eleven (11) provinces of Mozambique, from Angola, Cap-Verde, Portugal, South Africa, Canada, and Tanzania. Ms. Paula Simas Magalhães the OHCHR coordinator to Mozambique, Ms. Andrea M. Wojnar, the UNFPA representative to Mozambique, Mr. Przemyslaw Walotek, representing the Food and Agricultural Organisation of United Nations (FAO)'s Representative to Mozambique and H.E. Maria Paiva, the Ambassador of Portugal to Mozambique, also participated in the opening of the event extensively covered by the media.

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<sup>1</sup> Due to last minute constraints, Guinea-Bissau and Sao Tome e Principe have not been able to join and participate in the Conference and Training.

Practical workshops provided a platform for the sharing information and sensitized key insights of individuals and organizations on the human rights approach, principles and frameworks, while interactive panel discussions capacitated attendees on organisational planning, coordination, networking, fundraising, lobbying and advocacy, as well as communication techniques. Analysis and discussions of the RAP, as well as Mozambique's Action Plan supported the brainstorming sessions on next strategies for action.

Participants were presented with certificates by Ms. Myrta Kaulard. The UN Resident and Humanitarian Coordinator, together with the Al Bachir Macassar, the Director of Human Rights (MJCR), the IE Ms Ikponwosa Ero, the OHCHR coordinator and UNESCO Representative presided the closing ceremony of the conference. This report summarizes the main discussions, results achieved so far, key challenges facing PWAs, and sheds light on recommendations and way forward made by participants.

## 1. Definitions

**Albinism:** Is a relatively rare, genetically inherited, non-contagious condition resulting in a deficiency of melanin pigment in hair, eyes, and skin. Many PWAs experience adverse health outcomes due to their condition, compounded by a lack of or poor access to information, healthcare and other key rights. A major health concern associated with PWA is skin cancer, the major cause of premature death among them in sub-Saharan Africa. Albinism affect people worldwide regardless of ethnicity or gender. In addition to skin cancer, PWA often have disabilities because of visual impairment and attitudinal barriers owing to albinism. They have also been recognized as persons who face racial discrimination and stigmatization on the ground of colour (<https://undocs.org/A/74/190>).

**Inclusive education:** An education system that enables schools and education staff to adapt itself to meet the specific learning needs of every student regardless of their physical or mental condition (<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>).

**PALOP countries:** Also known as Lusophone Africa, are a linguistic group of five African countries (Angola, Cape Verde, Guinea-Bissau, Mozambique, São Tomé e Príncipe) formed in 1992, in which Portuguese is the official language. Equatorial Guinea, though being a Spanish-speaking African country, joined the PALOP in 2011 (Banco de Portugal, 2019).

**Persons with Disability:** Those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. They also face discrimination and do not full enjoy their rights (<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>).

## 2. Albinism in PALOP Countries

**Table 1: Summary of implementation of the Regional Action Plan**

Country	Prevention	Protection	Accountability	Equality & non-discrimination
Angola	1%	3%	1%	1.8%
Cape Verde	No data	No data	No data	No data
Guinea Bissau	No data	No data	No data	No data
Mozambique	4.4%	13.1%	1%	6.5%
São Tomé e Príncipe	No data			

Source: <https://actiononalbinism.org>



Albinism is a global phenomenon. Attacks, stigma, discrimination, violence and other human rights violations against PWA occur globally, in general, and in sub-Saharan Africa in particular. Despite the relatively high prevalence of albinism in the region, official data only exists in five countries: Ivory Coast, Malawi, Namibia, Sierra Leone and the United Republic of Tanzania. The lack of credible data is due to the little capacity of monitoring bodies serving PWAs. Most of the time, even government data are

not adequately disaggregated to enable deep analysis (<https://actiononalbinism>). According to the UN's 2019 Report on albinism worldwide, the prevalence of persons with albinism in Africa varies from one person in 5,000 to one in 15,000, with selected populations in Southern Africa having a prevalence of one person in 1,000. The Regional Action Plan on Albinism in Africa, 2017–2021 mentions that over 600 attacks and other violations against PWAs have been reported in 28 African countries since 2006. Under the Same Sun (UTSS), a Civil Society Organisation (CSO) that promotes and protects the human rights of PWA, recorded 206 killings and 365 attacks, including survivors of mutilations, violence, rape, attempted abductions, missing persons, grave violations, asylum and other refugee cases, 571 crimes in total, in 29 countries ([www.underthesamesun.com](http://www.underthesamesun.com)). Furthermore, according to International Organisation for Migration (IOM), there are many undocumented cases of attacks, human rights violation and killings of PWA in Africa (International Organisation for Migration, 2019). Moreover, UNFPA has found that young persons with disabilities, including those with albinism, are almost four times more likely than their peers to be victims

of abuse, and that girls and young women are more likely to suffer such violence than men and boys (UNFPA, 2018).

