Survey Report of the Human Rights and Advocacy Priorities of Organizations Supporting People with Albinism in Africa

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Prepared by: ImpactMapper

Africa Albinism Network

IMPACT MAPPER

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Abbreviations

AAN	African Albinism Network
AU	The African Union
DRC	Democratic Republic of Congo
FGD	Focus Group Discussions
GAA	Global Albinism Alliance
NGO	Non-Government Organization
PWA	Person(s)/People with Albinism
UN	United Nations

Executive Summary

African Albinism Network (AAN) commissioned ImpactMapper to conduct research to understand the general landscape and trends on advocacy and human rights work for people with albinism in Africa. The goal of this research is to provide an overview of the albinism movement by mapping the profile, priorities, issues of focus, and governance structures of organizations that are working to ensure the human rights of people with albinism in Africa. The study employed a mixed methodology namely - focus group discussions (FGDs) and a survey, reaching 48 organizations from 23 countries. Organizations participating in the study represented work across the Sub-Saharan African region, such as Angola, Benin, Burundi, Cameroon, Côte d'Ivoire, the Democratic Republic of Congo (DRC), Eswatini, Ghana, Kenya, Madagascar, Mali, Malawi, Mozambique, Namibia, Niger, Nigeria, Rwanda, South Africa, Tanzania, Togo, Uganda, Zambia, and Zimbabwe.

Below are the key findings of the study:

- **The majority of the organizations have strong experience in human rights and advocacy work,** having worked in the sector for more than five years. The organizations' leaders have been trained in human rights and advocacy work and noted that they are generally comfortable doing advocacy work on human rights. Some even articulated that they see themselves as experts in this field.
- At the policy level, **while the majority of the organizations (85%) are aware of the African Union (AU) Plan of Action on Albinism, half of the respondents noted that their countries have not yet adopted it. In fact, only five of the 48 respondents said that their countries already adopted the plan of action.**
- **The use of National Action Plans on Albinism emerged to be the top advocacy strategy employed by organizations.** Other top strategies used for advocacy work are evidence-based research to present reliable data for decision making and public education and community forums to gather key information and converge key stakeholders. Use of media is also used to sensitize the audience on the realities of people with albinism.
- **Public awareness is the top advocacy activity[1] the organizations in the sample identified as important, followed by media and government advocacy. Capacity development and training of people with and without albinism are also important activities of desired focus.**

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[1] Activities: For the survey, AAN sought to understand what activities the organization works on and the reach of their activities. This means the activities they carry out to achieve their goals. A key difference from priorities is that these are activities they implement to achieve and contribute to achieving access to health, for example.

- **Main target audiences for advocacy work and other services included: people with albinism and their families, especially those living in 'hotspots' of attacks, followed by government, media and teachers/educators.**
- **Aside from general strategic advocacy, advocacy for basic services are also necessary, such as provision of devices for low vision and health services, employment promotion for people with albinism, and support services for victims of attacks.**
    - Access to the right to health and education emerged to be the top advocacy priorities[2] of the organizations meaning the majority of respondent organizations work in these areas. This is followed by advocacy work to access employment and justice for people with albinism.
    - Main areas of work in health rights advocacy revolved around access to skin and eye care while advocacy work on education focused on inclusive education and promotion of access to adaptive devices to aid in coursework.
    - Advocacy work on employment concentrated on access to vocational training programs for people with albinism, followed by access to information for employment opportunities, inclusive employment, and safe working conditions.
    - To promote access to justice, organizations' work includes guiding and providing information about laws, key experts, and cost of lawyers; as well as advocacy for speedy judicial proceedings such as court follow ups.
- **The highest funding amount received annually by the organizations surveyed is above $50,000 (n=11) while some shared that the highest they received annually is $5,000 (n=7). Only six out of the 48 respondents reported not receiving any funding. Twelve organizations received between $25,000 and $50,000.**
    - The majority of organizations received funding, and the highest funding amounts came from international NGOs, government, academia, law enforcement, religious groups, legal institutions, and private corporations.
    - The organizations have partnered from various sectors such as healthcare, media, international NGOs, government, academia, law

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[2] Priorities: AAN sought to understand what the human rights and advocacy priorities were for organizations. More specifically, it is something they are doing right now, NOT what they wish they would do. It's current priorities. Short to medium term (now and in the next three years).

enforcement, religious groups, legal institutions, and private corporations.

- **The organizations recommended that governments, donors and AAN, could further support through funding and providing capacity development on operations, resource mobilization, and advocacy work.** AAN is also needed to address issues in the area of innovation, low buy-in of stakeholders and other duty bearers, lack of unity among leaders, partnership gaps among ecosystem actors, lack of proper system/mechanism to register people with albinism, lack of proper system/mechanism to document attacks on people with albinism and insufficient representation of people with albinism in decision-making processes that affect them.
- **Another recommendation for governments and donors is to support developing the capacities of organizations through implementing a holistic training strategy to include topics such as leadership, management, resource mobilization, etc.**, and supplemented by provision of core support for the organizations' operations (e.g.., getting office space, transportation costs, etc.). Setting up a monitoring and evaluation framework is also vital to programmatically guide, monitor, and sustain these capacity development interventions over time.
- **At the macro level, governments, donors, and AAN can support in strengthening movement building and advocacy.** This includes forging stronger relationships and facilitating dialogues within and among existing networks. It is also important for AAN to expand reach by reaching out to like minded organizations, creating alliances with key regional and international stakeholders and/or organizing a general assembly to draft a resolution or launch a campaign. Governments and donors can further support by funding innovative collaborations and coalitions, mobilization strategies, and regional advocacy and campaign strategy. AAN can also support in mapping and monitoring state efforts in national data collection efforts, map and compare policies and practices across countries, and conduct further research such as emerging issues on people with albinism - all towards scaling up advocacy efforts in the region.

Introduction

Established in February 2021, the Africa Albinism Network (AAN) is a consortium of organizations working to promote the dignity and welfare of people with albinism and their families through human rights-based advocacy. In this context, the AAN is committed to developing the capacities of organizations representing people with albinism in Africa and to ensuring that the African Union (AU) Plan of Action to End Attacks to people with albinisms (2021-2031) is implemented effectively at the national level.

AAN commissioned ImpactMapper to conduct a survey to understand the general landscape and trends on advocacy and human rights work for people with albinism in Africa. The goal of this survey is to provide an overview of the albinism movement by mapping the profile, priorities, issues of focus, and to a lesser extent, the governance structures of organizations that are working to promote the enjoyment of human rights by people with albinism in Africa. The survey has focused on identifying the financial, technical, and capacity development needs of these organizations to reach advocacy goals and how governments, donors and AAN can further support them. The survey also explores the advocacy priorities and strategies within and across the respondent organizations to gain insights into the growing African albinism movement. Ultimately, the findings should provide concrete insights to AAN, other nonprofits, stakeholders and funders in general, on the current trends and future needs for advocacy on the human rights of people with albinism.

The report opens with an overview of the survey methodology, followed by a context analysis of the human rights situation of people with albinism in Africa as well as milestones in the corresponding advocacy taking place to address the human rights situation. The next section presents the profile of respondent organizations, discusses key insights and analysis of the data from FGDs and the survey, and follows with conclusions and recommendations to AAN, and similar stakeholders.

Caveat: This report presents the basic trends emerging from the data submitted by survey respondents. It does not present a disaggregation of the data or a cross comparative analysis. To the extent that these may be done meaningfully, the ensuing findings will be published at a later date and affixed to Appendix of the online version of this report which will be housed in the “Resources” section of the website of the Africa Albinism Network.

Methodology

A mixed methodology, including collecting data from surveys and FGDs, was employed for this research. Overall 48 organizations and 1 Government from 23 countries, participated in the survey and FGD. Respondents were selected by AAN taking into account geographic and linguistic representation. AAN specifically selected organizations that were active in advocacy work and in safeguarding the welfare and dignity of people with albinism in the region. To capture rich and varying perspectives, organizations included more established and newer organizations, some of which were partners of AAN and others were not.

The survey, which ran October 1-31, 2022, was collected through the ImpactMapper software in three languages - English, French, and Portuguese. Seven surveyors, speaking one or more of the three survey languages, were trained and administered the survey through phone calls to increase the response rate. Organizations were invited to participate primarily through email, though if unresponsive, surveyors reached out to them via WhatsApp. AAN developed the survey tool/questionnaires and its own content was reviewed and approved by its human rights consultants and advisory board respectively, including people with albinism. 48 organizations answered the survey and their responses were analyzed and visualized (through charts and graphs) through the ImpactMapper software.

There were six online FGDs organized in which 43 NGO representatives plus 1 Government representative participated. All FGDs were facilitated by ImpactMapper and ran from October 26 to November 2, 2022. Each FGD ran for 1.5 hours and involved between 6-10 respondents respectively. The FGDs were implemented in English, French, and Portuguese. Most of the FGD respondents were also survey respondents and this was a method to probe deeper into the survey results. Data from the FGDs were entered, coded, visualized, and analyzed using the ImpactMapper software.

