



REPORT

REGIONAL ACTION PLAN ON ENDING ATTACKS AND HUMAN RIGHTS VIOLATIONS AGAINST PERSONS WITH ALBINISM IN AFRICA

(2017-2021)

By Dr. Marika Toumi, Ikponwosa Ero and Herbert Tawata



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II. INTRODUCTION

Context

The Regional Action Plan (“RAP”) emerged from the Mandate of the United Nations Independent Expert on the enjoyment of human rights by persons with albinism (the “Independent Expert”) to respond to the hundreds of reported attacks and extreme violations of human rights against persons with albinism in 29 countries of the African continent. Such attacks range from mutilation, maiming and murder to kidnapping, human trafficking and the desecration of graves (to steal and traffic body parts from the corpses) of persons with albinism. The most recent attack at the time of writing this report, is the case of mutilation of a baby with albinism in Zambia, in May 2021.

Reports indicate the existence of a black market for body parts of persons with albinism. It is also reported that many cases of attacks and other violations go unreported because of the involvement of family members in many instances, the weak monitoring capacity from the State and civil society organizations (CSOs) alike and also because of the secrecy that surround these practices, most of which are ritual attacks.

To tackle these atrocities, in 2016 the Independent Expert brought stakeholders together to elaborate and adopt a regional action plan as follows.

History and methodology

The RAP was drawn up by the Independent Expert following wide consultation and using recommendations from relevant resolutions of the United Nations and the African Union, particularly those of the African Commission on Human and Peoples’ Rights and the African Committee of Experts on the Rights and Welfare of the Child.

The RAP was also built upon recommendations made by United Nations’ Treaty Bodies and recommendations made by the Universal Periodic Review mechanism as well as from national responses, such as the multi-sectoral action plan from Mozambique, the action plan of Malawi, and the task force of Tanzania. De facto and de jure national responses from other countries, such as Kenya, Nigeria, and South Africa, were also considered.

The initial draft of the RAP was subsequently scrutinized at consultation workshops. These included a two-day forum entitled “Action on Albinism in Africa” held in June 2016 in Dar-es-Salaam, United Republic of Tanzania, with over 150 participants from at least 26 countries in the region.

In November 2016, a high-level meeting in Pretoria reviewed and improved the draft. In the same month, a Task Force, whose members were elected at the end of the forum in Dar-es-Salaam and who had the mandate to collate, finalize and adopt the substantive text on behalf of all participants, met in Nairobi for two days to refine the proposed plan. Participants in the workshops included staff from various United Nations agencies, the

African Committee of Experts on the Rights and Welfare of the Child and the African Commission on Human and People's Rights, and representatives of civil society, including organizations representing persons with albinism, Governments, national human rights institutions, and academia.

The Independent Expert also solicited input during the whole of the year 2016 through regular correspondence with a wide range of stakeholders, including those who were unable to attend the workshops and consultations. Altogether, more than 200 participants from the majority of countries in the region of Africa participated, lending technical expertise and legitimacy to the document.

The Regional Action Plan on Albinism in Africa was translated from English into French, Arabic and Portuguese – the four official languages of the African Union. It was subsequently disseminated by the Independent Expert to all stakeholders who had been consulted and through her social media platforms, reaching tens of thousands of persons, particularly in Africa. It was also posted on the webpage of the Independent Expert and presented to the Human Rights Council in 2018 during its thirty-seventh session¹ (see A/HRC/37/57/Add.3).

In February 2018, the Independent Expert organized a consultation in Nairobi to develop **targets** for the Regional Action Plan. Participants included representatives of organizations of persons with albinism from at least 25 countries in Africa, national human rights institutions, international non-governmental and governmental organizations, and the Office of the United Nations High Commissioner for Human Rights (OHCHR). At the end of the consultation, 40 targets were adopted to realize the 15 measures identified in the Plan. Those targets were also linked to the Sustainable Development Goals to facilitate and mainstream implementation by Member States and other key stakeholders.

While the RAP applies to the entire Africa, the engagement from governments and civil society came mostly from Sub Saharan Africa. This is likely because extreme discrimination such as attacks have not been reported in the Northern part of the continent although some information on discrimination and stigma have trickled in recently. Therefore, the monitoring process and implementation described apply to Sub Saharan Africa alone.

Institutional Endorsements

a) African Commission on Human and Peoples' Rights (2017)

To promote awareness of the Regional Action Plan in Africa, a panel and a side event were organized in 2017 during the 60th ordinary session of the African Commission on Human and Peoples' Rights to discuss the RAP further. This led to the adoption of [resolution 373 \(LX\)](#) 2017. In addition to endorsing the RAP, the Commission, in its

¹ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/363/74/PDF/G1736374.pdf?OpenElement>

resolution, urged all States parties to the African Charter on Human and Peoples' Rights to take all the measures necessary for its adoption and implementation and invited the relevant organs and bodies of the African Union to give due regard to adopting and implementing the Plan.

b) European Parliament (2017)

In 2017, the European Parliament adopted resolution 2017/2868 [on the situation of persons with albinism in Africa, notably in Malawi](#), in which it also endorsed the Plan and called upon the European Union and its member States to, inter alia, support efforts to address the rights of persons with albinism on the basis of non-discrimination and social inclusion by providing the necessary financial and technical assistance.

c) Pan-African Parliament (2018)

In 2019, the Pan Africa Parliament adopted a resolution on persons with albinism in Africa² in which it, inter alia, condemned the attacks on persons with albinism and the violation of their human rights, endorsed the RAP and called on the member States of the African Union to take all measures to ensure the effective protection and promotion of the rights of persons with albinism and to promote regional cooperation to address cross-border crimes, notably the trafficking of persons and children as well as body parts of persons with albinism.

d) The Regional Action Plan becomes AU-wide Policy.

In July 2019, as a result of the continued engagement of the Independent Expert with the African Union, the Regional Action Plan was considered at the Executive Council of the African Union and was subsequently adopted as a continent-wide policy and was to be known as the ***Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031) (“Plan of Action”)***.

This Plan of Action will therefore replace the Regional Action Plan (2017-2021) by mid-2021, when the latter, 5-year span would have concluded.

The Plan of Action is incorporated into the larger disability architecture of the African Union, thereby giving further legitimacy to the need to implement the measures contained therein. The African Union also decided at the same session that a **special envoy** would be appointed to ensure the implementation of the Plan of Action, an important step towards having a dedicated high-level official to oversee and drive the necessary actions under the Plan.

In November 2020, the Department of Social Affairs of the African Union, co-led with the Independent Expert the elaboration of an implementation strategy for the Plan of Action. This consisted of a consultation and validation at an online meeting with stakeholders.

² PAP.4/PLN/RES/05/MAY.18

Participants included civil society organizations representing persons with albinism and representatives of national human rights institutions and United Nations agencies, including the United Nations Educational, Scientific and Cultural Organization (UNESCO) and OHCHR. The implementation strategy is now completed and has been incorporated into the Plan of Action and can be viewed online at actiononalbinism.org.

III. MEASURES & TARGETS OF THE REGIONAL ACTION PLAN (2017-2021)

The RAP was the first-ever regional mechanism to proactively address eradicating discrimination and violence against persons with albinism in Sub Saharan Africa. Its overarching objective was to guide and monitor efforts by multiple stakeholders across Africa to protect and integrate persons with albinism and realize their enjoyment of peace and human rights.

It sets out **15 specific measures which are divided into four key pillars:** (A) prevention, (B) protection, (C) accountability and (D) equality and non-discrimination.

The Regional Action Plan is also deeply guided by the 2030 Sustainable Development Agenda and its principle that no one should be left behind, beginning with those furthest behind first.

The 40 targets were time-bound over the immediate, short to medium terms (0 to 5 years) and long term (beyond five years). The full version of the RAP is available at: https://actiononalbinism.org/uploaded_documents/1602584835173txjw8qyy96q.pdf

This report will present an abridged version of the 15 measures and four pillars.

Pillar A: Prevention Measures

The prevention pillar centers on demystifying the condition of albinism to combat ignorance, misconceptions, and superstitions that generate stigma and discrimination.

The measures under this pillar are:

- Measure 1: Carry out public education and awareness-raising campaigns maintained (not ad hoc) for at least 2 years.
- Measure 2: Collect disaggregated data and perform needs assessment (including security needs) to identify the true scale and specific nature of the needs of persons with albinism.
- Measure 3: Identify and address root causes through research (legal, anthropological, academic and other forms).

Pillar B: Protection

This protection pillar was centred on ensuring that the national legal framework and the social security systems protect persons with albinism.

- Measure 4: Ensure effective law enforcement in response to attacks and violations against persons with albinism.
- Measure 5: Review of legislative frameworks, including with regard to trafficking in body parts, witchcraft and traditional medicine, and the recognition of colour as a ground of discrimination.
- Measure 6: Train health care workers and midwives about albinism.
- Measure 7: Include persons with albinism in social welfare schemes.
- Measure 8: Monitor and reporting. In particular, support with resources, civil societies who work in advancing the rights of for persons with albinism.

Pillar C: Accountability

This pillar was aimed to ensure that persons with albinism vulnerable to attacks, benefitted from the protection of the State, in particular, justice and the rule of law.