Data that resulted from Ms Ero's visit reveals that the PALOP countries, compared to English and French speaking African countries, are further behind regarding the implementation of non-discrimination, accountability, protection and promotion of the human rights of PWA's measures (see table 1). Mozambique and Angola's implementation rates of the action plan, for instance, are 6.25% and 1.7% respectively, which are further behind other African countries, such as Kenya (11.1%), Ivory Coast (16.1%), Nigeria (21.8%), Burkina Faso (15.6%) and Tanzania (7%). Other PALOP countries have no recorded data at all. The IE visited Mozambique two times (once on a mission in 2016 and another for this conference). Other PALOP countries had not been visited by the IE yet. However, she has kept in touch with contacts in Angola and has made a lot of attempts to get information from all PALOP countries including through dedicated staff managing the action on albinism website. The situation per country is described as follows:

**D) Angola:** The biggest (the seventh-largest) and the most populated PALOP country, Angola is a west-coast country of South-central Africa bordered by Namibia in the South, the Democratic Republic of the Congo in the North, Zambia in the East, and the Atlantic Ocean in the West. Its population is estimated at 31,825,295 people. Two third of its population (66.1%) is urban and the median age is 16.4 years (<https://www.worldometers.info/world-population/angola-population/>).

As in most African countries, there are no adequate monitoring and reporting mechanism on the challenges faced by PWA in Angola. The NGO, Adventist Development and Relief Agency (ADRA) reports that Angolans' PWAs suffer mostly from harassment, discrimination and



stereotyping from their families and communities. *Figure 3: Mr. Guilherme dos Santos (Angola), on the left*

The Edelmiro Antonio Foundation (EAF) reported that Angolan with albinism do not suffer as much as nearby nations from physical violence nor social segregation (<https://actiononalbinism.org>). However, they do not receive the necessary medical and social assistance that they require. Guilherme dos Santos, a member of the Angolan Association of Person with Albinism (AAAA), mentioned that PWAs in the country suffer mostly from lack of healthcare, which leads to premature death between 30 to 40 years old due to skin cancer. They are also subject to infanticide. Cultural misbeliefs also lead Angolans with albinism to social exclusion.

“Because of stigma and discrimination, I only started seeing other PWAs when I was 15 years old. I grew up in my community thinking that I was the only PWA. That is why I think that fighting cultural misbeliefs and investing in education is key for the promotion of our human rights. I overcame societal barriers because I had access to education”

...Guilherme dos Santos.

Angola has not yet adopted its National Plan on Albinism (NAP) but it is implementing some initiatives to address the obstacles faced by PWA. Through a pilot urban development programme (*municipalização da acção social*), registration of PWA is ongoing across the country though with difficulties due to logistic challenges to cover the so many small villages nationwide. Concerning healthcare, there are some initiatives in the provinces of Luanda, Huíla, Uíge and Zaíre with reserved days for dermatological consultations. However, PWAs and other potential beneficiaries are often unable to profit from these services due to the financial constraints. It was also reported that a partnership with an optical firm avails Angolans with albinism 5-6% discounts to purchase glasses.

**II) Mozambique** is located in Southeast Africa bordered by the Indian Ocean to the East, Tanzania to the North, Malawi and Zambia to the Northwest, Zimbabwe to the West, and

Eswatini (Swaziland) and South Africa to the Southwest. Its 2019 estimated population is 30.366 inhabitants out of which 37.8% is urban. The median age in Mozambique is 17.2 years (<https://www.worldometers.info/world-population/mozambique-population/>). The 2019's International Organisation for Migration study estimates that there are between 20,000 to 30,000 Mozambicans with albinism dispersed across the country. They are subject to discrimination, exclusion, verbal and physical violent attacks, which can lead to body parts and other organs' removal, trafficking and murders.

According to the IE (Ero, 2018), there has been over a hundred attacks against PWAs between 2014 and 2015 in Mozambique. The number could be higher because there is no systematic mechanism to facilitate the monitoring and reporting on such cases. Although some cases have been reported throughout the country, Zambézia province is the most affected, with children being the most targeted group. PWA are referred to as '*fortuna*', '*bolada*' (lump sum, jackpot), terms of derision in reference to the alleged value of their body parts. Cases of parents selling their children with albinism (CWA) to foreigners from neighbouring countries, such as Tanzania, have also been reported.

Guided by NAP, Mozambique is however implementing some measures to address the challenges faced by PWA. The three regional central hospitals in Maputo, Beira and Nampula provinces provide free dermatological and ophthalmological services though access to those facilities is often not subsidized. The



Figure 4: Mr. Albachir, 2nd from the left, the National Director of Human Rights

Ministry of Health has a traditional medicine department to ensure medical practitioners and traditional healers are sensitized towards the need of PWA, and to demystify associated harmful myths. In response to attacks, the Government adopted a new Penal Code in 2014, which provides the police and the judiciary system with resources to deal with cases of attacks against PWA. A year after, the government adopted an Action Plan on 24 November

2015, mentioned Albachir Macassar, the National Director of Human Rights at the MJCR. At government level, there is an albinism multisectoral working group composed by focal persons from nine ministries, two national institutes and various actors from both academia and civil society organizations working on the subject under the leadership of the MJCR. However, while some government institutions have taken certain planning measures, particularly in the area of awareness raising, the overall implementation of the Plan remains weak at 6.25%.

