



Pilot Report 2021-2023



Qstn 1		
govt	CSO	Dup Partners
* Protects it's people (PWA).	* Advocacy and Lobbying	
* Link different partners	* Context and framework.	

table of CONTENTS

2021 - 2023 Milestones	02
Introduction	03
Our Strategy	04
Background	05
Regional Context	06
African Union Plan of Action on Albinism (2021-2031)	07
National Action Plans "NAPs" on Albinism	08
NAP Pilot Phase Progress	09
NAP Progress by Country	10
How we supported Human Rights Advocacy on Albinism	14
AAN Learning Forum 2023	15
Pan-African Albinism Survey	16
Challenges & Lessons Learned	18
Conclusion	19
AAN Funding Partners	20

2021 - 2023 Milestones

16

Multi-day collaborative activities to support the development of National Action Plans "NAPs" in 8 countries

25

High stakes Human Rights Advocacy events conducted at the African Union (AU) and United Nations (UN) Level in collaboration with grassroots albinism groups

52

Albinism groups were actively engaged and supported either through NAPs or human rights-based advocacy activities

3

NAPs adopted/virtually adopted as of date of this report: Kenya, Uganda, and Tanzania





INTRODUCTION

The Africa Albinism Network (AAN) was formed in 2021 by the former UN Independent Expert on albinism. The pilot entered its test or pilot phase from April 2021 to March 2023.

VISION

For people with albinism in Africa to take their rightful place throughout every level of society, and that the days of discrimination will be a faint memory

MISSION

To promote the implementation of the African Union Plan of Action (AU PoA) to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021-2031).



To achieve our mission, AAN aims to replicate the “Kenya Model” namely the use of strategic advocacy, led by national albinism organizations, to move government and relevant stakeholders to adopt a national action plan on albinism **(based on the African Union Plan of Action on albinism)**; with multi-year budgets.

OUR STRATEGY

Objectives of the Pilot Phase

Partnerships with grassroots albinism organizations to:

Support the **Development of National Action Plans** on Albinism

Support the **Implementation of National Action Plans** on Albinism

Method of Work

Focus on **eight priority countries** for National Action Plan development

Capacity Development through **Joint advocacy** at AU and UN for both priority and non-priority countries

Learning forums for both priority and non-priority countries

Professional Outfitting including efficient staffing, agile work process and a Communications Strategy

Ongoing consultations with albinism groups and an Advisory Board

BACKGROUND

Persons with albinism “don’t die, they disappear.” This is the myth propagated in several African nations where persecution and discrimination against persons with albinism (or “PWA”)—who are demonized, dehumanized, and whose body parts are believed to possess magical powers—is still prevalent. In the last decade, atrocity reports in several African countries shook the world and revealed the depths of human rights violations against marginalized persons with albinism. These violations include murder, trafficking in persons and body parts, and grave desecrations. These crimes are consequences of widespread stigma and discrimination against PWA due to myths and superstitious beliefs intertwined with harmful practices such as ritual attacks and ignorance.

“
There are 1 in 5,000 to 1 in 15,000 people with albinism on average on the Continent. This makes the number of crimes more staggering.
”

*The former UN Expert on albinism, Ikponwosa Ero, reported additional cases that brings the overall total closer to **900+ cases in the last 13 years.** These are reported cases alone. Due to the frequent involvement of family members as perpetrators, both the UN Expert and civil society organizations (CSOs) believe that cases are underreported.*



REGIONAL CONTEXT

Southern Africa

Reports of attacks were recorded in every country in Southern Africa over different periods of time, with 6 of 11 of them reporting cases in the last five years. Malawi and Mozambique are the countries leading in reports of attacks and where governments have taken several steps to deal with the situation. The most recent case from Malawi involved the disappearance of a man with albinism in January 2023. Madagascar has over 33 reported cases of attacks in the last 2 years with 5 cases reported in February and March 2023. These cases involved trafficking of children ranging from ages of 9 to 15 and one case of decapitation.

West Africa

Reports of attacks against persons with albinism have been less prevalent in the western part of the continent in comparison to other regions. Nevertheless, murder, mutilations, trafficking, and grave desecrations have been reported in Benin, Burkina Faso, Cameroon, Côte d'Ivoire, Ghana, Guinea, Mali, Nigeria, Senegal, and Togo. The most recent attack was reported in Ghana in April 2023. Although reported attacks in this region have been decreasing, an increase in attacks in other parts of the continent might influence the return to this practice in this region due to the cross-border nature of the violence. Moreover, because the root causes of attacks, such as ignorance about albinism and harmful practices such as ritual attacks still exist in most of the region, there is a possibility that attacks can flare up even after an apparent decline.