The methodology had the following limitations:

- The survey was kept as brief as possible to achieve a balance between an insightful report and a minimal burden on respondents given the following limitations. This meant that more extensive technical questions that would otherwise enable further analysis were set aside to be considered at a follow-up survey in the future.
- Survey respondents were primarily invited through email, and some were unresponsive or had delayed responses. To address this, the surveyors used WhatsApp to follow up with the respondents. This ultimately improved

response rates such that 48 organizations successfully completed the survey out of the 58 targeted organizations.

- Internet connectivity was an issue for some countries, which led to longer calls and connection drops occurred intermittently. Despite this challenge, the survey was still completed. The respondents were enthusiastic to share their insights. Two of the surveyors were also people with albinism, and this made the respondents comfortable in sharing their inputs with a person that related to the issues being discussed.
- In some locations, groups faced internet access issues. To overcome this, AAN provided data stipends. Per AAN, this was seen as a way to support albinism groups in low resource settings to ensure connectivity for both survey and FGDs. Still connectivity and inexperience with collaborative online work were limitations.
- Some FGD respondents had limited experience in using online tools (i.e., navigating Zoom and using Google document and Miro Board) so it was a challenge for them to relay their insights and exchange ideas during the FGD session. To overcome this issue, the team asked the FGD respondents to type their responses to the chat box instead. There were also instances that the moderators typed the respondents' response to a google document in real-time, which were also simultaneously shared during the FGD session. AAN also supported by following up with FGD respondents who would have wanted to share more during the FGD session but were hindered by technical issues.

Context

The Context in Which Albinism Groups Operate in Africa

Globally, albinism occurs at an estimated ratio of 1:17,000-20,000, and may increase to a ratio as high as 1:1,000 in regions of Africa.[3] Albinism is a non-communicable, genetic condition that results in a lack of melanin in the membrane, body hair, and eyes. People with albinism often experience other physical effects, including vision impairment, and vulnerability to sunburn and damage to the skin as well as skin cancer.

Organizations have emerged to ensure the protection of people with albinism and their rights. One of these organizations is the African Albinism Network, a non-governmental organization, operating to promote the human rights of people with albinism. It also advocates for the well-being of people with albinism and their households. The administrative center of the AAN is spearheaded by Under the Same Sun. The network is committed to developing strong connections with several state and cross-national organizations representing people with albinism in Africa. Their goal is to ensure that the African Union's (AU) agenda of stopping attacks and other violations of the rights of people with albinism is met and that the AU's goals are implemented at the state level with multi-year plans.

Individuals with albinism can experience prejudice and stigma due to lack of understanding of the condition, which in its extreme forms can lead to social exclusion and violence.[4] Between 2006 and 2016, more than 600 assaults and other offenses against people with albinism have been documented in 28 countries in Africa.[5] However, many attacks go unreported, so this number is likely higher. The statistic exposes the depth of the discrimination and prejudice that exists, and which must be addressed. Individuals with albinism may also experience stereotyping and discrimination, being referred to as 'white goats', 'ghosts', or 'white people'[6].

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[3] United Nations. International Albinism Awareness Day.
https://www.un.org/en/observances/albinism-day

[4] Ibid.

[5] International Bar Association. 'Waiting to disappear' International and Regional Standards for the Protection and Promotion of the Human Rights of Persons with Albinism. June 2017.
https://www.ibanet.org/medias/

[6] Reimer-Kirkham, S., Astle, B., Ero, I. *et al.* Mothering, Albinism, and Human Rights: The Disproportionate Impact of Health-Related Stigma in Tanzania
https://link.springer.com/article/10.1007/s10699-020-09701-0#Sec20

An evaluation on albinism and cultural activities and human rights reported that psychological health problems such as low self-esteem, anxiety, and suicide can result due to the levels of discrimination they face.[7] Moreover, other reports include challenges in accessing important medical care, such as antiretroviral drugs, education, and social services out of fear of being easily identified in public.[8] [9]

What Has Worked in Terms of Advocacy in Africa and Globally

Advocacy for the human rights of people with albinism is key in addressing the misconceptions on albinism and the corresponding stigmatization as well as access to quality and inclusive healthcare, education, and employment. People impacted by albinism, human rights defenders, civil society organizations, governments and duty bearers, and regional and international intergovernmental organizations are all key in the advocacy processes for the realization of the human rights of people with albinism.

Civil society organizations are a critical part of society as they are sources of information for both citizens and governments; monitor government policies and actions and hold government accountable; engage in advocacy and offer alternative policies for government, the private sector, and other institutions; deliver services, especially to the poor and underserved; and, defend citizen rights and work to change and uphold social norms and behaviors.[10] Their collaboration with governments is thus vital in the upholding of human rights of citizens and in this case advocating for the implementation of national action plans with budgets and other health and education policies that support the rights of people with albinism. Some civil society organizations advocating for the human rights of people with albinism have played key roles in the design, development, and implementation of laws, policies, and services addressing the needs of people with albinism.[11] For example, the Ministry of Health in Nigeria partnered with the National Hospital in

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[7] Reimer-Kirkham, S., Astle, B., Ero, I. *et al.* Mothering, Albinism, and Human Rights: The Disproportionate Impact of Health-Related Stigma in Tanzania https://link.springer.com/article/10.1007/s10699-020-09701-0#Sec20

[8] African Union Plan of Action (2021-2031). 2021. https://africaalbinismnetwork.org

[9] OHCHR. Report on albinism worldwide. https://www.ohchr.org/en/calls-for-input/report-albinism-worldwide

[10] Ingram, G. (2020, April 6). Civil society: An essential ingredient of development. Brookings. https://www.brookings.edu/blog/up-front/2020/04/06/civil-society-an-essential-ingredient-of-development/

[11] Ero, I., Muscati, S., Boulanger, A.-R., & Annamanthadoo, I. People With Albinism Worldwide: A Human Rights Perspective [Review of People With Albinism Worldwide: A Human Rights Perspective].2021. https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf

Abuja and The Albino Foundation to coordinate a project on free skin cancer treatment. The Government of the United Republic of Tanzania engaged with civil society groups to run a sunscreen production and distribution program.

Civil society organizations have also advocated for persons with albinism to be considered as a special group with specific needs requiring special attention. In response to this call, the United Nations Human Rights Council in 2015 created the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism to engage in dialogue, consult with states and other stakeholders and ensure that reports were made to the Human Rights Council and the General Assembly.[12] A key policy framework for advocacy for people with albinism exists through the AU Plan of Action on Albinism (2021 to 2031).

The AAN, a regional network, is a good example of network building of 'like-minded entities prioritizing human rights-based support to persons with albinism in Africa through the promotion of implementation of the AU Plan of Action on Albinism'.[13] Part of the mission of the AAN is creating awareness to, and developing the capacities of strategic groups such as governments, civil society, and faith-based groups with the end goal of supporting the implementation of the AU plan of action (2021-2031) at the national level across several African countries. This creates an environment with key national influencers who are aware of the plight of people with albinism and their respective national contexts and who can push for the development and implementation of national policies upholding the enjoyment of human rights by people with albinism. On the global front, in 2020, led by the UN Expert on albinism, a group of civil society organizations from across the globe assembled in Paris, France, to lay the foundation for an international coalition to combat the attacks, stigmatization, and discrimination faced by people with albinism worldwide.[14] Here, they unanimously voted to form the Global Albinism Alliance (GAA) to promote solidarity among albinism groups around the world.

Generally, advocacy movements are stronger when stakeholders are united along similar messages. The same goes for people with albinism. For people with albinism to carry out effective advocacy, there is a need to build a strong united front carrying the same advocacy messages. This includes building movements and networks that bring together and empower people impacted by albinism and human rights

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[12] OHCHR. Mandate of the Independent Expert on the human rights of persons with albinism. https://www.ohchr.org/en/special-procedures/ie-albinism/mandate-independent-expert-human-rights-persons-albinism

[13] About • Africa Albinism Network. https://africaalbinismnetwork.org/

[14] About GAA. Uniting Albinism Organizations Globally. https://albinismalliance.org/en/about-gaa/

defenders whose agenda includes advocating for the enjoyment of human rights by people with albinism. These joint calls for action and burgeoning coalitions and movements are occurring in some settings. In Uganda, for example, the Albinism Umbrella was created to be a joint voice for people with albinism. Through advocacy and support of the Albinism Umbrella, the first person with albinism was employed by the Government of Uganda.[15]

Active public education and awareness-raising campaigns aimed at countering prejudice, superstition, misconception, and stigma, with a view to diminishing the multiple and intersecting forms of discrimination affecting people with albinism are efficient in changing narratives.[16] Innovative practices have included an app developed by Positive Exposure Kenya and a weekly radio program by The Albinism Foundation (TAF) in Nigeria to educate the public on albinism and issues that people with albinism face. Examples of artistic approaches to raising awareness are the beauty pageants in Kenya and Zimbabwe hosted specifically for people with albinism. These public education programs and awareness campaigns target the public to promote positive perceptions, create salience of the challenges people with albinism face, and foster acceptance and inclusion of people with albinism in the society via - holistic sociocultural changes.