- Measure 9: Combat impunity; Prioritize prosecution of cases of attacks against persons with albinism.
- Measure 10: Support victims of attacks and their families.
- Measure 11: Safe reintegration of the persons with albinism that have been displaced.

Pillar D: Equality and Non-Discrimination

The measures of this pillar aim at establishing access to other key human rights such as the right to education, employment and health care. These create the condition to promote equality and non-discrimination and to protect persons with albinism from poverty which often predisposes them to attacks and other human rights violations.

- Measure 12: Create a post of officer on albinism in the disability ministry or other human rights framework nationally to ensure the implementation of the measures contained in this Plan among others.
- Measure 13: Reasonable accommodation; Provide and ensure adaptive devices and vision support are available at school and the workplace; Provide essential skin care items.
- Measure 14: Provide access to preventive and curative health care against skin cancer for persons with albinism.
- Measure 15: Develop intersectional programs for persons with albinism, that address the multiple and intersecting discrimination they face, particularly women and children.

IV. IMPLEMENTATION OF THE REGIONAL ACTION PLAN: THE COORDINATION PLATFORM

Multi-stakeholder Implementation

Action plans for persons with albinism should be developed with their active participation and inclusion. Article 4 (3) of the Convention on the Rights of Persons with Disabilities requires States to closely consult with and actively involve persons with albinism in decision-making processes about issues that concern them. This entails partnerships with persons with albinism, putting them at the center of the decision-making process, awareness-raising and public education campaigns, and supporting their capacities and efforts as agents of change in their families and communities.

The Regional Action Plan adopted a participative and multi stakeholder approach to implementation and designates the intended implementers for each target as either civil society organizations or State or a mix of both.

Online Coordination

To promote the implementation of the Regional Action Plan and to coordinate the various stakeholders and resources involved, an online platform (“Action on Albinism”³) was created.

Its main functions were as follows:

- Collect information on the implementation activities carried out by the various stakeholders. Information was obtained either from reports issued by albinism organizations about their activities and sent/emailed proactively to the platform; or by the platform coordinator contacting organizations leaders for updates; or by monitoring and oversight of topical publications, social networks and other official government or media sources.
- Measure the indicative implementation of the RAP by applying basic indices to the information obtained and convert the collected data into progress represented by scores. This is done with the assistance of rules and guidelines that have been drafted alongside the RAP with the support of the Independent Expert and a Task Force specific to the creation of the Platform. The Task Force comprised international development partners working in the Africa region, as well as organizations as well as civil society organizations representing persons with albinism in the Africa region.

³ www.actiononalbinism.org

- Collect data on albinism in multiple formats (articles, laws, government publications, reports, academic papers, theses, videos, leaflets, educational material, etc.) into a free online library to support implementation of the RAP and to provide the albinism community as well as the public with a knowledge and resource. Coordinate and respond to requests for information and help from various stakeholders; connect stakeholders to each other, provide a platform for exchanges about efforts by national, regional, and international levels with a commitment to implementing the RAP.

V. CAVEATS: MEASURING IMPLEMENTATION AND PROGRESS

Prior to commenting on national progress in implementing the Regional Action Plan, it is important to underline the limitations of this exercise. The RAP did not have an enforcement mechanism or a requirement by Member States to report. This is because it was not official AU policy although a reflection of the intent of a wide range of stakeholders and had received various high-level endorsements including at the AU. Fortunately, the new Plan of Action (2021-2031) being AU policy should have less challenges in this regard.

Moreover, neither the Independent Expert nor the Implementation Platform have permanent representation on the ground in the countries concerned. Furthermore, the geographical area concerned by the RAP is immense with more than 1 billion inhabitants, where internet and phone connections are often unreliable and where people speak a multiplicity of languages that make communication challenging across the region. This is bound to produce very wide information gaps in our attempts at capturing a standardized picture of the RAP's implementation progress in the region. Although efforts have been made at reaching out to as many albinism organizations possible from the English-speaking, French-speaking and Portuguese-speaking areas, not all were reachable nor available to respond. One must keep in mind that the information we were able to collect, to a certain extent, over-represents the English-speaking, internet-connected, urban and economically developed regions over the rest.

Furthermore, for the reasons mentioned above, the process of data collection is mostly indirect and relies on the goodwill and good faith of civil society organizations to communicate or verify information about their government's activities as well as their own on implementation of the RAP. Despite the general willingness to cooperate that was enjoyed from Civil Society, there was limited control on the completeness, and accuracy of these reports. This concern was only partly addressed by crosschecking information with multiple sources where possible. For instance, organizations supported their written reports with photos; email communications with press articles; oral interviews with official letters, leaflets, and documents.

The size and sophistication of the organizations also influenced their ability to monitor and report data. A few civil society organizations have built up enough size and experience to have hundreds or thousands of persons with albinism as registered members. They have improved their organization and capacity for recording their activities and publicizing them; they are better staffed, better funded and more apt at communication about their implementation activities. These organizations would often have the critical mass necessary to move up their scores and indices on the Platform which cannot record very fine levels of implementation.

However, the types of organization described above is still a minority. The majority of Civil Society Organizations representing persons with albinism, are small to very small entities, with no state funding or sponsors. Consequently, most of them work with extremely limited and irregular resources, doing what they can to provide *ad hoc* support within a limited geographical scope, often no wider than a village or a city. They often provide modest support that may not amount to more than a few bottles of sunscreen or items of protective clothing or just moral support to extremely vulnerable women, children and men. These very small structures are difficult to reach and to integrate within the albinism advocacy community due to various factors such as language, access to internet/email/phone, level of education, etc. It means that countless small support programs or awareness-raising activities dispensed to parents of children with albinism, or the local school, or the community police station go unregistered by our platform because we do not know about them.

The contrary may also happen that the implementation activities of small organizations may be given undue relative significance in an effort to have their existence recorded and acknowledged by the blunt quantitative instruments of the implementation platform. Efforts have been made by the platform coordinator to mitigate the over and under-representation of implementation activities when scoring activities with the assistance of fairly detailed rules and guidelines. However, this remains an important caveat when interpreting the implementation progress below.

The Regional Action Plan itself for all its merit in attempting to encapsulate in simple and clear language, achievable targets and measures that advance the rights of persons with albinism, does not cover all eventualities. There is therefore some degree of appreciation and subjectivity left to the data collector and platform coordinator as to whether a particular activity, piece of regulation, program or event does fall within the narrowly worded scope of the RAP and if so, under which pillar and under which measure. Once that scope has been established after careful consideration, the second level of appreciation is to gauge the extent to which the particular activity fulfills the RAP's measures and targets, oftentimes in the absence of, or with only very minimal statistics or quantitative information to aid measurement.

Furthermore, the RAP and Platform are young mechanisms with relatively recent existence. Knowledge of them, their role, their potential benefits is spreading but is still patchy across the region and among civil society organizations, and particularly those

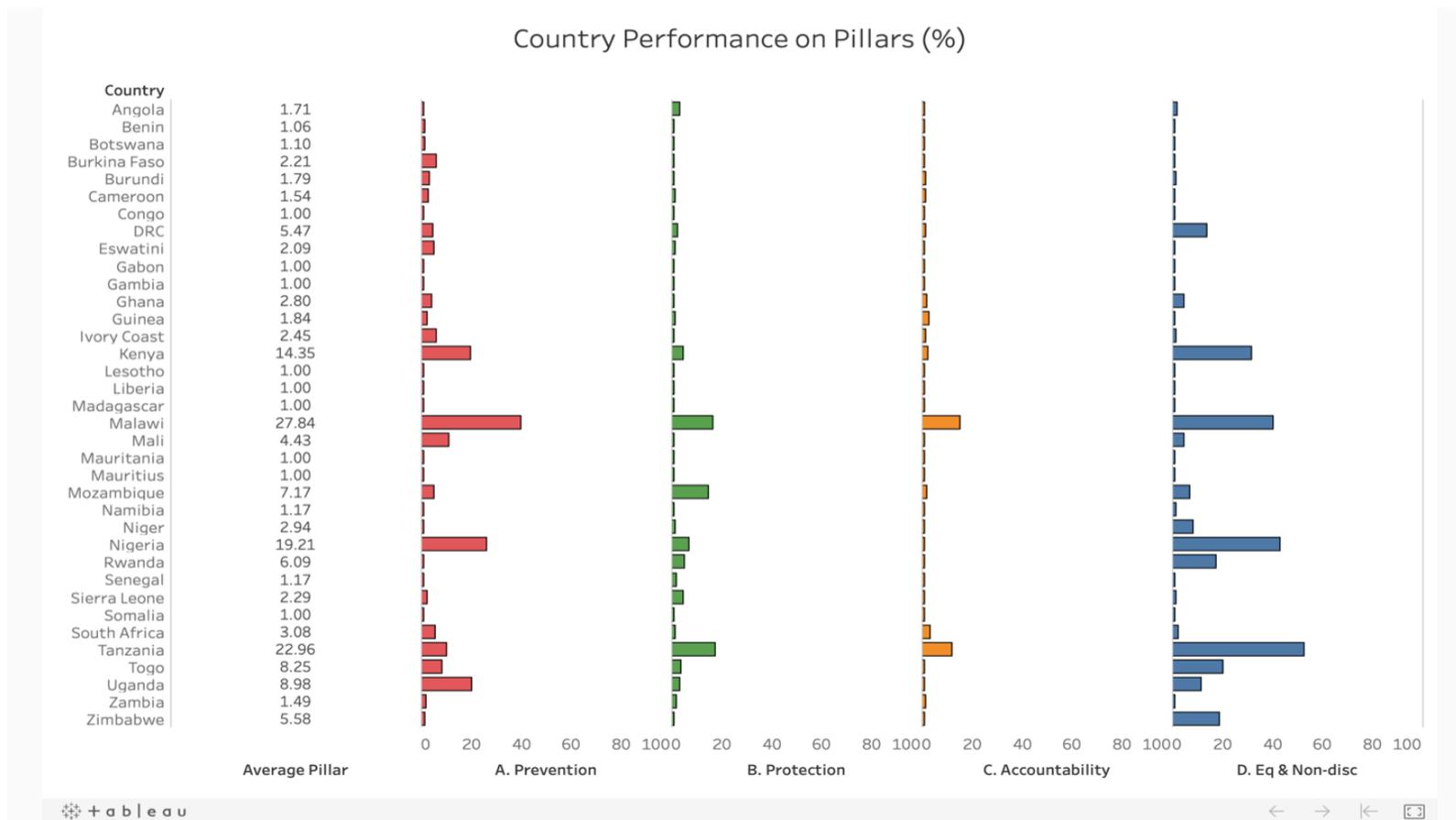
that are francophone and Portuguese-speaking. Not all organizations representing persons with albinism in Africa know about the mechanisms, nor how to make use of them or that they can contact the platform to report implementation of the RAP. This point contributed to the information gap.