**III) Cape Verde** is an island country spanning an archipelago of 10 volcanic islands in the central Atlantic Ocean. Cape Verde has a population of about 540,000 inhabitants. A large proportion (236,000) of them live on the main island, Santiago. Many more live abroad in the Cape Verdean diaspora in



*Figure 5: Participants during a group work session*

mainland Africa, Europe, U.S., Brazil, etc. (<http://worldpopulationreview.com/countries/cape-verde-population/>). Dos Nascimento, from Cape Verdean National Human Rights Commission, mentioned that PWA are subject to the same challenges and barriers in Cape Verde. Nevertheless, because there are fewer cases compared to other African countries, including the PALOP, there are no specific policies, strategies or Action Plan to address the obstacles affecting PWA.

**IV) Guinea-Bissau** is located in west Africa bordered by the Atlantic Ocean, Senegal, and Guinea. In 2019, the population of Guinea-Bissau was estimated at 1.92 Million inhabitants, which ranks 150th in the World (<http://worldpopulationreview.com/countries/guinea-bissau-population/>).

**V) São Tomé e Príncipe** is an island country in the Gulf of Guinea, off the western equatorial coast of Central Africa. It has a population of 197,541 making it the 184th largest in the World (<https://www.graphicmaps.com/sao-tome-and-principe>).

Due to last minute administrative and logistic constraints, the Conference and Training did not benefit from the participation of the delegations from Guinea-Bissau and São Tomé e Príncipe and there are no credible data regarding PWA for the two countries. However, it has been reported that there is a gap in terms of baseline studies, monitoring and reporting mechanism on PWAs and disaggregated data collection, which should be addressed.

### 3. Rights of Persons with Albinism in Africa: progress and challenges

Since the adoption of the Universal Declaration of the Human Rights (1948), the African Charter on the Human Rights of People (1981), the UN Convention on the Rights of Persons with Disabilities (2006), The Regional Action Plan on Albinism (2017) and other global and regional legal frameworks, policies and strategies, there has been progress, but also setbacks regarding the implementation of general and specific measures to address the violation of human rights affecting PWA in PALOP countries. At the Conference and Training, detailed presentations were provided on the international and regional human rights treaties and mechanisms that provide guarantees for the protection of PWA. Some of which are detailed below.

#### 3.1. Adoption of the UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities is an international human rights treaty of the United Nations aiming at protecting the rights and dignity of persons with disabilities. All State Parties are required to promote, protect, and ensure the full enjoyment of human rights by PWD and ensure that they enjoy full equality under the law. According to Paula Simas Magalhães, the OHCHR coordinator to Mozambique, the Convention has served as a major catalyst in changing the approach to disability from a charity, medical and social to a human rights approach. From then on, advocacy and awareness-raising campaigns are pushing the global society to see persons with disability (PWD) as full and equal members of society, with human rights that must be guaranteed. The CRPD was adopted by the UN General Assembly on 13 December 2006, and opened for signature on 30 March 2007. Following ratification by the 20<sup>th</sup> party, it came into force on 3 May 2008. As of November 2019, 181 State parties had ratified the Convention; there are nine signatories and eight countries that have not taken action yet. To monitor its implementation by party States, the UN established the Committee on the Rights of Persons with Disabilities. An optional protocol to the CRPD allowing for individual communications and undertaking of inquiries by the Committee entered into force at the same time as the Convention. So far, it has been ratified by 95 countries, whilst 28 are signatories and another 75 have taken action.

The Convention is the major catalyst in the shift of the global pro-persons with disability movement from charity, medical and social approach to human rights approach.

All PALOP countries ratified the Convention. By ratifying the Convention these countries made a commitment to advance the human rights of PWD, including PWA. They agreed to make the necessary changes at policy and operational levels to address the physical and societal barriers affecting PWD. However, as mentioned above, most of these countries are behind in terms of implementation and reporting. CSOs dealing with issues pertaining to PWA often lack capacity or are not provided the space for advocacy to shape the policy-making processes regarding inclusion of disability and human rights. Both state and non-state stakeholders often have challenges in monitoring, reporting and providing redress for violations against PWA. Mozambique, for instance, has not yet submitted its first report on the implementation of the CRPD. Nonetheless, Mozambique is due to submit its third cycle report on Universal Periodical Review (UPR) at the end of October 2020, which will have to address past recommendations from various human rights mechanisms and from the last UPR, which touched upon issues affecting PWA. This process is a unique opportunity to revisit and launch new policies and actions for promotion and protection of the rights of PWA. Mozambique is also due to submit its Voluntary National Report in 2020, a national status report for SDGs implementation. There is currently a momentum to work collaboratively with the multi-sectoral ministerial group, CSOs and other UN agencies to push for PWA's agenda within the PALOP and through these international and regional mechanisms.

### 3.2. Creation of the position of UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism

Driven by the cross-cutting principle of the UN Sustainable development goals: “leaving no one behind...starting with the furthest behind first.”, concerned with challenges and barriers faced by PWA and determined to advance their human rights, the UN Human Rights



Figure 6: Ms Ikponwosa Ero, the IE

Council adopted the resolution A/HRC/RES/28/6, on 10 April 2015, which establishes the Independent Expert on the Enjoyment of Human Rights by PWA.