Advocacy for the fulfillment of human rights by people with albinism calls for the involvement of the society at all levels, from the local to the global levels.

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[15] Ero, I., Muscati, S., Boulanger, A.-R., & Annamanthadoo, I. People With Albinism Worldwide: A Human Rights Perspective [Review of People With Albinism Worldwide: A Human Rights Perspective]. 2021. https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf .

[16] Ibid.

Findings

A. Demographic Overview of the Sample

The survey sample included 48 albinism organizations[17] from the Sub-Saharan Africa region, including Angola, Benin, Burundi, Cameroon, Côte d'Ivoire, Democratic Republic of Congo (DRC), Eswatini, Ghana, Kenya, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Madagascar, Rwanda, South Africa, Tanzania, Togo, Uganda, Zambia, and Zimbabwe. They mostly represented organizations that had more than five years of active advocacy for the protection of people with albinism as seen in Figure 1.

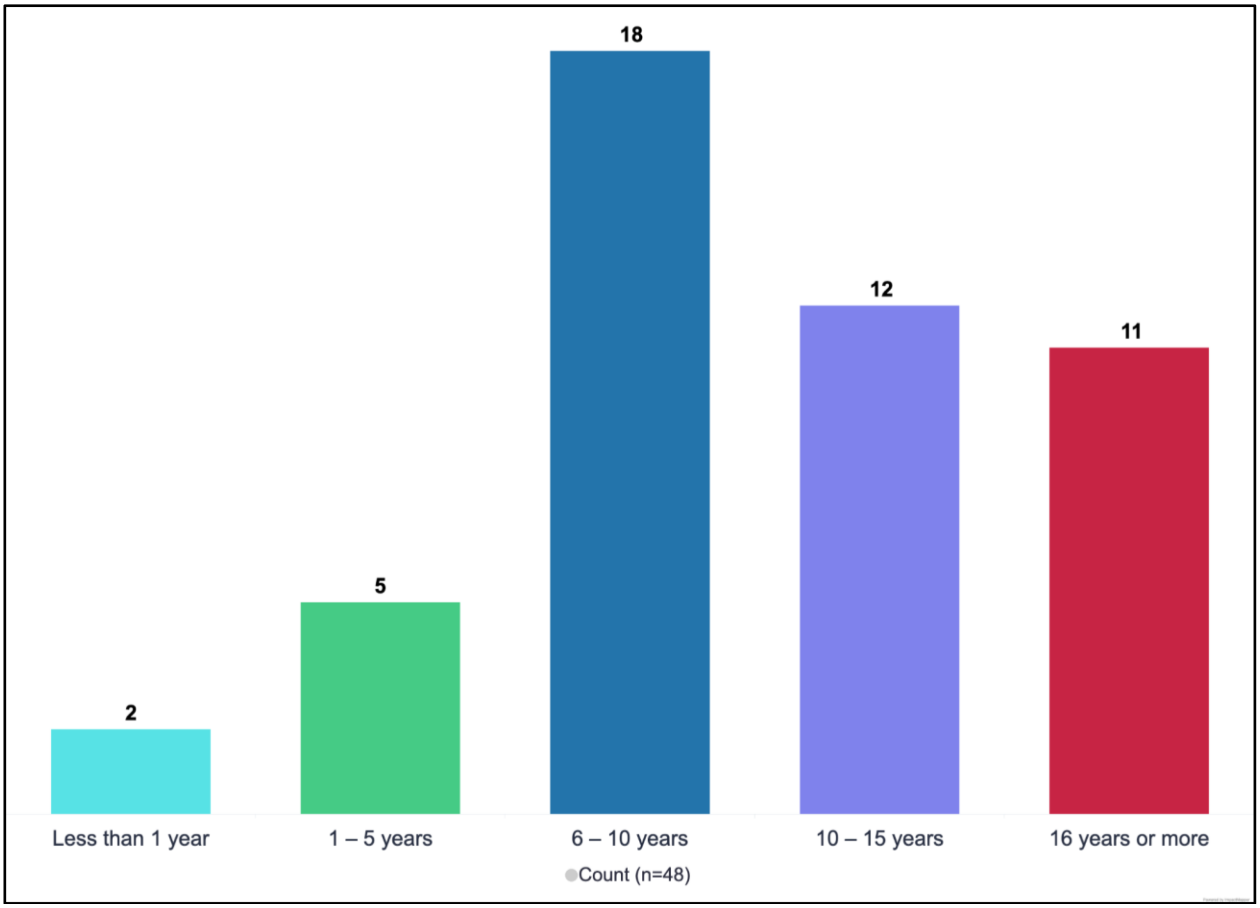

Figure 1: Number of years of active advocacy for the protection of people with albinism

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[17] In this report, “albinism organizations” will be used as an abbreviation for organizations supporting persons with albinism.

The majority of the respondents (n=31) work in multiple regions or provinces within their countries. They mostly use English (n=25) and French (n=18) as their working languages. Seven use Portuguese and the rest (n=13) use other local languages such as Swahili, Lingala, Kirundi, Bambara, and Nyanja[18].

Thirty-one organizations (65%) had an annual budget of more than $10,000 as seen in the visual below, with 18 organizations receiving $50,001 and above.

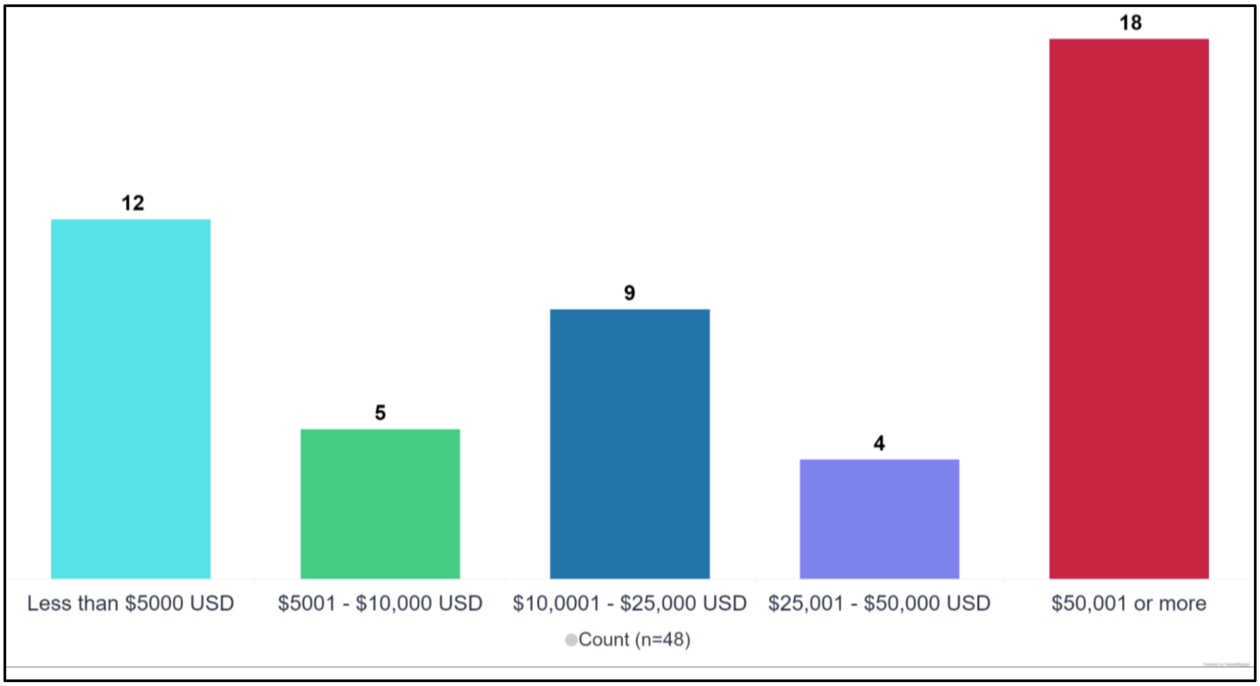

Figure 2: Annual budgets of organizations supporting people with albinism

The majority of organizations in the sample (n=18)[19] had less than six paid staff working either part time or full time. All the organizations engage volunteers; a majority of them (n=32) having 15 or less volunteers while five organizations have more than 100 volunteers.

B. Capacity and Reach of the Organizations in the Sample

The organizations in the sample overall had a strong foundation in human rights knowledge and advocacy. The majority of respondents (n=43) had people in their organization's leadership positions who have been trained on human rights advocacy. For most of them (n=21), the training was carried out between one and three years ago. Nine of the respondent organizations had this training as early as six

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[18] The number adds up to more than 48 respondents because it is due to the fact that 1 respondent could choose more than one response (i.e. English and other local languages, or English and French,...).

[19] For this question, we only had 29 responses.

or more years ago. The effect of this training is seen in how comfortable these organizations are with human rights advocacy as seen in the below visual.