It should also be noted that this report only assesses implementation of the RAP carried out during the period 2017 to 31.04.2021. Advances prior to 2017 are not captured by our measurement even if they are mentioned to provide some element of national context. In at least one case, namely the case of Kenya, national progress on albinism had advanced prior to the RAP being put in place. For instance, Kenya has a national policy approach with a substantial amount of 100 million Kenyan Shillings (nearly USD 1 million), multi-year budget dedicated to persons with albinism since the year 2013. Given that the platform measures implementation from the beginning of the RAP in 2017, most of this progress was not captured, and ongoing progress was not reported.

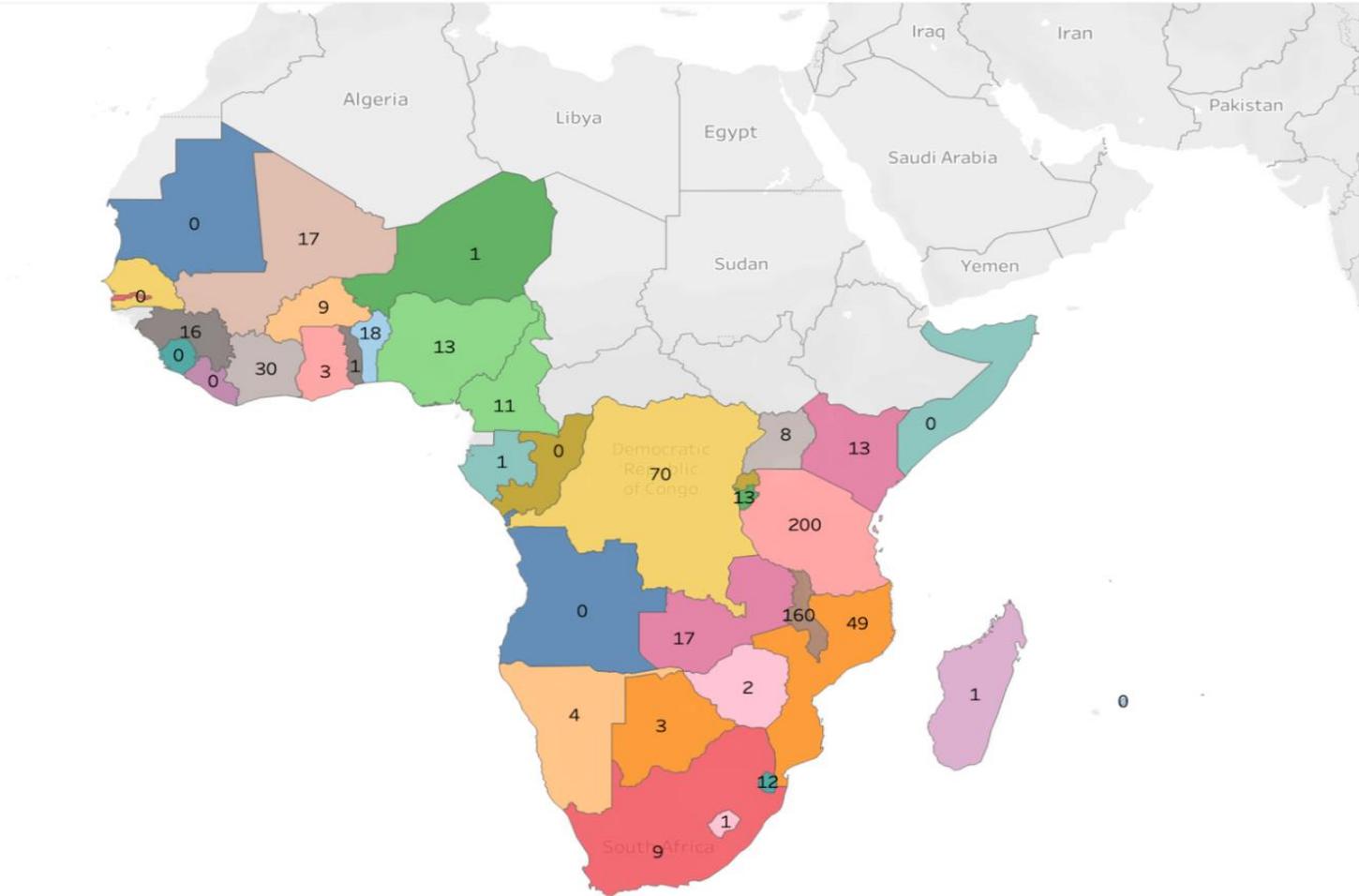
Therefore, with regards to all caveats mentioned above, the attempts that follow at gauging, comparing and estimating quantitatively, national advances in implementing the RAP, should not be read as exact representations of actual implementation progress. This would be misleading. Rather they should be considered as mere indications of very broad trends.

VI. NATIONAL IMPLEMENTATION PROGRESS OF THE RAP (2017-2021)

National Performance on the 4 pillars of the Regional Action Plan



Reported National figures of attacks against persons with albinism



Commonalities in the top 3 countries with the best overall implementation progress

Keeping in mind the caveats mentioned above, the 3 countries that show better **overall** progress in implementing the RAP according to our indices are **Malawi, Tanzania** and **Nigeria** in that order. Besides being English-speaking, these countries have several points in common: two of the three have a high number of recorded attacks against persons with albinism, all three have strong albinism organizations and their States show a relatively significant degree of commitment to implementation of the Plan.

a) High records of attacks against persons with albinism

Malawi and Tanzania both have the highest records of attacks against persons with albinism in Africa, with over 160⁴ reports of attacks for Malawi and over 200 records of attacks for Tanzania.⁵ Nigeria occupies a mid-range ranking with 13 reported attacks.⁶

The high number of reported attacks suggests that these countries were flagged relatively early for violations of human rights of persons with albinism which spurred civil society to organize, raise awareness and advocate to state authorities to address the issues even before the Regional Action Plan came into existence. Malawi and Tanzania have responded with more or less success to these pressures to act. They have also been countries of interest at the international level, and centres of concerted action. As such, they have the longest history and experience in representation and activism by persons with albinism. That said, the quality of day-to-day implementation such as an audit of impact in these top 3 countries were not available.

b) State commitment to implementation of the RAP

State commitment to the Plan correlates with progress in implementation even if that commitment does not evenly carry out measures across all 4 pillars of the RAP or all measures within a particular pillar.

⁴ *The National Action Plan on Persons with Albinism in Malawi (2018-2022)*, issued by the Malawi Government indicates 145 cases of attacks between the period 2014-2018 alone (see p.10) <https://actiononalbinism.org/en/entity/2fxeaqhyfe1?page=10> (consulted 11 May 2021). The NGO Under the Same Sun has recorded a further 15 attacks between 2018 and 2021 bringing the total of recorded attacks at 160 for Malawi. The latest attack at the time of writing being the abduction of a baby with albinism on 26 March 2021. https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20201%20page_0.pdf

⁵ This figure provided by civil society organizations is contested by the government of Tanzania who put the figure at closer to 60. The NGO Under the Same Sun records 200 attacks with the latest at the time of writing being the mutilation and murder of the 5-year-old boy in the Tabora region on 4 May 2021.

⁶ Figures are from the Under the Same Sun website:

https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20201%20page_0.pdf, consulted on April 10th, 2021.

i. State commitments in Malawi

In 2015, Prior to the Regional Action Plan, and in the context of alarming numbers of atrocities against persons with albinism, the Malawi Government demonstrated its commitment to addressing these human right violations by adopting its own National Response Plan. It was developed as an operational plan to guide all national initiatives aimed at addressing attacks on persons with albinism. It also acted as a resource mobilization tool for all national efforts to end the atrocities.