Ms. Ikponwosa Ero was the first appointed, in 2015 with a mandate to: 1) Engage in dialogue and consult with states and other relevant stakeholders, 2) Identify, exchange and promote good practices relating to the realization of the rights of PWA and their participation as equal members of society; 3) Promote and report on developments towards and the challenges and obstacles to the realization of the human rights of PWA, and to make recommendations to the Human Rights Council in this regard; 4) Gather,

The mandate provides the opportunity to influence and shape global, regional and national policy-making process in order to mainstream disability in general and albinism in particular, in

request, receive and exchange information and communications from and with states and other relevant stakeholders, including PWA and their representative organizations and other CSOs, on violations of the rights of PWA; 5) Conduct, facilitate and support the provision of advisory services, technical assistance, capacity-building and international cooperation in support of national efforts for the effective realization of the rights of PWA and to prevent

violence; 6) Raise awareness on the rights of PWA and to combat stereotypes, prejudices and harmful traditional practices and beliefs that hinder their enjoyment of human rights and participation in society on an equal basis with others; 7) Report to the Human Rights Council, and to the General Assembly, and 8) Integrate a gender perspective throughout the work of the mandate.

With this mandate, stakeholders and PWA can report directly to the IE the most pressing issues affecting PWA. She has been advising organizations and governments around the world on human rights concerning PWA. She developed strategic initiatives involving regional and international human rights mechanisms, prepared guiding documents, and overseeing the implementation of recommendations made by the UN and other human rights organizations. Through her mandate, she is pushing regional organisations, such as AU and member states to advance the human rights of PWA, and the implementation of specific measures to facilitate the enjoyment of human rights by PWA. The mandate provides the opportunity to influence and shape global, regional and national policy-making process in order to mainstream disability in general and albinism in particular, in development process. She conducts research, produces country report and analysis on the human rights of PWA. The reports are presented at UN General Assembly, which is a key opportunity for global advocacy at the highest level.

This unique opportunity is crucial to influence global, regional and national legislation and policies. Through her mandate, she has the chance to provide information at high-level policymaking process. Accordingly, she has worked closely with the African Union in developing and recently entrenching the RAP into its policy framework. She can also share at UN General Assembly experiences of attacks on PWA on the ground. The Maputo PALOP Conference and Training benefited from her presence to share the situation analysis of PWA in the respective countries.

One of the biggest challenge of the IE in context of PALOP countries is the language barrier. Because most international human rights guidelines, standards and legal framework are in English or other UN languages, and few of them are translated into Portuguese. PALOP countries often have little access to information that might support the advance of the rights of PWA. This barrier was addressed by the inclusion of Portuguese on the website <https://actiononalbinism.org/>, a platform developed by the IE with key partners for monitoring the implementation of the RAP directly through NAPs. But, there is still a gap regarding situation analysis for PALOP countries. Resource mobilisation to build the capacity

of stakeholders to monitor and report the implementation of specific measures, weak governance structure of CSO for advocacy are other challenges of the IE mandate. This is why the informative training session conducted by the Open Society Initiative for Southern Africa (OSISA) during the workshop on fundraising, leadership, Organisational Structure, Grant-writing techniques and Advocacy, which the participants was important to strengthen the capacity of CSOs to advance the human rights of PWA.

### 3.3. Adoption of the Regional Action Plan on Albinism

Given the specific context of Africa, a continent with most human rights challenges regarding PWA, there was a need to adopt a context-specific Action Plan on Albinism. As pointed out by IE Ikponwosa Ero, the Regional Action Plan on Albinism, 2017-2021 (RAP) was adopted in 2017 and it aligns with the SDGs, the AU Agenda 2063 and the CRPD. It is a key achievement that comes with general and specific measures that enables coordinated and integrated action for promotion and protection of the human rights of PWA. The RAP

Thanks to the RAP, a number of African countries drew up National Action plans on Albinism (NAPA) and are monitoring and reporting their progress against goals.

consists of the recommendations made by various human rights bodies and mechanisms at the UN and AU levels which have been distilled into concrete and specific measures achievable over the immediate, short to medium term (0 to 5 years), while triggering long term initiatives (beyond five years). In 2017, the RAP was endorsed by the African Commission on Human and People's Rights. In 2019, the AU Commission, which is the apex body of the AU decided to adopt the RAP as official AU policy and will also appoint an Envoy to drive its implementation. This later development suggests that the RAP will have a shelf-life beyond the current limit of the year 2021.

The RAP is divided into four areas: prevention, protection, accountability and non-discrimination. States bear the prime responsibility of implementing these measures. However, support and investment from international development partners are crucial for implementing these measures and resources as well as technical support are needed to execute them.