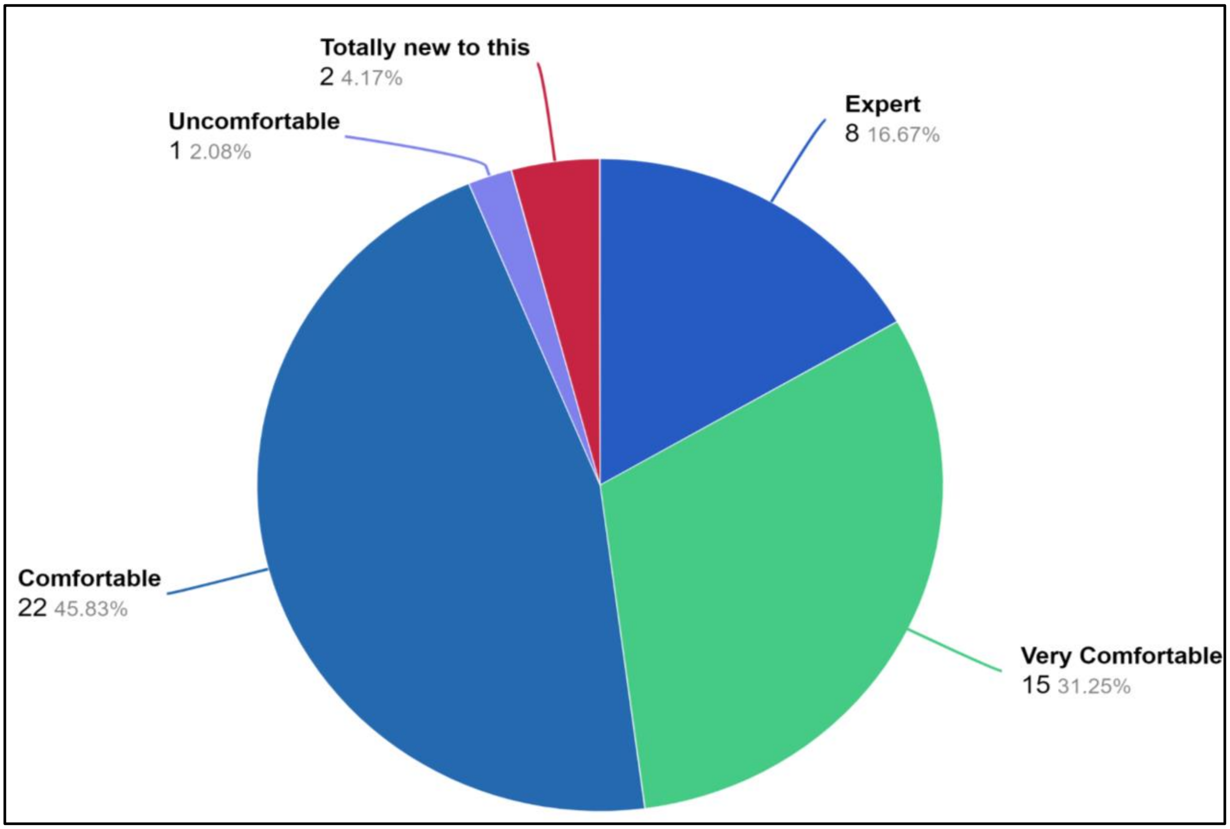

Figure 3: Comfort level of organizations with human rights advocacy

Eight of the respondents described their organizations as being experts in human rights advocacy. Meaning that they routinely engage with decision makers and can teach and help other colleagues in advocacy. The vast majority of organizations, 45 respondents, were comfortable, very comfortable or an expert in human rights advocacy.

In terms of knowledge of regional policies, more than 85% of the respondents highlighted that their organizations were aware of the AU Plan of Action on Albinism (2021 to 2031). However, most of the respondents (n=26) stated that their countries have not yet adopted the plan of action. Only five respondents mentioned that their countries had adopted the plan and ten responded that their countries are in the process of adopting it. Four respondents admitted to knowing little on the plan of action and also were not sure of what it meant for them. This calls for more awareness on the plan of action among albinism organizations as well as amongst decision makers in-country.

At the national level, 43 of the 48 respondents mentioned that they had disability laws and policies in their countries. Although controversial to some within the

Albinism Movement[20], there is a general approach to opt to advocate for inclusion of albinism issues using existing disability laws in the first place, and National Action Plans as an additional tool. Twelve respondent organizations mentioned that their countries had specific action plans on albinism. While only two mentioned having specific laws and policies on albinism in place already.

Organizations supporting people with albinism reach both people with albinism and those without the condition. People without albinism that are reached usually include teachers and healthcare professionals who are trained to ensure improved quality of life for people with albinism.[21] [22] From the visual below, we see that a majority of respondent organizations reach more than 250 people with and without albinism annually.

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[20] People with albinism usually grow and develop as everyone else. Due to the vision and skin impairment in a majority of those with the condition, as well as the social barriers they face linked to these impairment, people with albinism are often classified as people with disabilities according to the UN Convention on the Rights of Persons with Disabilities and most National legislations. Some in the albinism movement argue for the need of particular laws and budget to protect them particularly where they are under physical attacks. Since most countries in the region do not have this specific legislation in place, being classified as people with disabilities is the only way for people with albinism to attain human rights protection as well as access social and health benefits. Others including the AAN push for the disabilities approach in addition to specific action plans as the latter constitutes specific temporary measures often called for in the human rights space and recently amplified in the Sustainable Development Goals which aims to leave no one behind.

[21] Navarro, M. A. (2022, February 6). Training health professionals improves quality of life for people with albinism. Beyond Suncare. https://beyondsuncare.org/en/training-health-professionals-improves-quality-of-life-for-people-with-albinism/

[22] Lund, P. M. (2001). Health and education of children with albinism in Zimbabwe. Health Education Research, 16(1), 1–7. https://doi.org/10.1093/her/16.1.1

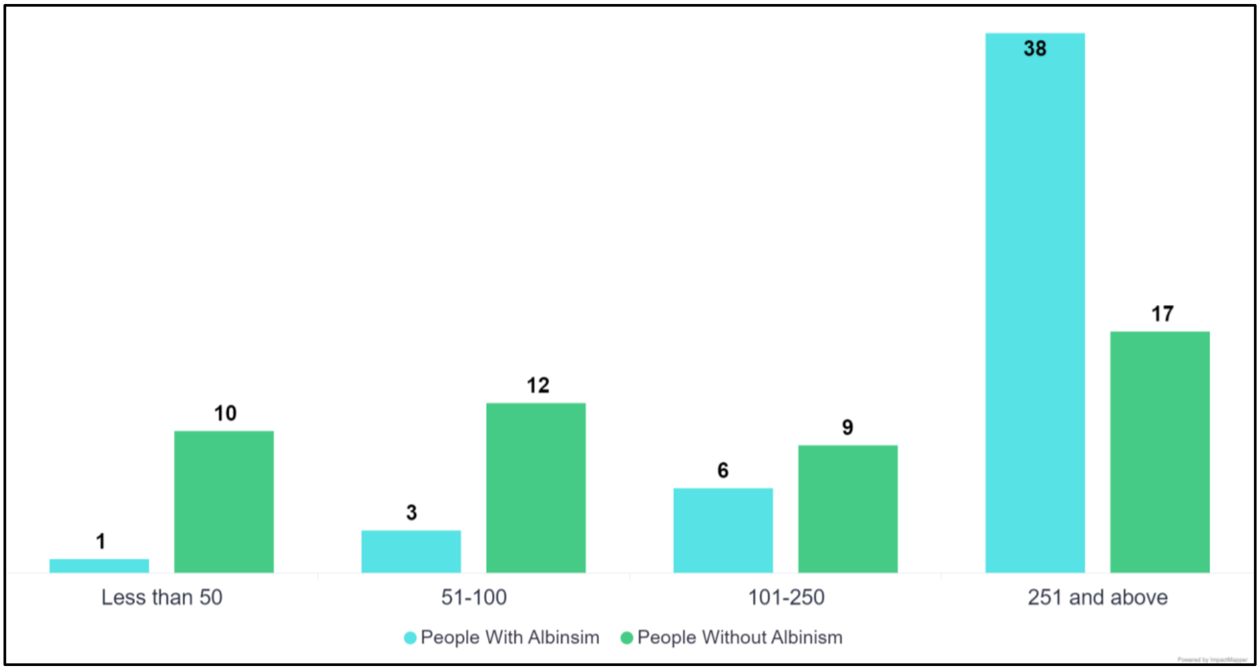

Figure 4: Number of people with and without albinism reached annually through the activities and services of services of organizations supporting people with albinism

The represented organizations engage in various activities that advocate for and support people with albinism. Key activities carried out by the organizations in the sample include public awareness (n=45), media advocacy (n=42), lobbying the government for policy, law, and action plans (n=41), and capacity development and training for people with albinism (n=41). Other activities include capacity development and training for key stakeholders such as teachers and family members of people with albinism (n=35), health services (n=35), promoting employment of people with albinism (n=32), provision of adaptive devices for low vision (n=31), and protection and support services for victims of attacks (n=28). Besides these, five respondents also stated either organizing beauty pageants and festivals, political and electoral participation of people with albinism, interaction with traditional healers and leaders, or referrals.