Malawi has registered positive change in many areas of interventions and kept the dialogue open with the albinism community by instituting a multi-sectoral National Technical Committee on Abuse of Persons with Albinism to discuss and agree with all concerned stakeholders on implementation of agreed initiatives and strategies.

In 2016, the Government of Malawi also invited the newly appointed UN Independent Expert for a country visit and in collaboration with the Independent Expert and civil society organizations representing and supporting persons with albinism, established a programme to strengthen protection of persons with albinism and to prevent further atrocities. This included a comprehensive range of interventions through advocacy and awareness-raising on the rights of persons with albinism, support for strengthened community-based protection mechanisms in ten affected Districts, support for ongoing investigations and prosecutions, a study on investigated and prosecuted cases, an audit of all cases reported to the police, a study on the root causes of the attacks, and support for law reform, including the amendment of the Criminal Code to include crimes and harsher penalties for crimes against persons with albinism.

Other interventions include training of prosecutors and investigators, the development of a Handbook for prosecutors, education and health interventions, capacity building of the Association of Persons with Albinism (APAM) including through training on human rights monitoring and reporting, advocacy and technical support for the collection of disaggregated data as part of the census of 2018, training of the media on human rights and on victim-sensitive reporting.

The Malawi Population and Housing Census of 2018 is to be commended for including an indicium for albinism which resulted to a census report indicating that there were 134,636 persons with albinism (0.8% of the population)⁷. However, this census did not provide any disaggregated information by sex, or age.

Equality and non-discrimination targets were partially addressed with the appointment of a person with albinism on the Malawian Human Rights Commission and a person with albinism was also appointed as special adviser to the President on disabilities.

⁷ See Malawi Population and Housing Census 2018, at <https://actiononalbinism.org/en/entity/wdmujcs8dc8?page=39>

Malawi has made some progress but there is still some way to go before persons with albinism can feel safe and are able to fully enjoy their human rights. Attacks are still ongoing and while some people have been arrested for crimes related to albinism, APAM and the Malawi Human Rights Commission have publicly expressed concern about the quality of police investigations.⁸

In 2018, a UNICEF study on prosecution of cases of attacks against person with albinism in Malawi⁹ gave an instructive picture of the particular challenges in the country. While the less serious offenses were dealt with swiftly by the courts (6 months on average), a majority of cases involving murder or attempted murder were still taking inordinately long to be prosecuted with an average of 3 years and many still not concluded. The thorough report listed the various challenges in prosecuting these types of cases. Chief among them, lack of resources for the judiciary and the police, resulting in a shortage of experienced magistrates in the Eastern region where cases take place, and insufficient police personnel, inadequate equipment and training to undertake essential and probing investigations. Other challenges include victims withdrawing complaints due to pressure or intimidation given the frequent family links between victims and suspects, unavailability of witnesses for that same reason or because they may have fled to neighbouring Mozambique, or because they may be too traumatized to testify, and even Magistrates expressing fear and a sense of insecurity when sentencing cases involving a person with albinism.¹⁰ In addition, the Independent Expert has received reports of suspects dying in custody in at least three cases. This indicates a range of issues from police brutality to torture to undue interference with the legal process. In 2018, the National Response Plan was revised, and the new **National Action Plan on Persons with Albinism in Malawi**¹¹ was adopted for 2018-2022. It is to be commended for being both comprehensive and clear, focusing on 7 areas¹², with clearly detailed objectives and monitoring mechanisms and indicators. The 2019/20 budget allocated MK400 Million (500'000 USD) towards its implementation and MK600 million (750'000 USD) for construction of housing for people with albinism and

⁸ "Apam president Overstone Kondowe said Malawi needs to accept that security and investigative measures have failed to bring tangible solutions to this national crisis." In 2019: <https://www.maravipost.com/us-ready-to-offer-asylum-to-malawi-people-with-albinism/> (Consulted 20 May 2021).

⁹ Study on Investigations, Prosecutions and Sentencing in Offences against Persons with Albinism in Malawi (2018), R.E. Kapundu for UNICEF, available at <https://actiononalbinism.org/en/entity/xxhpihur9hp?page=1>

¹⁰ *Ib idem*.

¹¹ National Action Plan on Persons with Albinism in Malawi (2018-2022), at <https://actiononalbinism.org/en/entity/2fxeaqhyfe1>

¹² (1) Civic education, awareness-raising and training, (2) administration of justice and support of victims of attacks; (3) Safety and security; (4) human rights monitoring, reporting and research; (5) mainstreaming and empowerment of persons with albinism, (6) access to affordable and quality health care services; (7) access to equitable and quality education

reinstated its commitment in the 2021/2022 budget earmarking MK 300 million (370'000 USD) and MK400 million (500'000 USD) respectively for the same posts.¹³

In 2020, Malawi also progressed in the fulfillment of improving access to health care by persons with albinism by adopting UMOZI Max as a standard sunblock brand. After a one-year pilot program, due process was being undertaken by the Ministry of health to make this commodity available countrywide through Central Medical Stores.

With a clear action plan and specific budget to implement it, Malawi leads the way in upholding the rights of persons with albinism. It cannot afford to be complacent however as attack figures have not dropped and mechanisms of ensuring effective implementation of the National Action Plan appear to be weak.

ii. State commitments in Tanzania

The high numbers of horrific attacks against persons with albinism attracted global attention to Tanzania from the year 2008 when the story broke on the BBC. In 2015, the government in conjunction with civil society undertook a joint investigative mission in eight regions of the Lake Zone where a high number of attacks were reported in order to follow up on them.

Prior to the Regional Action Plan, Tanzania had only mildly committed to acting to protect persons with albinism. It had introduced the Inclusive Education Strategy (2012–2017) for all children to have equal access to quality education in inclusive settings. The strategy included training teachers to provide adequate support for learners. Government incorporated a Guide for teachers of students with albinism in their teacher-training curriculum, which had originally been developed by the civil society organization Under the Same Sun.

The Prime Minister's Office also instructed the Ministry of Industry and Trade to produce assistive devices for persons with albinism as a constituency of persons with disabilities.

The Independent Expert was invited for a visit in 2017 and more significant implementation steps in the fields of protection and law enforcement were taken.¹⁴ In 2017, 34 people were charged for the murders of persons with albinism were sentenced to death for these attacks. While the death sentences drew condemnation including from the Independent Expert, they were seen to send a strong signal that perpetrators of attacks against persons with albinism were going to be held accountable.

¹³ See Malawi Budget Statement by the Minister of Finance, Economic Planning and Development (2019/2020), §88. Available at <https://actiononalbinism.org/en/entity/7r4k221hi72?page=32>

¹⁴ Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to the United Republic of Tanzania, A/HRC/37/57/Add.1 (2017).

With regards to law enforcement, regular meetings were held between the police of Tanzania and Burundi, at the local level, to facilitate cross-border police cooperation in case of attacks against persons with albinism. The government, with civil society, also traversed the northern region of Tanzania to investigate cases of attack.

Law enforcement measures also included the prioritization of investigation and prosecution of such attacks. In 2019, a government notice applying to all court's proceedings accelerated the determination of the outcome of cases involving persons from vulnerable groups by setting a time of 6 months for finalizations.¹⁵

Tanzania also made use of standing task forces with specialized law enforcement training at the peak of the attacks and major awareness-raising programmes. Those efforts were part of a timely response that enhanced deterrence.

Steps fulfilling the equality and non-discrimination targets in the 5-year span of the RAP have also been taken. There have been several appointments of persons with albinism in high offices to date in the posts of (1) Deputy Minister in Department overseeing disability, and (2) Deputy solicitor General, at the ministry of Constitutional and Legal Affairs. A Member of Parliament has also been popularly elected indicating that awareness-raising has been effective.

Nevertheless, civil society organization point out that a legitimate national action plan is yet to be adopted. The national action plan has been developed by a task force including government and civil society organizations. It is still pending approval from the government at the time of writing.

While efforts have been aimed at increasing accountability for crimes against persons with albinism to try and curb the number of attacks, CSOs underscore the importance of the other pillars of the RAP given that protection, prevention measures and addressing root causes are absolutely critical to prevent recurrent flare ups of attacks. The latest reported case, at the time of writing, being the mutilation and murder of a 5-year-old boy on May 4th, 2021, in the Tabora region of Tanzania.

iii. State commitments in Nigeria

There are 13 reported cases of attacks against persons with albinism in Nigeria, which is relatively low compared with Malawi and Tanzania. However, discrimination and stigmatization against persons with albinism in Nigeria are rampant. These 2 factors might explain why Nigeria, guided by The Albino Foundation (TAF), the largest civil society organization representing persons with albinism in the country, has approached

¹⁵ Government Notice n°110, Judicature and Application of Laws (Practice and Procedure in Cases Involving Vulnerable Groups). See at: <https://actiononalbinism.org/entity/9kqp3d69lom?file=1562265962670ovi1dvxujpl.pdf&page=1>.

albinism less from a law enforcement and public safety angle and more from a disability perspective with a policy to **mainstream** albinism into diverse sectors of development with the National Policy on Albinism adopted in 2012, which was revised in 2019.

In recent years, the Nigerian government has supported the work of TAF in several key ways to improve **inclusion and non-discrimination** of persons with albinism mostly within the wider policy framework of disability rights.