East Africa

Reports of attacks have been more prevalent in East Africa, specifically in the countries of Burundi, Kenya, Tanzania, and Uganda. Tanzania is the country with the most reported cases of attacks with the most recent one reported in November 2022 in the Mwanza region. Studies show that in Tanzania, PWA represent 1 in every 1,429 births, a much higher rate than other countries in the region. Tanzania is also affected by the cross-border nature of trafficking in persons and body parts of PWA as there are reported cases of luring persons with albinism and criminals found in possession of their body parts in neighbouring countries such as Burundi, DRC, Kenya, Malawi, and Zambia.



AFRICAN UNION PLAN OF ACTION ON ALBINISM (2021-2031)

In July 2019, during its thirty-fifth ordinary session, the Executive Council of the African Union (AU) decided to adopt a Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa, (Plan of Action 2021-2031) making it a continent-wide strategy. The AU also decided that a Special Envoy on Albinism would be appointed to ensure the implementation of the Plan of Action. It has therefore been our mandate to support organizations representing persons with albinism in Africa to implement the AU PoA. National Action Plans adopted to date can be found on our Resources page [here](#).

Despite the African Union's efforts to curb these attacks across the continent through the adoption of the Regional Action Plan 2017-2021 and its extension plan: the AU Plan of Action (2021-2031), most African countries including those with high reports of atrocities are slow to domesticate and implement the plan. Therefore, we recommend:

- Stronger cohesion between Government entities and albinism groups.
- Support movement building efforts and the creation of alliances between multiple albinism groups within countries.
- Increase in allocation of resources to enhance the capacity of albinism groups in their service to PWA and advocacy.

NATIONAL ACTION PLANS "NAPS" ON ALBINISM

We believe that the AU Plan of Action ("AU PoA") on albinism needs to be implemented locally through National Action Plans on albinism with multi-year budgets (NAPs). NAPs consolidate and direct the efforts of albinism organizations, other CSOs and Governments to resolve issues faced by persons with albinism which will have a replicating effect at the national, regional and continental level.

Central to achieving these goals is a **strong partnership approach with grassroots albinism groups** and **a framework for joint advocacy** as well as **capacity development and coaching** of albinism groups in areas of need.

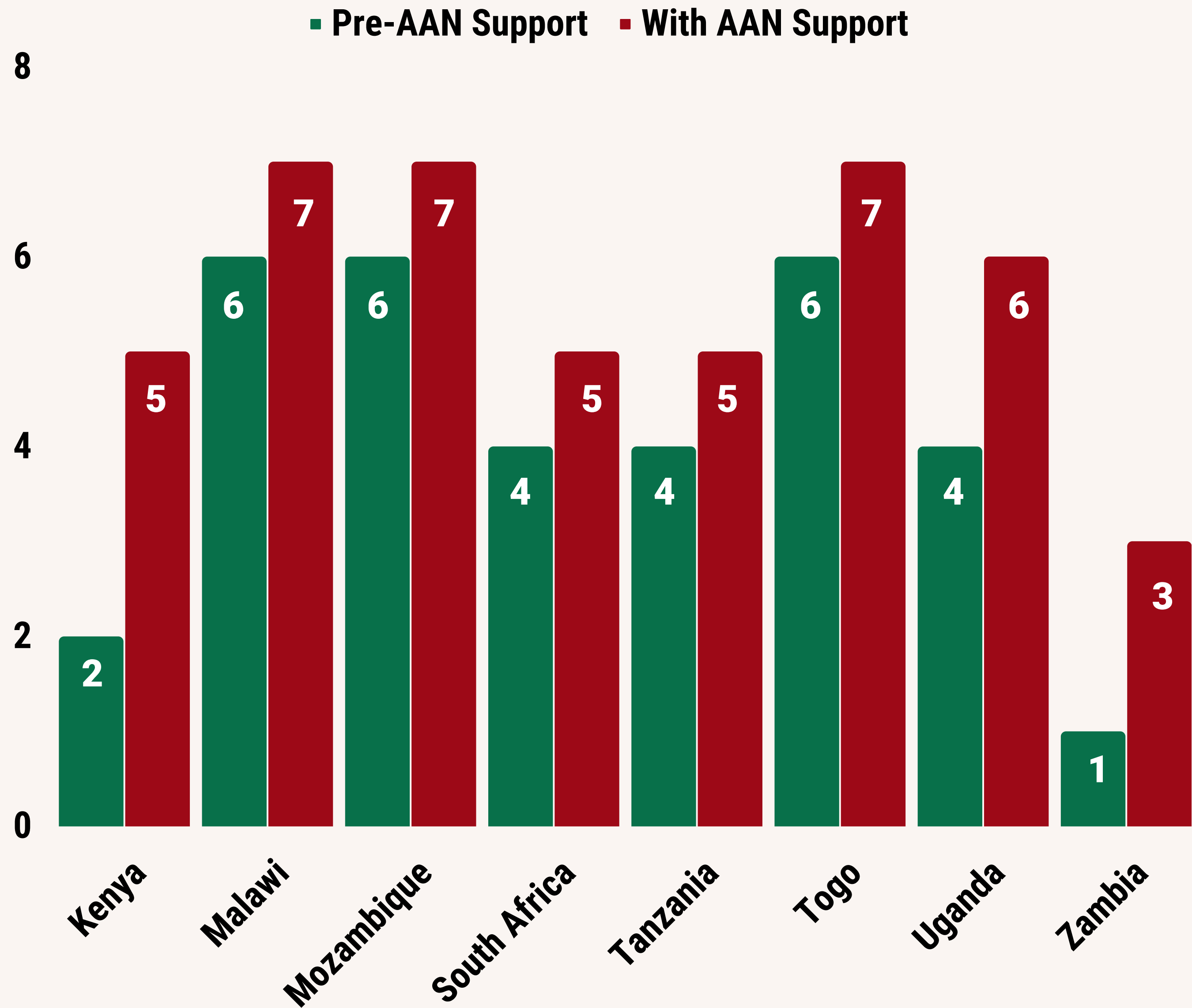
Our capacity development activities have often been **led by people with albinism** themselves, including albinism movement leaders who have been successful in various levels and forms of advocacy.