Activities	n
Public awareness	45
Media advocacy	42
Lobbying the government for policy, law, and action plans	41
Capacity development and training for people with albinism	41
Capacity development and training for key stakeholders such as. teachers and family members of people with albinism	35
Health services	35
Promoting employment of people with albinism	32
Provision of adaptive devices for low vision	31
Protection and support services for victims of attacks	28

Table 1: Activities currently conducted by respondent organizations. The symbol "n" represents the number of respondent organizations that indicated they currently work in each activity area.

> ***"I would love to have more access to information about what albinism is (so that we can spread it to the far away areas and regions of my city and my country. I wish we had more vibrant campaigns (like the ones for people living with HIV, or malaria). We need to mobilize people with albinism to speak about their challenges, their pains, their experiences and success stories (nothing for them without them). - Participant from Mozambique***

C. Human Rights and Advocacy Priorities of Organizations Supporting People with Albinism

In order to ensure a strong coordinated movement and agenda for action, advocacy efforts and messages need to be clear and consistent across albinism organizations.

The most important advocacy areas - deciphered from the number of organizations working in that area - were access to health and education, (mentioned by 46 and 41 organizations respectively), followed by access to employment (n=16) and justice and a focus on children with albinism (15 mentions each), and women affected by albinism (with 8 mentions). Other advocacy areas were access to political and electoral participation of people with albinism and social protection and victim assistance, capacity development and human rights education and promotion with one mention.

Health advocacy

Digging deeper into issues of health advocacy, the most frequently mentioned sub-issue in health advocacy included access to and affordability of skin care (n=46), followed by access to and affordability of eye care (n=39), providing psychological support and rehabilitation services for victims of violence (n=23), training of healthcare professionals (n=19) and lastly provision of rehabilitation services for victims of violence (n=9). These issues were also mentioned repeatedly during FGDs sessions, underscoring and triangulating their importance.

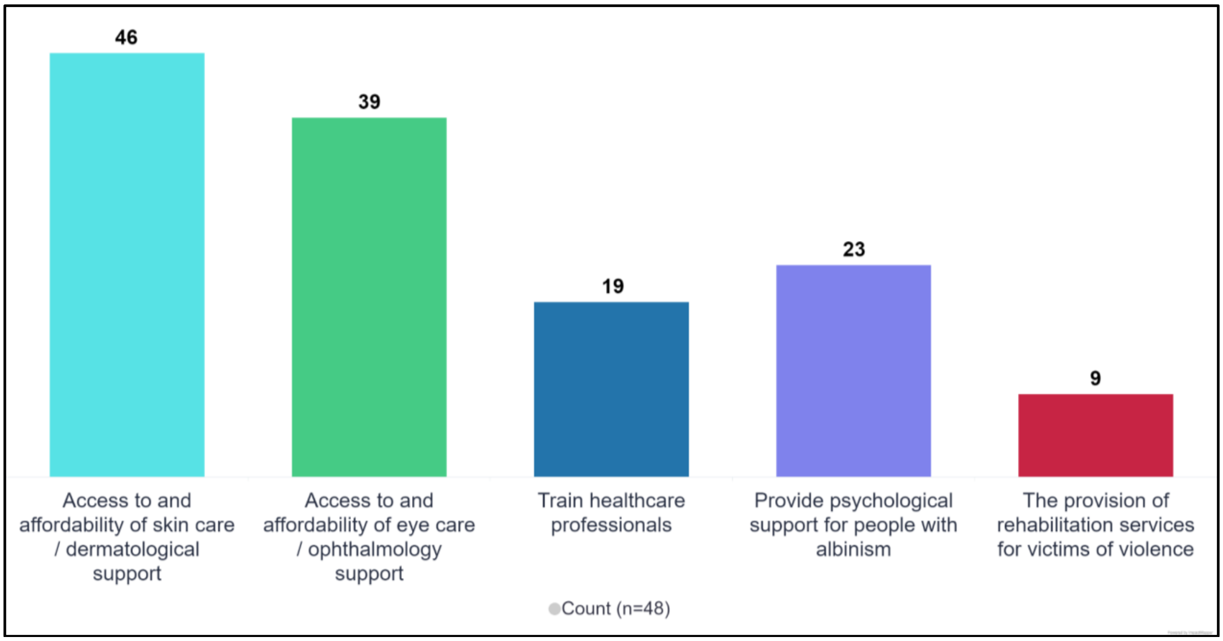

Figure 5: Top health advocacy priorities

Education Advocacy

Inclusive education ranked the highest (n=37) amongst education-related advocacy areas, followed by promotion of reasonable accommodation and access to adaptive devices for low vision (n=28), elimination of sociocultural barriers to accessing education for people with albinism (n=27), and teacher and non-teaching staff training (n=24). Other education-related advocacy areas were provision of tuition to guarantee access to education and revision of curriculum and teaching guide each with one mention.

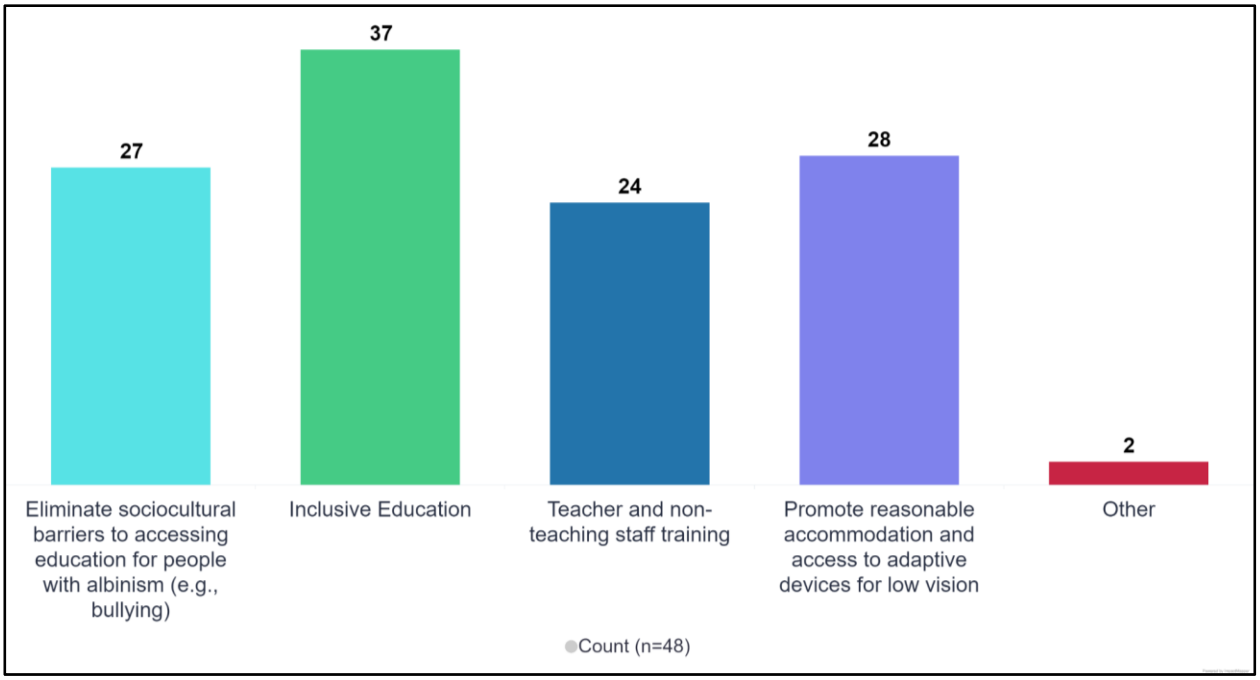

Figure 6: Top education-related advocacy priorities

Employment Focused Advocacy

In terms of employment-related advocacy priorities, respondents highlighted vocational training programs for people with albinism (n=14). This was followed by access to information about employment opportunities (n=8), reasonable accommodation at work (n=8), promotion of safe and favorable conditions for people with albinism (n=8), and training of current and potential employers on the inclusion of people with albinism (n=5). Another employment-related advocacy area was entrepreneurship with one mention.