- Collaboration between TAF and the Education Board of the Federal Capital Territory to sensitize hundreds of principals of primary and secondary schools on albinism rights.
- Engagement of the Federal Ministry of Education and National Council on Education on the approval for the Review of the National Policy on Albinism to include it as an emerging issue.
- Consideration of the Regional Action Plan on Albinism in Africa and how to domesticate its guidelines.
- In 2018, a baseline survey of 3,500 persons with albinism from 6 out of 36 States as well as in Abuja, the Federal Capital Territory, was carried out to generate comprehensive data on the size and characteristics of persons with albinism in Nigeria. The data collected thus provides the basis for informed planning and implementation of appropriate intervention programs and appropriate support systems that will facilitate the delivery of relevant, effective and timely services; and to develop a new national blueprint that will be used in addressing the cause of persons with disabilities in general among other vulnerable persons in Nigeria.
- Promote participation in the democratic process with a massive project sensitizing and including persons with disabilities and persons with albinism in the electoral process.
- Since 2007, the government has rolled out a skin cancer treatment program through which skin cancer is treated at no cost at the National Hospital in Abuja. However, the cost and distance of access to the services remained a barrier for many persons with albinism. In 2019, the Nigeria government decentralized free skin cancer treatment for persons with albinism to 6 teaching hospitals, thereby reducing some of the difficulty of access.

c) Strong Civil Society Organizations

The third common aspect in the top RAP implementing countries, is the strength of CSOs representing persons with albinism. Under the Same Sun and Standing Voice in Tanzania; APAM in Malawi, and The Albino Foundation in Nigeria are NGOs that are experienced, well organised, and have achieved competence, legitimacy, and confidence in mobilizing financial resources, efforts and commitments to defend the cause of persons with albinisms. In Malawi and Tanzania, they have developed essential support on the ground in more than one field including advocacy, health and

education. They are adept at harnessing the various legal instruments, bodies and mechanisms at national, regional and international levels.

i. Implementation by Civil Society Organizations in Tanzania

Tanzania has a relatively high number of organizations working on the situation of persons with albinism. It also has the oldest albinism support group on the continent - the Tanzania Albinism Society - which began in the late 1970s and continues to provide indispensable support to persons with albinism in the country. In particular it conducted the 2019 Baseline Survey in collaboration with the Karagwe Community Based Rehabilitation Programmes

Since 2008, the NGO, Under the Same Sun has launched massive advocacy programs in Tanzania and ultimately developed the "Guide for Teachers of Students with Albinism" which government has since adopted. It has been very active in raising awareness and empowering of persons with albinism, running summer camps and providing bursaries and placements to train young adults. It is also keeping a registry of all attacks against persons with albinism on the continent and was at the forefront of a majority of initiatives at the UN and AU concerning the rights of persons with albinism.

In 2012, the NGO, Kilisun, launched the first ever production center for sunscreen lotion near Kilimanjaro in Tanzania. Since then, the production of sunscreen is ongoing and distributed at no cost and on a regular basis, to thousands of persons with albinism with the support of the NGO Standing Voice.

Standing Voice has also contributed to very significant advances on access to skin cancer detection and treatment by persons with albinism. Officially endorsed by the Government of Tanzania and the United Nations, the Standing Voice Skin Cancer Prevention Programme trains local dermatologists to deliver a decentralized network of skin cancer prevention and surgery clinics. Furthermore, Standing Voice operates a Vision Programme that delivers eye care and education to nearly 4'000 people with albinism in 9 regions across Tanzania. They also target schools to improve educational performance and promote inclusive teaching practice.

iv. Implementation by Civil Society Organizations in Malawi

The Association of Persons with Albinism of Malawi (APAM), Beyond Suncare and Standing Voice are the main civil society organizations representing persons with albinism in Malawi. All work collaboratively on various initiatives. APAM's advocacy has been instrumental in getting the National Action Plan on albinism in Malawi, and with a budget. Its advocacy was also central to the appointment of two persons with albinism to senior public posts.

Beyond Suncare started their work in Malawi in 2009 and have since developed a very efficient and replicable model that combines local and customized sunscreen production, free and decentralized distribution networks in partnership with local stakeholders, education and awareness sessions and training, as well as impact measurements and follow-up on compliance. Beyond Suncare implement multilateral approaches to tackle albinism from a holistic perspective.

Standing Voice is the third element of this group of CSOs that collaborate on serving the needs of people with albinism in Malawi. As it does in Tanzania, Standing Voice adopts an integrative approach with community programmes delivering health, education and advocacy, reaching thousands and training local stakeholders (dermatologists, optometrists and health professionals, association leaders) to embed and develop care and education networks.

v. Implementation by Civil Society Organizations in Nigeria

Since its formation in 2006, The Albino Foundation of Nigeria has been at the forefront of advocacy, working with government in achieving many of the aforementioned milestones and leveraging government support with skill to complete several very successful private/public initiatives.

As mentioned above, the TAF was instrumental in conducting Nigeria's baseline surveys and Civil servants survey. It also collected detailed data on persons with disability and albinism in order to have evidence on which to base efficient and targeted policy proposals when advocating to government and development partners.

From December 2018 to December 2019, TAF with EU backing, carried out an extensive electoral inclusion project from the triple perspective of candidates, voters and electoral facilitators. It trained constituents with disabilities contestants on electoral and political guidelines with the overall aim of equipping participants with the necessary knowledge and skills to better vie for elective and political positions in Nigeria. It trained elections officers on disability issues and on how inclusion can be achieved in the electoral process by the provision of assistive aids for persons with disabilities/albinism such as magnifying glass, braille, pictorials and animations etc. TAF also did community outreach in 3 project locations to sensitize the community on electoral guidelines for disabled voters. Finally, it also trained and deployed election observers to evaluate the performance of various stakeholders towards the inclusion of persons with disabilities in the electoral process, reporting from over 500 polling units in the 3 states on the number of disabled voters recorded for each polling station and accessibility of polling stations.

TAF also created an Albinism Research Center in November 2020 in partnership with Afe Babalola University focussing on medical (skin and vision), social and psychological aspects.

It also led a stakeholder meeting on a bill for the establishment of a National Agency for the Welfare of Vulnerable Persons (NAWVP) and engaged the Federal Ministry of Education and National Council on Education.

TAF has launched multiple radio programs that reach millions of listeners.

Other civil society organizations in Nigeria such as The Albino Network and the Onome Akinlolu Majaro Foundation have used cultural activities to spread awareness at grassroots events and through various forms of traditional and social media.

Taken together, the civil societies organizations in Malawi, Tanzania and Nigeria have achieved great strides in implementing several measures of the Regional Action Plan, particularly in the fields of advocacy, health and education. **However, most of these initiatives are privately, not publicly, driven and funded.**

Commonalities in bottom 3 performing countries on implementation

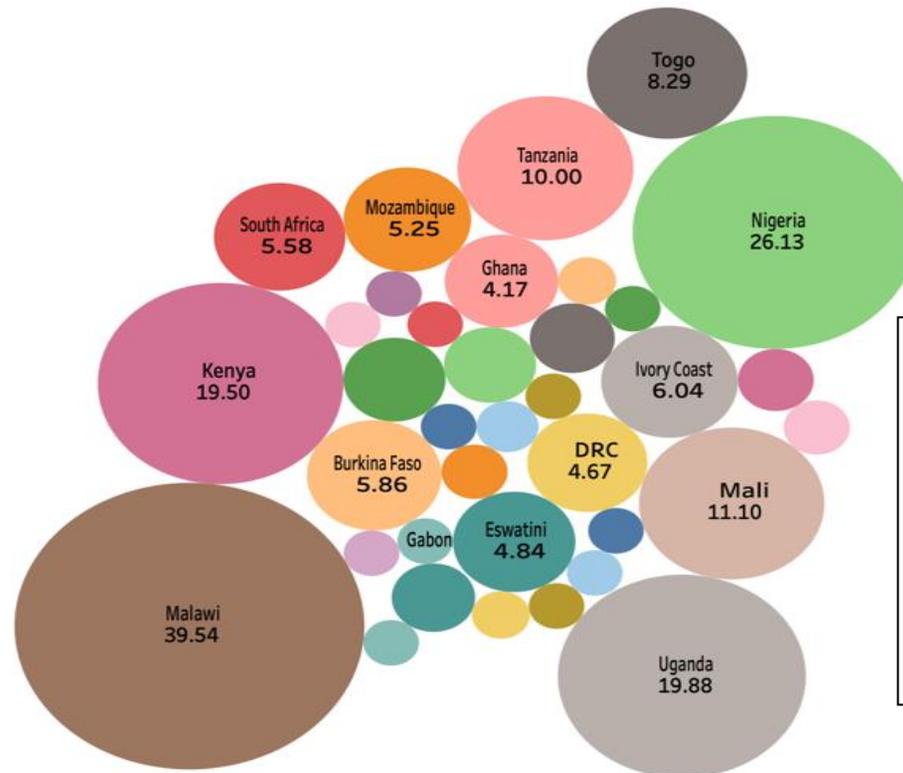
The common characteristics of poor performance in implementing the RAP are:

- absence of a strong and organised civil society movement representing person with albinism with the capacity to advocate effectively on behalf of persons with albinism to local or state authorities, development partners and the private sector.
- Total absence of commitment by the State to implement the RAP.
- Perception of the country as being “unproblematic” for persons with albinism due to the low number of reported violent attacks. Unfortunately, this causes the more silent issues of discrimination, stigmatization and skin cancer to be completely ignored.