Based on the RAP, some countries, such as Malawi, Tanzania and Kenya, drew their National Action plan on Albinism (NAP), are monitoring implementation. Kenya, for example,

reported several attacks on PWA and human rights violation. Given the strength of Kenyan CSO, the country managed to have a senator with albinism, Mwaura Isaac Maigua, which is a fundamental step for advocacy at high political levels. Mwaura Isaac Maigua is a disability advocate and currently a Nominated Senator in the Kenya's Senate, representing Persons with Disabilities. He is the first Member of Parliament (MP) in Kenya with Albinism. Tanzania, another country that designed its action plan based on the RAP, also reported a number of attacks on PWA and human rights violation. Like the RAP, the Tanzanian plan also has four areas: prevention, protection, accountability and non-discrimination. The country adopted its own Key Performance Indicators (KPI) to measure progress against objectives and goals. Burundi, Kenya, Burkina- Faso and Nigeria are doing well in terms of reporting. The most successful in West Africa is Niger. In southern Africa, Malawi and Zimbabwe are the successful cases in terms of reporting. Between the PALOP, Cape Verde, Guinea Bissau, São Tomé e Príncipe and Angola are the countries that have not yet adopted an Action Plan on Albinism.

More information about the RAP can be found on the website: <https://actiononalbinism.org>. This website is funded by the Open Society Foundation, USA; Under the Same Sun and Ford Foundation. It is managed by the IE in a collaborative effort with various international and regional partners including AU. The website is rich in content. It comes with a library with lots of relevant material on PWA and more. It can be used to request other information not available in the platform. It is translated into Portuguese and that will allow PALOP countries to catch-up with English and French speaking African countries.

### **3.4. Adoption of the Mozambican Multisectoral Action Plan on Albinism**

Amongst the PALOP, Mozambique is the only country with a National Action Plan on Albinism (NAP), which was adopted in 2015. The Mozambican Plan is multisectoral and resulted from insights from diverse stakeholders, CSOs (AlbiMoz, *Amor a Vida*), media (*Gabinete de Informação*), UN Albinism Working Group and government.

Since the adoption of the Action Plan, the interventions are more coordinated amongst the engaged actors, said Albachir Macassar. However several key challenges pertaining to the stakeholders' implementation capacity and the coordination still need to be addressed.

### **3.5. Media and Albinism: progress and challenges**

Concerning media, the conference revealed that in most PALOP countries there are legal frameworks granting the right to information to citizens, including PWA. Mozambique, for instance, has a law for the access of information and freedom of press. The majority of Mozambican media produce relevant information concerning the challenges and barriers faced by PWA. The focus is on physical violation, superstition, stigma, murder, and human trafficking. Consequently, emphasis is also placed on myths and misbeliefs related to body parts and organs, particularly from 2015 when most of the cases erupted in northern Mozambique, affecting the provinces of Niassa, Nampula and Cabo Delgado. However, the analytical and scientific dimension of albinism is often missing in media reports. The human rights-based approach is also missing in the media sector. The language used by media is not appropriate. Shirley Gunn, from Human Rights Media Centre, based in Cape Town, South Africa, mentioned the documentary that will be launched in Mozambique, in 2020. This documentary, which has been widespread in South Africa and in the region, will help to raise awareness about the challenges and barriers faced by PWA and solutions to address them.

### **3.6. Education and Persons with albinism**

Education is key for inclusion of PWA in development processes and is crucial in the enjoyment of their human rights, emphasized the Conference and Training. Poverty is a major barrier to education, given that children with albinism (CWA) often cannot afford the necessary assistive devices, tuition and sun-protective clothing and appropriate learning materials. This, in addition to other factors, mentioned above, often lead to high dropout rates of CWAs. Most PWA have low vision and school staff from the highest to lower level are not aware of this deficiency. In addition to their visual condition, PWA often suffer from stigma and bullying at school because of misbeliefs, particularly in African context. In the classrooms, there is often little to no reasonable accommodation for students with albinism, such as assistive devices, reading material with large print and additional time during exams. Teachers are often not trained and are therefore unaware, unable to respond to the needs of students with albinism. Similarly, schools are poorly equipped and do not have, or have little resources to invest and help with basic equipment and facilities that cost little to nothing, such as allowing students to copy from their notes.

Article 24 of the CRPD urges state parties to establish an inclusive education system. State parties, such as PALOP countries, must make the necessary legislative and administrative steps to design and adopt policies and strategies to render their education system inclusive for every person with disability, including PWA. Mozambique is currently drafting its National Inclusive Education Strategy, in coordination with UNICEF and UNESCO and teacher-training institutions have introduced braille and sign language classes.

Despite progress, many challenges remain. Access to quality education in the PALOP is still low and PWA are amongst the most excluded. The most commonly used approach still focuses on special or integrated education, instead of an inclusive education system, as recommended by the CRPD. The education material is not designed in a way that addresses visual impairment affecting PWA. Misbeliefs, prejudices and stigma are still common amongst education staff, students and parents-teachers associations. Parents still deny their PWA the opportunity to attend school, mainly because of misconception, risk of violence and possible crimes or killings.

### **3.7. Health and wellbeing of Persons With albinism**

Many PWA experience adverse health outcomes due to the condition, compounded by a lack of access to information and healthcare services. A major health concern associated with PWA is skin cancer, thought to be a major cause of death among PWA in sub-Saharan Africa.