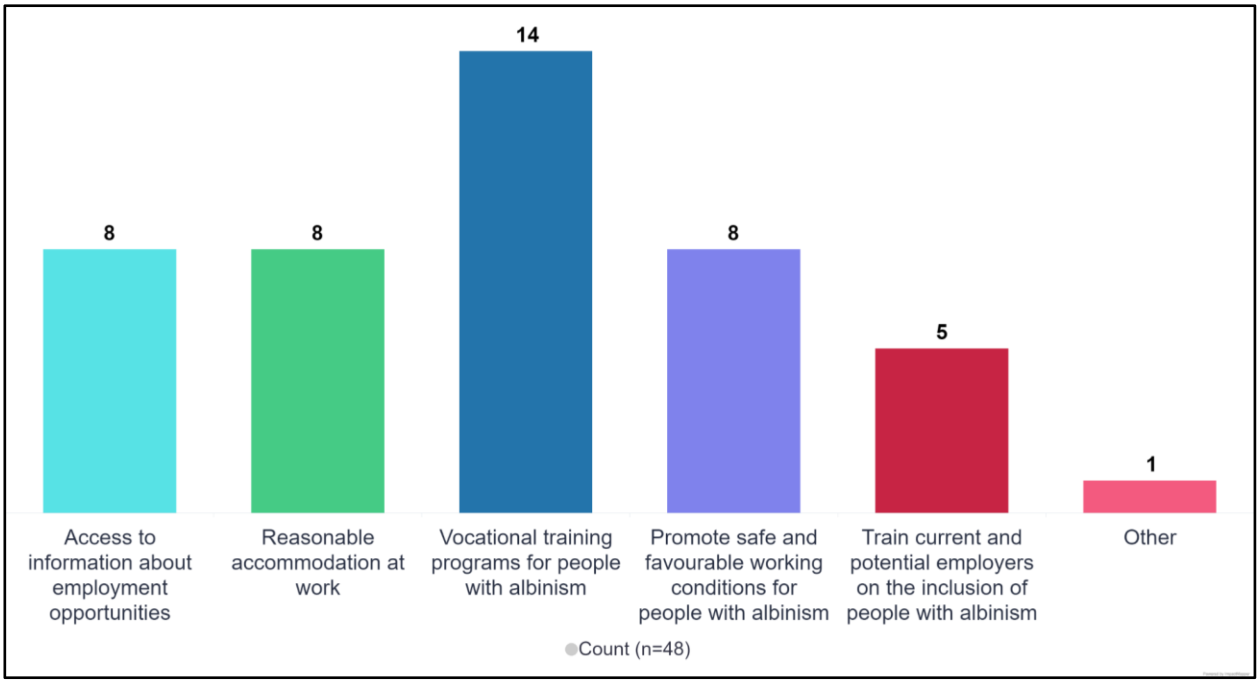

Figure 7: Top employment-related advocacy priorities

Access to Justice Advocacy

Access to justice is a fundamental human right, yet people with albinism may face challenges accessing justice after being attacked, persecuted, and discriminated against.[23] This includes the right to a fair trial where one has equal access to and equality before the courts. It also includes access to just and timely remedies through enforcement of appropriate laws and regulations.

The top areas for advocacy related to access to justice included mitigating the lack of knowledge on laws and experts and legal costs and following up with court proceedings and advocating for speedy judicial proceedings in attack cases with 10 mentions each, followed by the need to record attacks (n=8), psychosocial support to victims and family members (n=7), training of judiciary and law enforcement authorities such as police (n=6), and strategic litigation such as bringing a case to change law and/or practice (n=3). The other advocacy area related to access to justice was advocacy for inclusion and implementation of legal instruments, policies, and frameworks in the judicial sector with one mention.

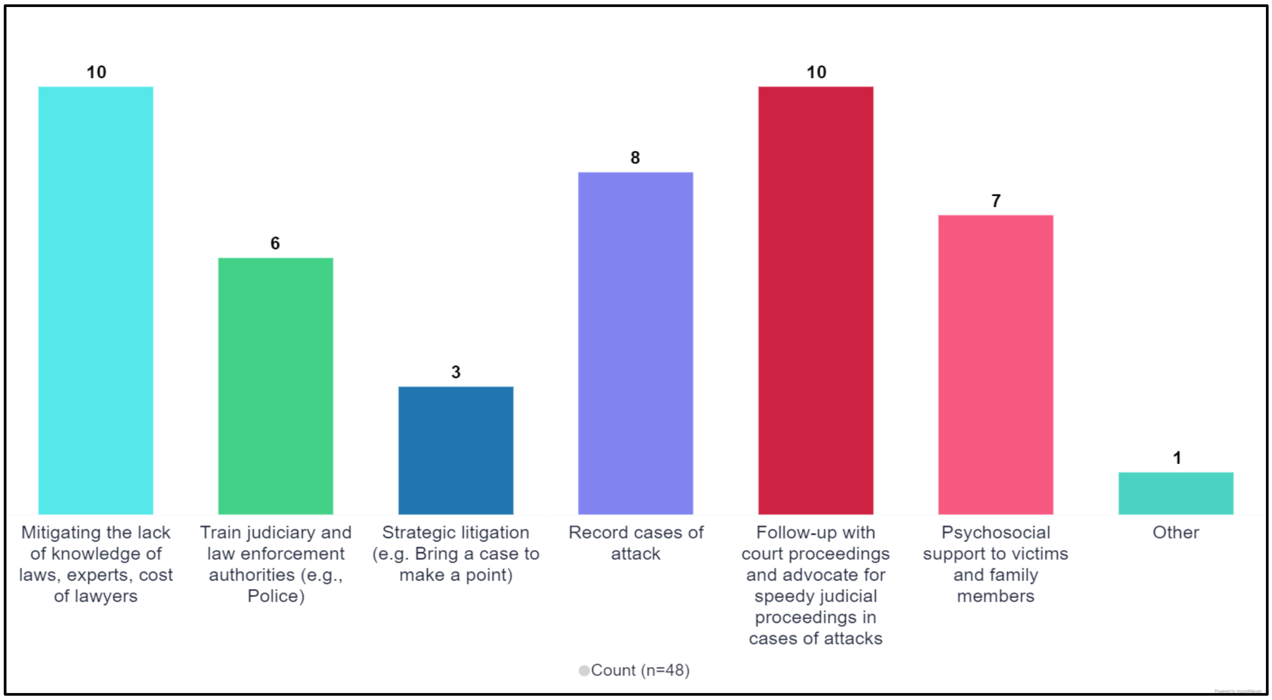

Figure 8: Top advocacy priorities related to access to justice

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[23] Ero, I., Muscati, S., Boulanger, A.-R., & Annamanthadoo, I. (2021, June 13). People With Albinism Worldwide: A Human Rights Perspective [Review of People with Albinism Worldwide: A Human Rights Perspective]. https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf

Advocacy on Women Impacted by Albinism

Very few organizations (n=8) or 16% highlighted advocacy priorities focused on women impacted by albinism.[24] For those that did, their main priorities were related to the protection of women against sexual and gender based violence (n=6), psychosocial support for women impacted by albinism (n=5), the elimination of harmful practices towards women with albinism (n=4), access to sexual and reproductive healthcare (n=3), elimination of gender-based violence and discrimination in employment (n=2), access to information for women with albinism (n=2), and general health services for women impacted by albinism (n=1).

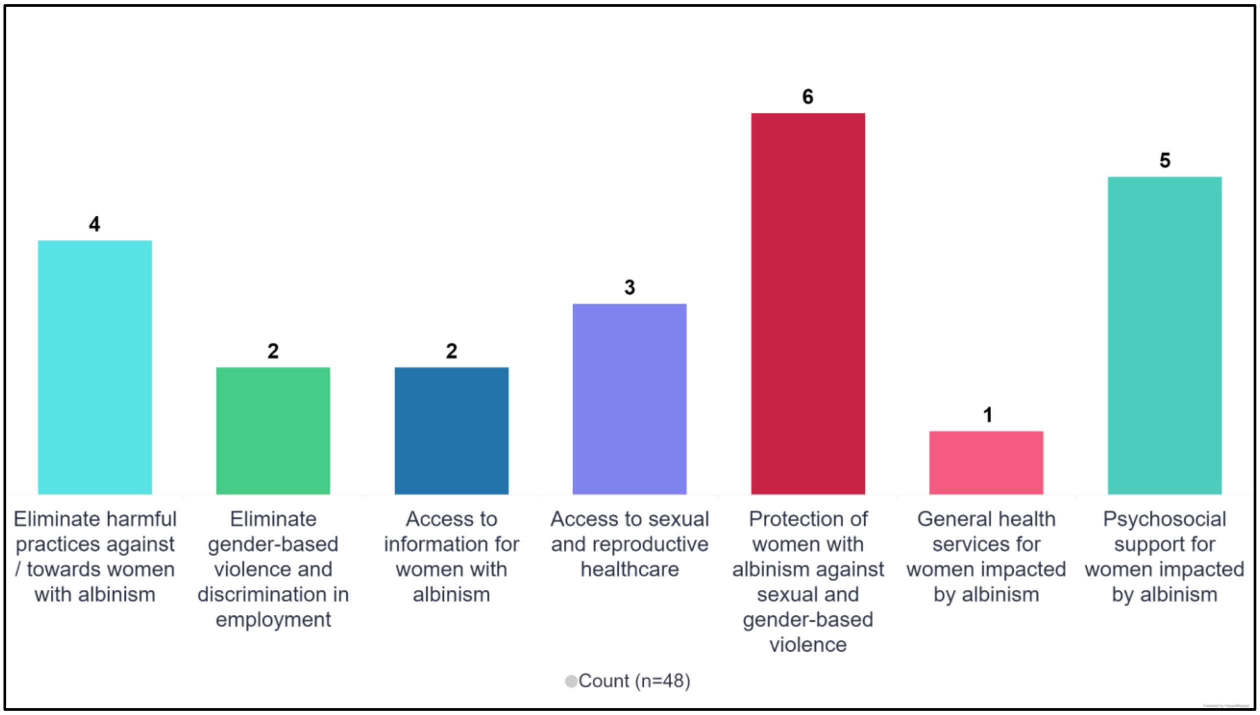

Figure 9: Top advocacy priorities related to women impacted by albinism

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[24] Women affected by albinism include women with albinism and spouses and caregivers of people with albinism.