VII. IMPLEMENTATION PROGRESS – BY PILLAR

A. Prevention Measures (%)

Malawi has the highest score of progress in Prevention Measures



The 3 Best overall performances on overall PREVENTION measures are:

- **Malawi: 39.54%**
- **Nigeria: 26.13%**
- **Uganda: 19.88%**

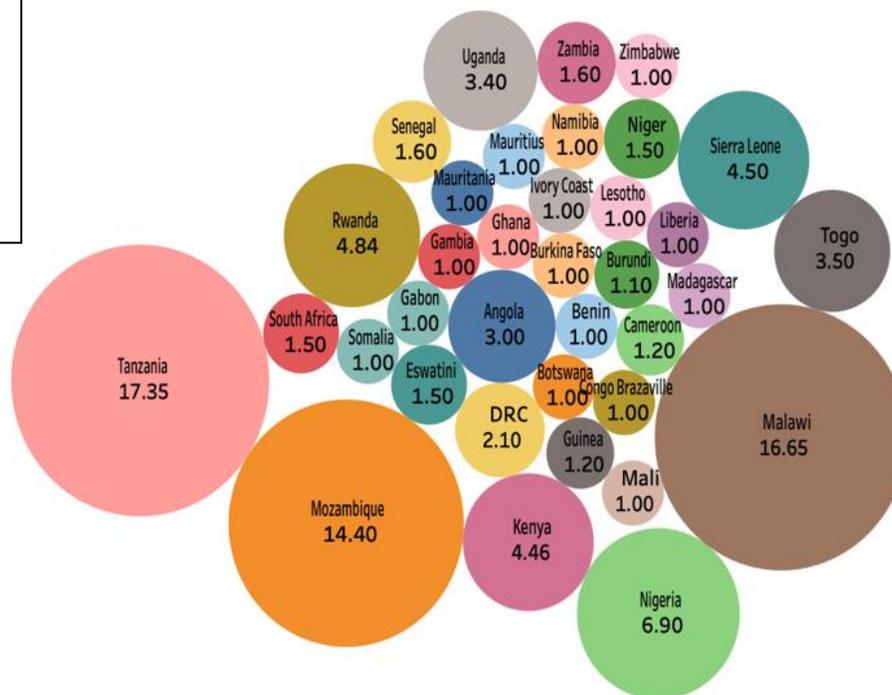
The Prevention Measures include:

1. Public education and awareness-raising campaigns, maintained (not ad hoc) for at least two years
2. Data collection: disaggregated data and needs assessment (including security needs)
3. Root causes — identify and address

The 3 Best overall performances on PROTECTION measures are:

- **Tanzania: 17.35%**
- **Malawi: 16.65%**
- **Mozambique: 14.40%**

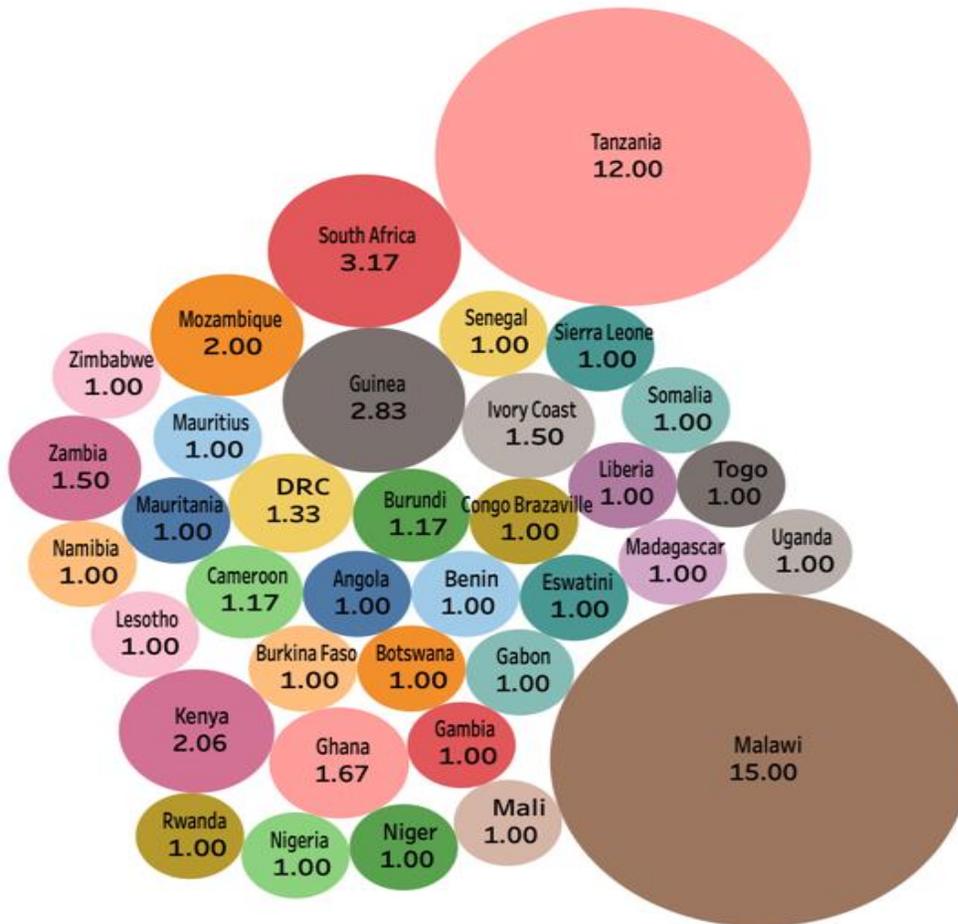
B. Protection Measures (%)



The Protection Measures include:

1. Effective law enforcement in response to attacks and violations against persons with albinism
2. Review of legislative frameworks, including with regard to trafficking in body parts, witchcraft and traditional medicine, and recognition of colour as a ground of discrimination
3. Training of health-care workers and midwives
4. Social welfare schemes that include persons with albinism
5. Monitoring and reporting — supporting the work of civil society

C. Accountability Measures (%)



The Accountability Measures include:

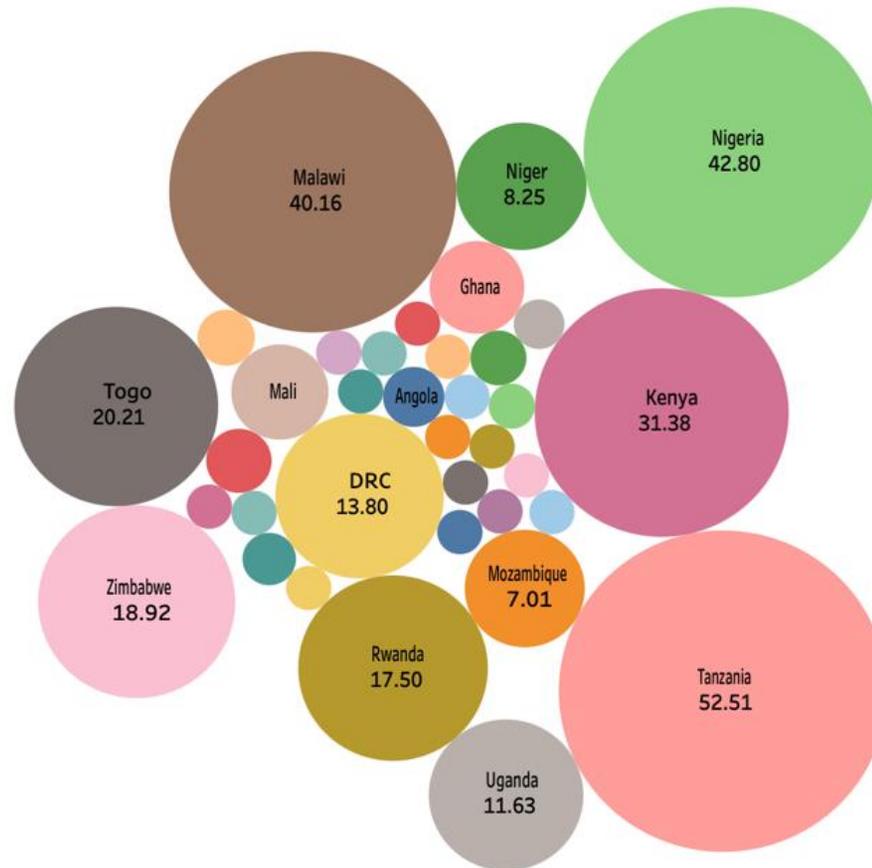
1. Combat impunity; Prioritize prosecution of cases of attacks
2. Victim support
3. Reintegration of the displaced

The 3 Best overall performances on ACCOUNTABILITY measures are:

- Malawi: 15%
- Tanzania: 12%
- South Africa: 3.17%

The targets of the RAP relating to accountability are linked to reported attacks and vary widely between countries. As mentioned previously Tanzania and Malawi stand out for their highest numbers of reported attacks against persons with albinism. The vast majority of other countries tend to regard themselves as unproblematic for persons with albinism and have made very little to no progress in addressing accountability of the less visible and less brutal yet numerous cases of discrimination, stigmatization, exploitation and violence against persons with albinism.