50% *INCREASE IN THE NUMBER OF NATIONAL ACTION PLANS ADOPTED OR ON THEIR WAY TO BEING ADOPTED WITH AAN'S SUPPORT*



NAP PILOT PHASE PROGRESS

STEP 1: AAN meets with country stakeholders
STEP 2: AAN identifies the national partner
STEP 3: Stakeholder engagement / Taskforce
STEP 4: NAP Draft and Review
STEP 5: Promote NAP Adoption
STEP 6: NAP Implementation
STEP 7: NAP M&E and Audit



NAP PROGRESS BY COUNTRY

Kenya

In 2022, AAN supported the validation of draft National Action Plan (NAP) and provided support for a human rights-based guidance on the draft NAP to ensure alignment with the AU Plan of Action. We collaborated with the Albinism Society of Kenya (National Partner), National Council of Persons with Disabilities (NCPWD) and Kenya National Commission for Human Rights (KNCHR). Kenya is set to adopt their NAP this year.



Malawi

In 2022, AAN collaborated with the Association of Persons with Albinism (APAM) in Malawi and the Malawi Human Rights Commission to support the review of the NAP. The review targeted district Commissioners and district leaders of APAM to share what their experiences have been in the 4-year period of NAP implementation. We also provided Human Rights guidance on the elapsed NAP and how it could be improved for the coming implementation period. Malawi has domesticated the AU PoA in the last five years and is in the process to support the audit & review of their NAP and waiting for final adoption.

NAP PROGRESS BY COUNTRY



Mozambique

In 2022, AAN collaborated with UNESCO Mozambique, the Ministry of Justice, and three albinism groups and other development stakeholders to support the review their NAP. We also provided human rights guidance and advice to ensure their renewed NAP would be in line with AU Plan of Action with a multi-year budget. Mozambique has domesticated the AU PoA in the last five years and is in the process of auditing their NAP and waiting for final adoption.

South Africa

In 2022, the AAN provided human rights guidance for their NAP to bring it in line with best practices and the AU Plan of Action. We also collaborated with the South Africa Albinism Task Force to host an online convening with albinism groups during South Africa National Albinism Awareness month. Participants tracked progress, challenges, and discussed ways forward on the NAP adoption by government.

The poster is for the National Albinism Awareness Month South Africa event. It features the logos for the Africa Albinism Network (AAN) and the National Albinism Task Force (NATF). The main title is 'UNITED IN MAKING OUR VOICE HEARD'. The event details are: DATE: 6 OCTOBER 2022, TIME: 10:00 SAST, VENUE: ZOOM. A registration link is provided: Register on Zoom: bit.ly/AAN-NAFT. The poster also lists the participants: Mpho Tjope (Chairperson, National Albinism Taskforce), Nontsikelelo Loteni (Secretary, National Albinism Taskforce), Zulmira Nhatave (Deputy Secretary, National Albinism Taskforce), Patrick Wadula (Member, National Albinism Taskforce), and Kwame A. Daklo (Host, Advocacy Associate, Africa Albinism Network). The tagline at the bottom is 'Tracking progress, challenges and the way forward.'