Advocacy Focused on Children with Albinism

In terms of advocacy priorities focused on children with albinism, the most frequently mentioned area of focus was on information accessibility and inclusive education (n=11), followed by provision of quality general health services and ending harmful practices against children with albinism (n=9 each), and psychosocial support and improving access to inclusive education (n=7 each).

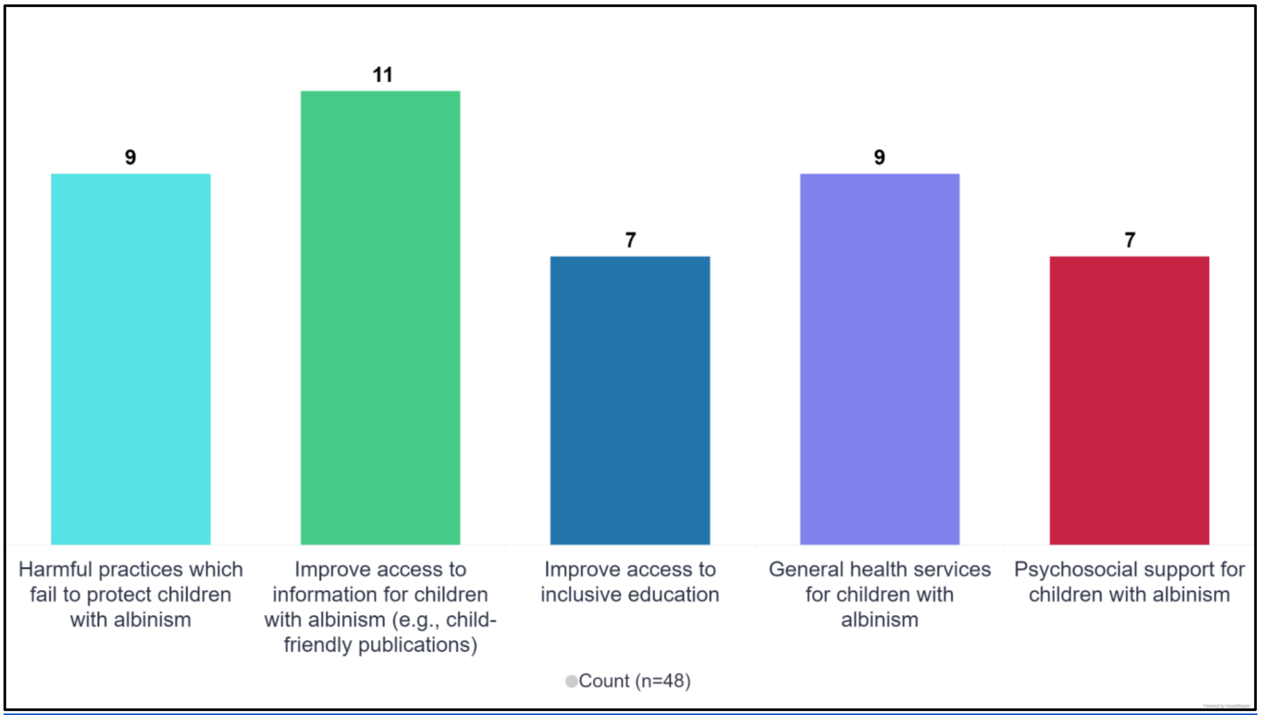

Figure 10: Top advocacy priorities related to children with albinism

Scaling up Advocacy Efforts

An important part of advocacy efforts is ensuring that efforts are reaching the right people, and that messages are targeted and specific. The following audiences were highlighted as important to engage with in different ways.

The top target audience for advocacy and protection work identified was people with albinism and their families (n=44), followed by the advocacy with the government around policies and service delivery (n=29), people with albinism living in hotspots or areas of reported attacks (n=17), teachers and media (n=16 each). Other target audiences included healthcare professionals (n=12), non-governmental organizations (NGOs) (n=5), intergovernmental organizations such as AU and UN (n=3), and village residents (n=1).

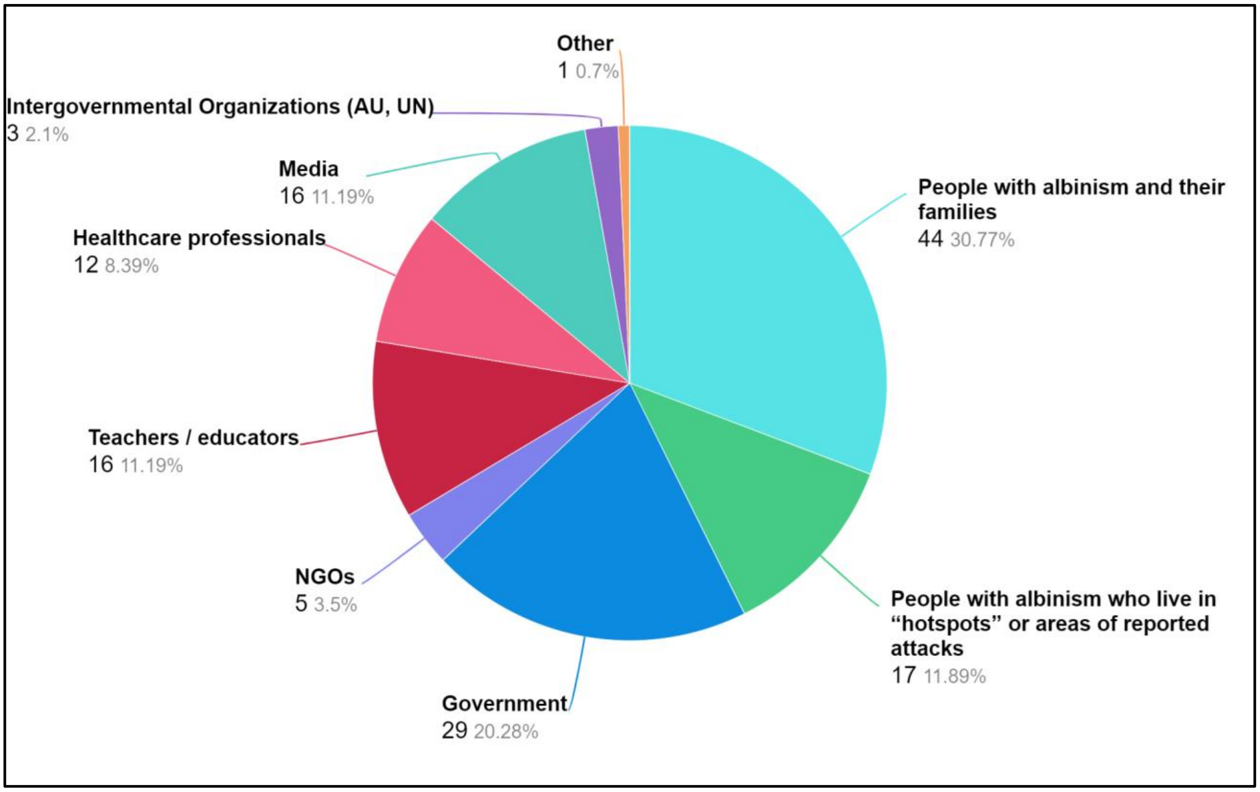

Figure 11: Key target audiences for advocacy done by organizations supporting people with albinism

Advocacy Strategies

Majority of the respondents (n=36)[25] in the sample ranked promotion of national action plans on albinism to be a high priority advocacy strategy.

> ***"Effective application of the national action plans are the key advocacy tools." Participant from Mali***

This was followed by research and data collection (n=34), and greater public education and community forums (n=34).

Other highly prioritized advocacy strategies are traditional media engagement (n=28), workshops, training, and seminars (n=28), and digital advocacy or social media (n=26).