There have been progresses in some PALOP countries regarding access to health-care for PWA. In Mozambique, Kanimambo, a CSO that promotes and protects the human rights of PWA, in partnership with the University Uni-Lúrio is planning to create a centre for dermatological research focused on PWAs. This centre will conduct research on skin cancer that affects PWA. The University is also looking for alternative ways to prevent skin cancer by using Vaseline, a skin-care cosmetic with a reduced cost.

In Angola, because of the activism of the Angolan Association for the Support of PWA (AAAA) in collaboration with the Ministry of Health, PWAs have reserved days for health-care.

Although there has been progress, the health-care challenges are still significant within the PALOP. Access to general and specialized health-care services to prevent skin cancer is often

hindered by poverty and social exclusion. Other barriers include the unavailability of sunscreen- particularly those with high sun protection factor. Lack of government support in the integration of PWA into the general health-care system also seriously impinges on the enjoyment of the right to health by PWA. Furthermore, visual impairments and sensitivity to light are also major concerns as inaccessible environments limit their mobility and access to information. Although no statistics exist for PALOP countries, statistics in other parts of the region suggest many PWA die prematurely between the ages of 30 and 40 due to skin cancer. Less than 2% of PWA reportedly have access to the needed health-care in PALOP.

### 4.1. Conclusion

Persons with Albinism face many challenges in the enjoyment of their human rights and barriers to participation in development process as defined by the SDGs, CRPD and the RAP. That said, there has been remarkable progress in many African countries. However, compared to other African countries,



*Figure 7: Ms. Myrta Kaulard, UN Resident and Humanitarian Coordinator to Mozambique, second from the right.*

the PALOP are left behind in terms of implementation of general and specific measures in the four areas, namely prevention, accountability, non-discrimination and protection. To address the remaining and persistent obstacles amongst the PALOP, the Conference and Training highlighted 14 concrete recommendations in different areas and levels. None of them can be achieved in isolation. All relevant stakeholders must come together in a network to coordinate their intervention and maximise their comparative advantages. The government must take the lead and be proactive. They have a key role at policy level but also in enforcing the existing legislation and strategies, said Ms. Myrta Kaulard, the UNRC to Mozambique.

**“The Global North needs to be engaged in the struggle for the Human Rights of Persons with Albinism, but the Global South should take the lead. Because, though the issue is global, the Global South is much more affected.”**

(IE Ero, Maputo, 29/12/2019)

## **4.2. Recommendations**

### **4.2.1. Education system must be inclusive**

Education is key to include PWA in any sustainable development process and to empower them to participate and equitably enjoy their rights. The conference recommended that there should be public education/awareness raising on albinism with emphasis on the rural and community levels, schools and homes. In countries, given the recorded attacks, these activities should be carried out in all areas with a specific emphasis where attacks occurred. To that end, innovative public education programmes involving traditional/classic and social media should be carried out with both traditional and social media. In countries with a National Strategies such as Mozambique where the overall objective of the new 10-Year Education Plan is ‘Competitive Inclusive Quality Education’ (MINEDH), specific measures for PWA should form parts of strategic and operational plans as well as the day-to-day activities. At UN level, UNESCO has a specific mandate on education and culture. Thus, the organisation should continue its commitment and support to albinism and PWAs and, in close coordination with key stakeholders, coordinate key interventions pertaining to its domains of competence, especially in education, culture, science, and in communication/information with specific focus on gender equity. Due to the lack of data, very limited reference is so far made to violence, discrimination and crimes against girls and women with Albinism but, many stakeholders insist to have a specific monitoring and reporting on them. It is most likely that the general discrimination against girls and women apply in the area of PWAs.

### **4.2.2. Provision of health-care tailored to the needs**

Addressing the health and well-being of PWA remains a top priority. PWA within PALOP, especially those in rural areas, face challenges in accessing health-care. Appropriate policies and strategies aimed at addressing access to health-care services for PWA and PWD should be part of public policies. New prenatal diagnostics and genetic testing methods, genetic risk assessment for individuals, families, communities, and novel genetic markers that are used for developing new therapeutics for treating albinism should be promoted across targeted countries. In cases where skin cancer screening and treatment exist, robust monitoring and reporting mechanism by the government is needed to assess their effectiveness, an essential component to achieving the highest attainable standards of health. Healthcare workers, including traditional midwives, should be trained on all issues pertaining to the human rights of PWA. Notwithstanding effort to support constraints, it is important to point out that skin cancer is a highly preventable form of cancer that generally responds well to preventive and curative treatments upon early detection.

### **4.2.3. Adoption of a national action plan on albinism**

Out of the five PALOP countries, Mozambique is the only one country with a NAP, the conference recommends that the four other countries develop and promote theirs as a priority without further delays. Action Plan is key to define priorities, and to set goals, objectives and indicators to measure, monitoring and report on progress made at national, regional and global levels through the IE. The Plan is also relevant to coordinate interventions among key players and between them and other stakeholders at national, regional and global levels.

#### **4.2.4. Establishment of a PALOP network on Albinism**

Changes that are required for the enjoyment of the human rights of PWA can best be achieved collectively with a mechanism that enables effective coordination of stakeholders at regional level. For that purpose, it is recommended that a PALOP Regional Network on Albinism be created to facilitate collaboration, experience sharing of good practices and mutual support for individuals and organisations working on the promotion of human rights of PWA. The development of such a network should start from the follow-up of discussions initiated during this first conference on albinism and the drafting of the relating Terms of Reference (TORs). This initiative can benefit from the Mozambican experience.