D. Equality & Non-Discrimination Measures (%)



The 3 Best performances overall on EQUALITY AND NON-DISCRIMINATION measures are:

- **Tanzania: 52.51%**
- **Nigeria: 42.80%**
- **Malawi: 40.16%**

The Equality & Non Discrimination Measures include:

1. Creation of the post of officer on albinism in the ministry responsible for persons with disabilities or in a national human rights framework
2. By 2021, reasonable accommodation is available at all level of education for children and adults with albinism
3. Access to adequate health care for those with skin cancer
4. Principle of intersectionality

There is better overall implementation on equality and non-discrimination measures than on the other 3 pillars of the RAP. Equality and discrimination measures relate to a wider array of measures ranging from reasonable accommodation to mainstreaming persons with albinism within the disability framework, to the appointment of person with albinism to senior public posts. Reflected in these figures are also the increased awareness of albinism as a dermatological condition and advances in skin cancer prevention and care, with several countries leading the way in the local production of sunscreen and skin care clinics - although most of these were provided by civil society organizations.

VIII. INDIRECT IMPLEMENTATION

Various indirect implementation activities have been carried out in alignment with various measures of the RAP.

These include the development by the RAP Task Force¹⁶ of rules for measuring implementation progress of the RAP. A series of capacity development of organizations representing persons with albinism was organized by the Center for Human Rights of the University of Pretoria, focusing primarily on human rights skills for advocacy. To date, training workshops have been held in Mozambique, Senegal, South Africa, and Uganda, as well as online to enhance participation across the region. The sessions have been conducted in English, French and Portuguese. Moreover, extensive efforts in advocacy, public awareness and data collection have been made by various UN entities such as the Office of the High Commissioner for Human Rights (OHCHR), UNESCO, UN Women, IOM, UNICEF, UNDP, among others. In the same vein, extensive work in public education and advocacy has been carried out by large human rights organizations such as Amnesty International, particularly regarding the SADC regional economic community and Human Rights Watch. As relative heavy weights in the human rights field, the voices of these organizations served to amplify and generate support for the voice and work of grassroots organizations promoting the rights of persons with albinism.

In addition, there has been the creation of an interdisciplinary research network on albinism with the support of various universities in Ghana, Tanzania, South Africa, Canada and the UK, namely, the Mothering and Albinism project.¹⁷ This project maps and studies patterns of resilience at the juncture of gender, colourism, religion, and human rights, in context of mothers impacted by albinism.

¹⁶ About the RAP Task Force see: <https://actiononalbinism.org/page/g21dqw5v8x3cj5m0ulqc15rk9>

¹⁷ See <https://motheringandalbinism.com/>

The RAP has been featured in numerous awareness-raising events such as conferences, and in particular the media; most of the latter, led by the Independent Expert.

Various entities stepped forward to support particular initiatives at the grassroots, national and regional levels, directly aimed at persons with albinism, and in so doing, indirectly implemented the RAP. Other entities stepped forward to support the incorporation of persons with albinism as beneficiaries of broader programs on disability, education, health, women, children, marginalized and vulnerable groups, among others. These entities included regional bodies such as the AU, EU, national diplomatic corps, the UN family of agencies, national governments, private foundations and the private sector.

IX. EXAMPLES OF BEST PRACTICES

Since the launch of the Regional Action Plan, there have been many examples of best practices across the continent even when the overall implementation progress in the countries where these ideas emanate from remained lagging. We have selected a few here for acknowledgement of the work achieved, for encouragement and as inspiration for others.

Best Practices in PREVENTION

a) Data collection in Kenya

In 2019, following a 10-year campaign by Albinism Society of Kenya, and the further push provided by the UN Independent Expert's visit and in collaboration with OHCHR, Kenya introduced a specific indicium on persons with albinism in its national census.

b) Innovative mobile application in Mali to raise awareness, collect data and prevent attacks

A multi-stakeholder initiative driven by the Association Malienne des Personnes atteintes d'Albinisme (AMPA) developed a free mobile phone application launched in December 2019 called **YÉFÉKÉ**. A bilingual application (French and Bambara) with an interface that includes many oral descriptions and voicemail options for people with low vision. YÉFÉKÉ has been downloaded by 1172 persons with albinism in Mali at the time of writing and meets several RAP objectives, including: awareness raising since the interface provides information on albinism; collection of disaggregated data as users are invited to fill in questionnaires about their health and education status among other areas. The application also has a mechanism to sound alarm as well as an emergency number linked to relevant authorities. Voluntary testimonies on the social status of

persons with albinism and their family members as well as discrimination they face, are also being gathered as a part of a situation analysis and report to government.

c) Advances in evidence-based methods, research and data collection in Togo

The first doctoral thesis in medicine on albinism at the University of Lomé in 2020 was based on extensive consultations of persons with albinism in the area of dermatology, namely skin health.¹⁸

Best Practices in PROTECTION

a) Facilitating access to police services in South Africa with the 6 Points Plan

The South African Police Service was engaged by The Albinism Society of South Africa (ASSA) to have its police force participate in training programs about albinism. A 6-points Plan displayed in the entrance of police stations sensitized on how to facilitate access to the police to Persons with albinism and to encourage reporting of attacks. There are also regular police training events during Albinism Month in September in South Africa

b) A Law on the Protection and Promotion of the Rights of Persons Living with Albinism in the State of Guinea

In April 2021, after a high-profile case of exploitation of children with albinism by adults, Guinea became the first country in Africa to develop specific legislation on persons with albinism.¹⁹

Best Practices in ACCOUNTABILITY

c) Effective law enforcement in Malawi

The Government and the judiciary have clamped down on perpetrators of attackers against persons with albinism with a series of death sentences handed down in cases of killings of persons or children with albinism in 2019 and 2020. This sends a strong signal that crimes against persons with albinisms will be investigated and punished

¹⁸ Mentioned in the annual report of the Association Nationale des Albinos du Togo (ANAT): « Epidémiologie et profil des dermatoses chez les personnes atteintes d'albinisme au Togo en 2019 », by medical intern Kassang, under supervision of Professor Saka.

¹⁹ See Décret Portant Promulgation de la Loi L/2021/0016/AN sur l'Albinisme en Guinée (30.04.21).

severely.²⁰

Best Practices in EQUALITY AND NON-DISCRIMINATION

a) Project: “Disability Inclusion Nigeria” (2018)

A project that centred on disability inclusion in the political arena, including through putting in place of reasonable accommodation measures such as magnifying glasses in voting sites. Priority privileges to avoid standing in line in the sun and also to avoid name calling and ridicule; development of training manual for the electoral body to know how to help PWA in the election process.

b) Access to health care to tackle and prevent skin cancer in DRC

The civil society organization, Corbetta DRC obtained a 2-year grant for the years 2020-2021 to establish a network for research and multidisciplinary medical care for people with albinism in the DR Congo. The expert network of complementary medical specialists will be situated in 3 different sites in the Democratic Republic of the Congo (DRC), aiming to establish strong links with support groups of persons with albinism and a durable change in the approach of persons with albinism by providing accessible, evidence-based health care, delivered by a multidisciplinary expert team employing tailored electronic health records. This will equally provide a strong basis to promote long-term follow-up and research as well as capacity building among medical personnel. This strong network will provide the anchoring point for future initiatives to promote the well-being of persons with albinism, including in psychosocial and legal aspects.

c) Intersectionality

Albinism Umbrella, a civil society organization in Uganda has raised 70 million Uganda shillings to develop a center for persons with albinism in Uganda. The vision is mainly to provide a location for capacity building, empowerment and research. It is envisioned that various person making a difference in the lives of persons with albinism will meet, share experiences, and have a coordinated effort to reduce the levels of stigma and discrimination. It should be emphasized that the center will not be an exclusive place for persons with albinism. This would further discrimination. It is intended to be a place to showcase the untapped potentials of persons with albinism. The center will however have a small accommodation facility to house the distressed, homeless or those who need counselling before returning to society.

²⁰ See for instance: *Chilumpha Sentenced to Death for Killing Child with Albinism* (sept 2020); *Three people slapped with death sentence for killing albino* (Aug 2019)

d) Action for empowering women with albinism in Togo

In 2020, as part of the implementation of specific measures in favor of women with albinism, the Women's Cell of Association Nationale des Albinos du Togo (ANAT) launched the School of Female Leadership project which aims to strengthen the leadership of a group of young women with albinism so that they participate effectively in enhancing the image of persons with albinism in Togolese society.

X. BUDGET FOR NATIONAL ACTION PLANS

These are preliminary findings from a brief study on the budget allocated by national governments to support implementation of the Regional Action Plan through the financing of its components, a National Action Plan or policy on albinism. The sample is semi-random with a fixed inclusion criteria being the allocation of a budget or particular expenditure to the National Action Plan /Policy or to the issue in general.

Inadequate public finance allocations

The two sampled countries with the most substantial public finance allocations for the RAP, in absolute terms, were Kenya and Malawi. But even in these countries, important finance gaps remain, and it appears that current allocations are not adequately reaching all persons with albinism.