NAP PROGRESS BY COUNTRY

Tanzania

In 2022, AAN collaborated with Standing Voice, the Tanzania Albinism Society (TAS) and Karagwe Community Based Rehabilitation Programme (KCBRP) to strategize and to review their draft NAP. In February 2023, during the AAN forum in Dar es Salaam, a representative of the Government of Tanzania announced that the government will adopt the NAP in June 2023 on International Albinism Awareness Day.



Togo

In 2022, AAN supported ANAT, the National association of persons with albinism in Togo, Government entities, and other development partners to review their NAP, provide human rights guidance to align to the AU Plan of Action and to draft, as well to validate a new NAP for the 2023 -2027 period. Togo is a good example of a country advancing on the National Action Plan with little to no financial support from government. Rather, multiple stakeholders are involved in implementing the Plan.

NAP PROGRESS BY COUNTRY



Zambia

In 2021 and 2022, AAN supported the creation of the Zambia Albinism Task Force unifying over 10 albinism groups. AAN collaborated with Amnesty International to support the task force to implement one team building and two capacity development activities to lay the groundwork for their NAP. We also collaborated with UNICEF Zambia to contribute to the Situational Analysis of Persons with Albinism.

Uganda

In 2022, the Network supported three activities in Uganda. We provided human rights-based guidance for their draft NAP and in collaboration with Albinism Umbrella, supported the launch of their adopted NAP in Lira, Uganda in June 2022. We also supported the public dissemination of the NAP with albinism groups and government officials in December 2022.



HOW WE SUPPORTED HUMAN RIGHTS ADVOCACY ON ALBINISM

AAN supported the capacity development of albinism groups in strategic human rights engagement at the AU and UN. This involves participating at high-level meetings to advocate for Member States to adopt NAPs on albinism. During the pilot, we conducted joint advocacy with grassroots albinism groups at the:

- UN: Human Rights Council and the Conference for State Parties to the Convention on the Rights of People with Disabilities
- AU: African Commission on Human and Peoples' Rights and the African Committee of Experts on the Rights and Welfare of the Child

At these high-level meetings, our partners can interact directly with AU and UN mechanisms, respond to statements made by State representatives (often providing facts and counter-facts), make inputs to reports that are of relevance to the rights of people with albinism, and contribute to human rights monitoring processes such as the Universal Periodic Review (UPR) with the view to drive action on albinism through States and non-State actors such as the UN and AU agencies.

14 **ALBINISM GROUPS FROM 14 AFRICAN COUNTRIES CONTRIBUTED TO AU AND UN HUMAN RIGHTS REPORTS**

Partnership with the Namibia Office of the Ombudsman and UNESCO to publish the first Report on the Public Hearings on Persons with Albinism in Namibia

AAN LEARNING FORUM 2023

The Learning forum took place from 7-9 February 2023 in Dar es Salaam, Tanzania. Participants included 40+ representatives from **30 albinism groups from 14 African countries** (Angola, Benin, DRC, Ghana, Kenya, Madagascar, Malawi, Mali, Mozambique, South Africa, Tanzania, Togo, Uganda, and Zambia). There were also Representatives (specifically Persons with albinism) from Government ministries or agencies; representatives from international development organizations, foundations/donors/funding partners (current and prospective), and a Government representative from the host country of Tanzania.

The AAN Learning Forum 2023 was a unique opportunity for albinism groups across Africa to learn from each other, share perspectives as well as receive training from the Network and its partners. Emphasis was put on how to implement the AU Plan of Action through the development of country-equivalents i.e., National Action Plans on albinism (“NAPs”).

Participants were trained in how to mobilize resources and develop working strategies to advocate for NAP adoption by their governments. Most of the participants to the forum drafted a project proposal outline as a key output of the Forum, through which they would practice some of their learning.

The AAN Learning Forum has triggered NAP processes in three countries (Angola, Benin, and Ghana).



PAN-AFRICAN ALBINISM SURVEY

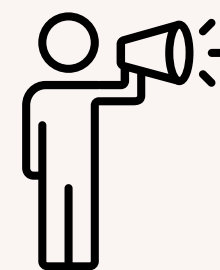
In 2022, AAN commissioned ©ImpactMapper to conduct the first pan African survey to understand the general landscape and trends on advocacy and human rights work for people with albinism in Africa. The goal of this research was to provide an overview of the albinism movement by mapping the profile, priorities, and issues of focus of organizations that are working to ensure the human rights of people with albinism in Africa. The study employed a mixed methodology - focus group discussions (FGDs) and a survey.