#### **4.2.5. Research and Data collection and analysis**

There is lack of knowledge and accurate data on albinism amongst the PALOP countries. Stakeholders, such as research institutions and universities and others should conduct more systematic research to inform on the phenomenon, set baselines to inform planning and decision-making processes. These researches should also be in Portuguese and ought to include a cultural and religious dimensions, particularly concerning African religions. Research activities should include activities aim at updating and promoting knowledge of the phenomenon and involve stakeholders from the inception stage. National census should equally include questions relating to albinism and other forms of disabilities for national planning and budgeting purposes. Similarly, a sound monitoring and reporting mechanisms should be developed to capture and reflect all forms of violence, crimes and discriminations against PWAs. Similarly, policies and strategies aim at disseminating key normative, preventive and curative instruments regarding discrimination, violation and crimes against PWA must be developed and enforced.

#### **4.2.6. Capacity Building and Development of Stakeholders**

Capacity building and development are fundamental to empower stakeholders for effective intervention, advocacy and awareness-raising campaigns. The target group should be communities, private but also public service providers, such as school and health workers, CSO, personnel of media, community and religious leaders and practitioners of traditional medicine. on the needs, deficiencies and challenges pertaining to PWA to better guide their tailor interventions. The training on fundraising, leadership, governance, planning and management, resource mobilisation, advocacy and communication, which took place during the Conference and Training, should be replicated in other PALOP countries and at provincial level for Mozambique.

#### 4.2.7. Coordinated, Advocacy and campaign

Advocacy and awareness-raising campaigns at global, regional and national levels is key for change. It is strategic to keep advocacy messages clear and short so that people can easily understand them, be empowered, and in turn, be unable to promote them and defend the cause. Lobbying and advocacy strategies should consider the following questions:

Q1: Which are my rights?

Q2: What are the documents that protect my rights?

Q3: Who is in charge to protect the rights (ensure your advocacy is reaching those identified)?

Q4: What is the situation on those rights?

Q5: What are the barriers that prevent that right to be realized?



*Figure 8: The Conference-Training resulted from coordinated efforts of all key partners. From the left to the right are: Myrta Kaulard, the UN Resident Coordinator; Paul Gomis, UNESCO Representative; Paula Simas Magalhães, OHCHR Coordinator; Albachir Macassar, Director of Human Rights (Ministry of Justice); Ikponwosa Ero, IE with a participant (in Red) to the conference receiving her Attendance Certificate*

### Three things to remember:

Human Rights are universal, they are interdependent, and They are indivisible.

#### 4.2.8. “Twin-Track” Approach

In this context, twin-track approach recognises that development programs need to be accessible to PWD but that for a proportion of them, for instance PWA, there are also disability specific needs (as compared to the main stream), which must be met to enable PWA accessing development processes. This means additional to others, specific measures summarised in the RAP as follows: **1) prevention measures:** public education and awareness-raising campaigns, study and disaggregated data-collection and baseline study to identify and adequately address their needs; **2) protection measures:** effective law enforcement in response to violation of their human rights, discrimination, attacks and violations against PWA. This sometime requires review of legal frameworks, training of health-care and workers and midwives as well as educators and social welfare schemes that cover them, monitoring and reporting mechanism; **3) accountability framework and measures:** monitoring reporting mechanism, combat against impunity, victim support, reintegration of the displaced; **4) equality and non-discrimination measures:** e.g. creation of the post of officer on albinism in the ministry responsible for persons with disability or in a national human rights framework, access to adequate health-care for those with skin cancer, reasonable accommodation for education for children and adults with albinism.

#### 4.2.9. Multi-Sectoral Approach

Because this is a collective endeavour, all stakeholders must be engaged in the promotion and protection of the human rights of PWA, and governments should take leadership, particularly in ensuring that the requisite legal frameworks, policies and strategies and an adequate enforcement mechanism are in place. The diversity of stakeholders and their particular role in their respective societies should bring the necessary changes and ensure the enjoyment of human rights by PWA. The UNESCO inclusive multidimensional approach to Albinism and PWA promoted during the Conference and Training – that combines human rights and protection; education; health and wellbeing; culture and governance to promote sustainable change - must serve as reference for the next steps forward.

#### 4.2.10. Context-Specific Interventions

Because realities and social dynamics are diverse, each intervention should be tailored to the specific context of each region, country or province. It is therefore important to consider specific cultural practices, beliefs, representations that lead to verbal, physical and silent attacks and crimes aggressions against PWA. This is why situation analysis plays a key role for awareness raising, prevention and informed policy-making process. Context-based interventions combined with effective national, regional and global policies and strategies

remains the most efficient approach to positive and sustainable social transformation in support of PWAs.

#### **4.2.11. Gender Approach**

In African contexts, women are amongst the most disadvantaged group, and they play a key role in the family and society as individuals, sisters, professionals, mothers and support structures. That is why interventions should have a gendered lens, in other words, pay particular attention to the effect of gender on the experiences of women, in this case, women with albinism and mothers of children with albinism and respond accordingly. There are specific gendered measures in the RAP that ought to be adapted into NAP implementation strategies. Data collection should be disaggregated by disability, age, sex and location or origin.