Available information suggests that allocations are not commensurate with the population of persons with albinism in either country: in Malawi for example, after deducting the costs of a small-scale house building programme and excluding an unquantified tax waiver, the remaining budget allocation for persons with albinism in 2019-20 comes to only around 2971 Malawian Kwacha (around 4 USD) per person with albinism.

In addition, available evidence indicates that there have at times been challenges in accessibility (Kenya), adaptability (Malawi) and quality of services provided. Moreover, coverage of the different areas of the RAP is uneven.

Variances in public finance allocations

A simple comparison between countries cannot, on its own, give a full picture of how far those countries are supporting the implementation of the RAP at the national level. As noted in section above, even the countries that perform better in such comparisons still have a long way to go. However, comparisons can be useful in highlighting gaps. The following analysis presents two different ways of comparing the commitment public finance allocations for the RAP in the five countries studied. Both show substantial variation across the different countries.

Comparing public finance allocated to total resources

On the basis of this first type of comparison, **Malawi** stands out for its level of ambition.

The five countries in the sample that was studied – Kenya, Malawi, Nigeria, Togo and Ghana, have widely differing levels of resources available to uphold the rights of persons with albinism. This is based on many considerations²¹ including but not limited to domestic factors.²² Whichever dimensions are emphasised, it is clear that Malawi is one of the more resource constrained countries in the sample. Yet – based on the available data – Malawi also allocates a comparatively high level of public finance for implementation of the Regional Action Plan.

Table 1 below shows public finance allocated for the Regional Action Plan (RAP) in different countries, compared against two examples of measures that give some indication of the level of resource availability and economic constraints in each country. (This is emphasised with a basic colour coding system: roughly, darker shading indicates greater resource constraints – though of course this coding masks some nuance).

Table 1: Public finance allocated to the RAP, compared with selected economic indicators.

Country	Public finance allocated to the RAP (million USD) ²³	Gross National Income (2019, million USD) ²⁴	Economic and environmental vulnerability index (2018) ²⁵
Malawi	Over 1.4	7,164	47.1
Kenya	Over 1	91,824	26.4
Ghana	Very low but not quantifiable	67,508	33.7
Nigeria	Very low but not quantifiable	407,589	34.2

²¹ As set out in, for example, the Center for Economic and Social Rights' OPERA framework

²² As highlighted in the Regional Action Plan and also in, for example, the Maastricht Principles on Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights, particularly pp.10-11

²³ Please see country fact sheets for more detail on the data in this column. Totals are for 2019-20 or 2020, depending on the fiscal year of the country concerned.

²⁴ Source: World Bank, [Gross National Income 2019, Atlas method](#)

²⁵ The economic vulnerability index is a measure of barriers to 'sustainable development' and of vulnerability to economic shocks. It is one of the criteria used to define Least Developed Countries. A higher score represents greater vulnerability. For more information, see UN Department for Economic and Social Affairs, '[LDC Identification Criteria and Indicators](#)' (accessed 20 March 2021).

Togo	Very low but not quantifiable	5,605	28.3
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(**Caution:** while Table 1 gives a general sense of how the countries in the sample compare, and illustrates the overall finding on Malawi, it is advised not to use it for detailed comparisons, in the absence of analysis on a broader range of measures and their indicators.)

In addition, comparing public finance for the RAP with countries' total resources available, it is also instructive to compare with the share of the countries' total resources that are channelled through public budgets. In this comparison too, Malawi appears to stand out.

Table 2 below shows available data on public finance allocations for the RAP, compared against total budgets. (**Caution:** every effort has been taken to state the 'total budget' figures, in the right-hand column of the table, on a like-for-like basis, but some small ambiguities remain. It is recommended to use the figures to give a general sense of scale, but not to use them for precise calculations).

Table 2: Public finance allocated to the RAP, compared with total national budget.

Country	Public finance allocated to the RAP (million USD) ²⁶	Total budget (million USD) ²⁷
Malawi	Over 1.4	2,300
Kenya	Over 1	27,700
Ghana	Very low but not quantifiable	15,100
Nigeria	Very low but not quantifiable	28,500
Togo	Very low but not quantifiable	1,600

XI. LOOKING AHEAD: CONCLUSION AND THE WAY FORWARD

The Regional Action Plan is a remarkable achievement that has provided a **framework for action** and given clear focus on how to advance the human rights of persons with albinism in Africa, Sub Saharan Africa in particular. It serves as a roadmap guiding actions of State institutions and civil society organizations.

The RAP is also useful to provide weight to advocacy as it carries the legitimacy of a document that has been elaborated through wide consultation of multiple expert stakeholders. That authority has been carried over into the AU Plan of Action on Albinism with content drawn largely from the RAP.

²⁶ Totals are for 2019-20 or 2020, depending on the fiscal year of the country concerned.

²⁷ Totals are for 2019-20 or 2020, depending on the fiscal year of the country concerned.

The itemization of the RAP targets and their monitoring efforts presented herein have helped to identify specific areas of strong and weak progress and indicate where efforts are being made and where more can be done to drive strategic action.

The measures and indicators also help to identify both geographically and on a country per country basis, the best performers and what States need to be encouraged to do more to advance the rights of persons with albinism.

The RAP contributed to a **sense of community** as all stakeholders defending the rights of persons with albinism rallied behind it to share the sense of ownership and common sense of purpose, focus and direction. This is an important aspect as civil society organizations representing persons with albinism tend to struggle alone with limited means, and for the majority of them, with limited public funding. The document has given a presence, a voice and a new confidence within the advocacy community, to a segment of the population that was mostly invisible and silent.

The progress witnessed, as well as subsisting challenges show the importance of albinism organizations who currently carry most of the burden of implementing the RAP. We have seen that there is a correlation between the strength and capacity of CSOs and the extent of national implementation. **The stronger the CSOs, the stronger the capacity and weight to lobby and advocate for the actions and budgets necessary to embed the RAP into domestic policy and institutions.**

The case of Nigeria in particular seems to demonstrate that enrolling state power even with relatively low budgetary commitments, through high-level advocacy serves to make some significant institutional and regulatory framework adaptations and advances in implementations of the RAP. **Considering the relatively low percentage of people with albinism to the rest of the population, the benefit of bringing together human resources, their energies, their talents, their imaginations, and their financial and logistical means in structured organizations and alliances, is large and directly linked to its ability to bring about concrete, positive and lasting changes to the enjoyment of their rights by people with albinism, their safety and well-being in the region.**

Looking ahead: the African Union Plan of Action (2021-2031)

- A longer time frame of 10 years for **longer term investment and projects.**
- The strategic outcomes have been broken down in specific and **clearly stated priority actions**, giving a more precise guide for implementation for improved efficiency.
- The entities responsible for implementation are clearly stated (ministries/public sector/ private organizations etc.) for **better accountability and more efficient, more realistic and fairer distribution of the implementation burden.** CSOs are not left alone to carry the burden of implementing the Plan of Action.

- **Indicators** are provided and listed for more accurate **monitoring, implementation and progress**, in line with the modern evidence-based policy approach.
- **Data Collection Mechanisms** are specified for every Strategic Outcome to help address the information gap.

With a legal framework now firmly established by the AU Plan of Action, the next task is to continue to strengthen and empower the African albinism community. Instruments have already emerged for that purpose. Some of them formal like the **Action on Albinism platform**, or the brand new **African Albinism Alliance**. Others more informal but no less lively and useful, such as **WhatsApp groups**, bringing together many stakeholders in various forums on albinism (eg OBEAC in DRC, Albinism Multipurpose Coop in Zambia, Corbetta in DRC). These groups are made up of several dozen or even hundreds of participants that weave an active network, exchanging information, good practices, alerts, support, documents, medical or legal advice.

Recommendations

The following recommendations are made to States as the primary duty bearer in human rights. Other stakeholders such as the international community, National Human Rights Institutions, the private sector and other stakeholders should support States in carrying them out, with and in consultation with persons with albinism and organizations representing them:

1. **Support Civil Society Organizations (CSOs) serving persons with albinism because these CSOs are key determining factors in the implementation of the AU Plan of Action.**
2. **Domesticate the AU Plan of Action by adopting a National Action Plan on albinism and/or by integrating it into relevant national legal frameworks such as on disability, health, and education, security, among others.**
3. **Adopt as part of National Action Plans a multi-year budget using the amounts allocated in Kenya and Malawi (estimated at 1 million USD annually) as best practices.**

Enforcement and accountability mechanisms

1. **Report as part of their obligations to report to the African Union mechanisms, in the areas of disability, health education, security among others, their implementation of the AU Plan of Action such as through National Action Plans or other measures.**
2. **The Action on Albinism platform (Actiononalbinism.org) should be continued to popularize the AU Plan of Action and serve as a community for organizations representing persons with albinism and all supporting stakeholders.**

- 3. The Action on Albinism platform should simplify monitoring measures given all the challenges in gathering data on implementation and should consider use of general and simplified indices such as whether a country has a National Action Plan, with a budget or not.**
 - 4. The African Union should continue to support the implementation of the Plan of Action on albinism including by ensuring that the Special Envoy on albinism is appointed, that State Parties are engaged in the implementation process and that a mutual relationship between the AU and persons with albinism continues to flourish in this regard, with a productive momentum that lasts all the way to the end of the Plan of Action in 2031.**
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