> **Participants: 48 Albinism Organizations from 23 African countries**



RESULTS

TOP ADVOCACY STRATEGIES

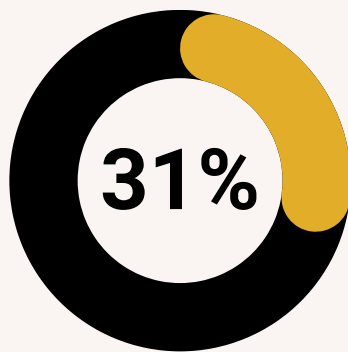
 Public Education and Awareness-Raising

 National Action Plans

TOP ADVOCACY PRIORITIES

 93% Access to Health and Access to Education

 33% Access to Employment

 31% Access to Justice

PAN-AFRICAN ALBINISM SURVEY

Key emerging themes from the survey

- Training should encompass resource mobilization and advocacy strategies, operational strategies including research, monitoring, and evaluation frameworks to sustain their work over time.
- The Right to Life appears to drive the advocacy priorities of albinism groups, hence why health, education, access to justice and employment, were the top four areas of work/priorities identified by the respondent albinism groups.
- The survey results affirm the measures identified in AU Plan of Action on Albinism.

Recommendations for Donors, Governments and AAN

- Support capacity development of albinism groups:
 - holistic training strategies (operations, resource mobilization, and advocacy work), supplemented by provision of operational support.
 - Set up an M&E framework to sustain capacity building interventions over time.
- Support movement building across countries



CHALLENGES & LESSONS LEARNED

CHALLENGES

- Remote work and lack of office space to foster collegiality
- Financial and resource constraints
- Linguistic barrier in some countries
- Lack of cohesion among albinism groups in some countries
- Government's unwillingness/inability
- Attacks and/or discrimination persist: Since AAN's inception, cases of attacks have been reported in a minimum of 12 countries namely including DRC, Madagascar, Malawi, Mozambique, and Zambia.

LESSONS

- Reduce the number of priority countries: To deepen AAN's depth of support while managing human resources, the Network will focus on up to 3, not 8 priority countries.
- Remove linguistic barriers by relying more on local stakeholders with bilingual capacity.

Despite the challenges, AAN made significant strides in supporting protection measures for people with albinism in Africa against discrimination and attacks. It is important that the AAN continues along this path because the **AAN is currently the only organization of its kind, promoting the rights of people with albinism in partnership with their representative groups to implement the AU PoA/NAPs.** We are happy to note that two others are soon to follow in our footsteps. The AAN's impact has already been felt by people with albinism themselves who for this reason, have repeatedly called upon the AAN - in the survey & feedback from the learning forum - to continue to carry out its vision and mission in the years to come.

CONCLUSION

The first two years of the AAN was a pilot or test phase. From all indication including meeting its objectives of promoting implementation of the AU Plan of Action on albinism through national action plans with budgets; conducting strategic advocacy and communications to promote implementation of the national action plans; the **AAN has proven that it is filling a crucial gap in the promotion and protection of the human rights of people with albinism.**

The inaugural survey of albinism groups commissioned by the AAN also indicated that the AAN is needed by albinism groups in the region to lead core aspects of the nascent movement including regional advocacy strategy and messaging as well as leadership training and capacity development.



As the albinism movement matures into the human rights space – disability, health, education, access to justice among other sub-fields - in Africa, it is bound to produce the fruit of inclusion of people with albinism in all aspects of life concerning them and to ultimately transform them into an existence where discrimination – in all forms – and attacks will become a faint memory. This trajectory is not automatic, however. It requires the intervention of strategic support from entities such as our funding and other core partners of AAN, who must be committed to this vision for the long-term.

AAN'S FUNDING PARTNERS

We are grateful for the generous contributions of all our funding partners including individual donors. Funding support enables AAN to continue to fulfill its mission to use the African Union Plan of Action as a foundation for action on albinism at the local level so that people with albinism may enjoy their human rights without barriers.

Listed below are the foundations and organizations that supported our work during the 2021 - 2023 pilot phase.

Ford Foundation

Under The Same Sun

Voice Global

Wellspring Philanthropic Fund

**Toward an Inclusive World for Persons with Albinism
FREE FROM BRUTALITY AND DISCRIMINATION**

www.africaalbinismnetwork.org