#### **4.2.12. More Active Media**

Since media plays a key role in raising awareness, informing and shaping public opinions, it should be empowered to be more active in terms of bringing public policies and strategies at all levels; disseminating information on research outcomes; alerting on human right violations against PWA and PWD, and promoting a culture of peace and non-violence for sustainable development, they should be further capacitated to perform their duties, such as informing and educating the public on albinism. Media should also adopt an appropriate language in referencing PWA and reporting on issues.

#### **4.2.13. Attitude and Behaviour Change**

Attitudinal and behavioural changes must be supported to develop more inclusive and tolerant communities where PWA and PWD should feel fully members and supported. Psychosocial support to individuals and family members of PWAs is strongly recommended to adequately anticipate and face possible harassment, discrimination and stereotyping. Finally, participative approach must be promoted as backbone of resilient and sustainable individuals, families and communities empowered to more actively participate in development process. This, in turn, will enable them to adequately face challenges facing PWAs and PWDs.

#### **4.2.14. Partnership Development and Resource Mobilisation**

Partnership development and fund raising are among key activities aimed at supporting PWAs and PWDs. However, the capacity of stakeholders, especially CSOs, to support individuals and communities develop/implement projects in support of PWAs and PWDs is

hampered by the lack of resources. This challenge, combined with the limited national budget allocated to address populations with specific needs, especially PWAs and PWDs, drastically affect possible supports to those groups.

Empowering individuals, community and CSOs leaders in the areas of partnership development and resource mobilization will complement all other capacity enforcement interventions recommended in this report. It is therefore recommended that such an activity be included in capacity building of partners involved in supporting PWAs and PWDs. To that end, building consortia of several CSOs to develop and submit joint proposals for funding to development partners (bilateral and multilateral donors e.g. the UN, INGOs, foundations and private sector partners) should be part of the series of strategies for supporting PWAs. Organisations should also have capacity to absorb and administer funds and to be able to deliver to scale whether as a single entity or as part of a network.

## 5. Moving forward

The progress achieved so far are catalysts to build synergies among stakeholders for a society where no one will be left behind because they have albinism. UNESCO will continue encouraging and working with other UN agencies, government and CSOs by doing the following:

	<b>Activity</b>	<b>Responsible</b>	<b>Deadline</b>	<b>Resource</b>
1	Conference and Training Debrief	UNESCO	2 <sup>nd</sup> Week January	
2	Finalizing Conference video editing	UNESCO	End January	Contracted video maker
3	Revising the Mozambican Plan on Albinism	UNESCO + Ministry of Justice, CSOs	January-February	Full day workshop
4	Implementation Strategy for the RAP to guide the Envoy of the RAP, Addis Ababa	AU and UNIE	31 March 2021	AU and UNIE
5	Establishment of the PALOP network on albinism	UNESCO + Ministry of Justice	Throughout 2020	TORs
6	Donor mapping: e.g. Austrian government, other UN agencies, private companies, embassies, foundations, crowdfunding,	Fundraiser	Continuous process	Communication material: reports, newsletters, leaflets, country strategy
7	Information sharing with donors	Fundraiser	Continuous process	Communication material: reports, newsletters, leaflets, country strategies

- I. Opening Remarks of the Vice-Minister of Gender Children and Social Action
- II. Programme of the Conference and Training
- III. Presentations
- IV. List of the Participants

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Gomis, Paul, UNESCO Representative to Mozambique, Welcoming speech

Kaulard, Myrta, United Nations Resident Coordinator, Keynotes

Ero, Ikponwosa, United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, 1) Keynotes and 2) Introduction to Human Rights and the Protection of Persons with Albinism

Mangrassé, Lucas, the Vice - Minister of Gender, Children, and Social Action, Opening remarks

Macassar, Albachir, The National Director of Human Rights at the Ministry of Justice, Situation Analysis of Albinism in Mozambique

Nlabu, Sascha, Project Manager at the International Organisation for Migration, Situation Analysis of Albinism in Mozambique

Cimalawoonga, Rajabo, UNESCO Consultant, Albinism in Mozambique: current situation

Joanguete, Celestino, Instituto dos Media para África Austral (MISA) Moçambique, Member, Albinism and Media

Bento, Nuno, Kanimambo, Albinism and Media

Chivite, Naldo, Forum Nacional das Rádios Comunitárias (FORCOM), Communication Officer, Advocacy and Lobby, Albinism and Media

Savanguane, Wiliamo Tomás, President of Albimoz, Testimony

Santos, Guilherme dos, Angolan Association of Persons with Albinism, Testimony

Banze, Stela, Ministry of Health, Albinism and Health-care

Mussagy, Ihdina Siril Bariate, Vice-President of Amor A Vida, Albinism and Health-care

Restrepo-Mejia, UNFPA, Albinism and Health-care

Selimane, Remane, Ministério da Educação e Desenvolvimento Humano (MINEDH), Albinism and education

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