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[25] n=number of respondents who ranked a strategy to be high priority

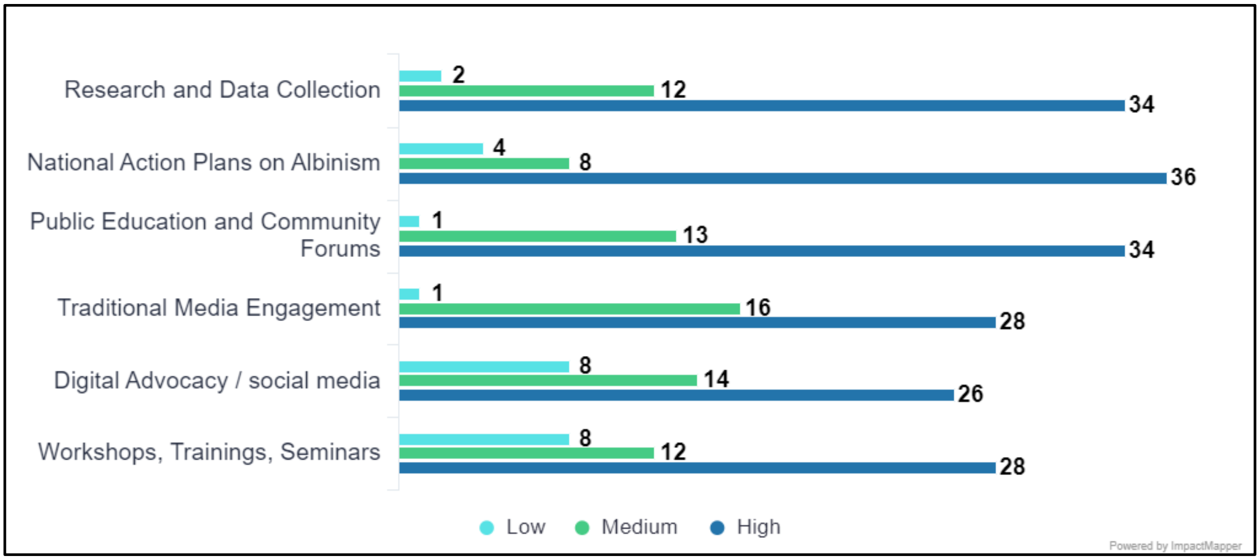

Figure 12: Priority of advocacy strategies employed by organizations

Evidence-based research has proven to be vital in the advocacy of human rights as it offers reliable data to be used in decision making or directing attention to particular issues. More importantly, disaggregated data can reveal intersecting experiences and discrimination faced by different groups of people with albinism. However, very few countries collect official data on people with albinism thus leaving the burden on civil society organizations or independent researchers.[26] Responses from the FGD also emphasized on the need for research and data collection. They called for support and more funding to conduct national mapping and analysis of the situation of people with albinism.

One way of tackling negative perceptions and misinformation on albinism is through public education and community forums. The 72nd session of the UN General Assembly included a report on the social development challenges faced by persons with albinism which challenged member states and civil society to address root causes of discrimination through awareness-raising campaigns, adapting them to local sociocultural contexts.[27] FGD respondents mentioned awareness campaigns being effective for advocacy and encouraged continued use.

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[26] Ero, I., Muscati, S., Boulanger, A.-R., & Annamanthadoo, I. People With Albinism Worldwide: A Human Rights Perspective [Review of People with Albinism Worldwide: A Human Rights Perspective].2021. https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf

[27] Seventy-second session. Item 28 of the provisional agenda* Social development. Social Development Challenges Faced by Persons with Albinism. 2017. https://www.refworld.org/pdfid/59ad2e824.pdf

Traditional and digital or social media have been used by civil society to sensitize communities on the issues faced by people with albinism such as marginalization, stigma, and discrimination.[28]

Respondents from the FGDs necessitated the need for innovation in advocacy. Some suggested practices included:

- Establishment of albinism ambassadors to highlight challenges faced by people with albinism and to create awareness of albinism
- Engagement of experts to help in formulating relevant advocacy material to minimize contradicting information on albinism issues

Funding

Six of the survey respondents (12.5% of the sample) mentioned never receiving funding from any entity. The rest received funding amounts from international NGOs (n=20), intergovernmental organizations (n=8), national governments (n=7), private corporations (n=1), and individuals or membership dues (n=1).

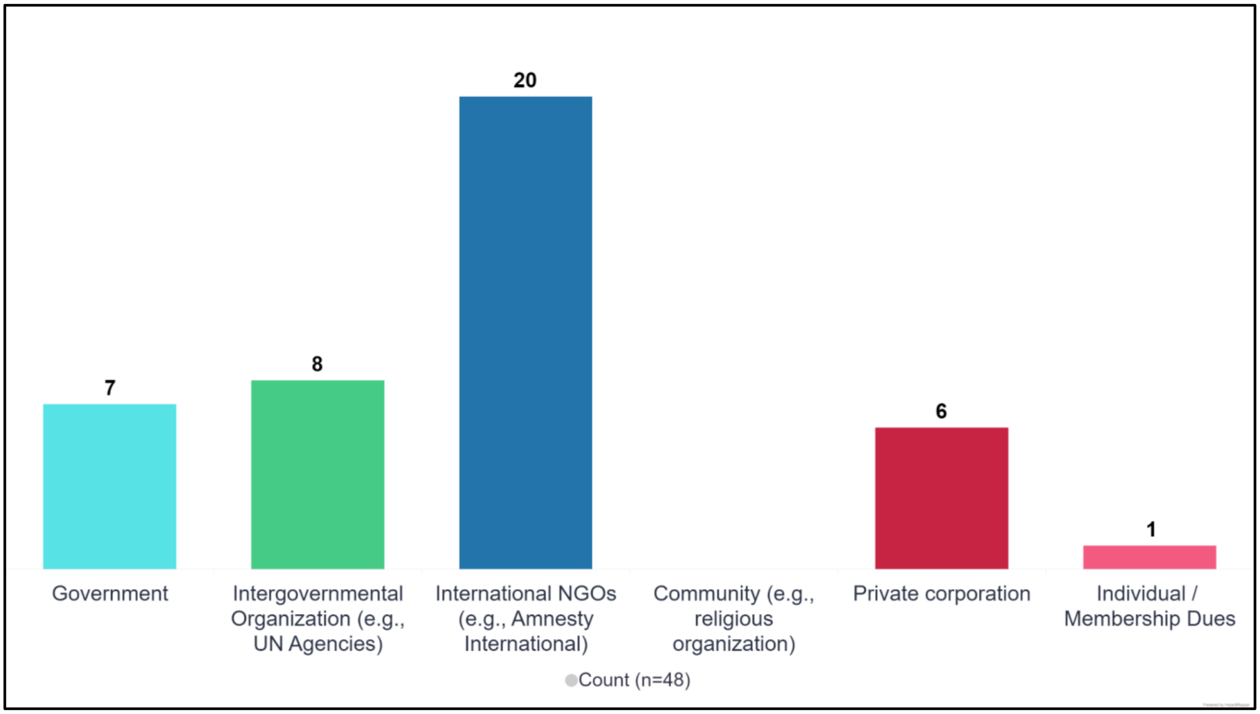

Figure 13: Entities that gave the highest funding amounts to organizations supporting people with albinism

Highest funding amount received annually is above $50,000 (n=11) while some shared that the highest they received annually is $5,000 (n=7). Only six out of the 48

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[28] Ibid.

respondents reported not receiving any funding. Twelve organizations received between $25,000 and $50,000.

One of the key activities, according to FGD respondents, that needed increased funding was advocacy and campaigning.

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> ***"We need adequate resources (financial support, human resource) to enable us to increase albinism movement." Participant from Zambia***

FGD responses point to a scenario whereby entities supporting albinism organizations will need to invest in training leaders of albinism organizations mostly regarding organizational management, advocacy and monitoring and evaluation, and evidence-based research, while increasing fundraising to improve the organizations' advocacy. This data also brings to light that a different approach to leadership would be required.

Argentina	• Adoption of a law for people with albinism in Argentina that focuses on health and education
Kenya	• Representation in the legislature, local government, and judiciary • Employment of people with albinism in the executive arm of government • Availability of a budget for the national action plan for the protection and promotion of people with albinism • Vital registration of people with albinism in the national census • Greater public awareness on albinism and acceptance of people with albinism
Malawi	• Have a united movement with trustworthy leadership • Stiffer punishments set for perpetrators of crimes against people with albinism • People with albinism are taking up political positions • Adoption of a national action plan
Rwanda	• Government-supported public awareness campaign in the media
Tanzania	• Protection against killings • Great investment from civil society supporting people with albinism

Uganda	- Inclusive disability act specifying needs of people with albinism - Government willingness to support people with albinism
USA and Canada	- Strong albinism organizations and mechanisms

Table 2: Survey responses on the question: in your opinion what countries have done well on human rights advocacy or the protection of people with albinism?

D. Partnerships and networks for a broader movement and effective advocacy

Building effective partnerships for change and linking organizations and activists across countries, regionally and globally is central to effective advocacy.

Currently, organizations in the sample form partnerships with broad and diverse groups of people. The following list is ordered in terms of the most frequent partnerships organizations made:

Organization Type	n
Healthcare professionals	43
Media	42
International NGOs	40
Government	38
Teachers	38
National Human Rights Commissions	37
Religious leaders	33
Law Enforcement Authorities (e.g. Police)	30
International Development Organizations (e.g. Embassies, UNDP Office)	30
Traditional leaders	29
Private Corporations (e.g. Airtel, Safaricom, Carrefour)	22
Legal Institutions and Legal Experts	21
Academic Institutions	21
Traditional healers	16

Regional Economic Communities (e.g. ECOWAS, SADC, EAC)	9
Other	3

Table 3: Type of Organizations

Within the movement itself there appears to be room for greater collaborations between albinism organizations, as well as with human rights movements. When it comes to civil society collaboration, competition for resources, varying and multiple objectives, and differences in perspectives and framework are all seen to be the major barriers to collaboration. Difference in technical knowledge and technological competences and challenges on finding common ground for leadership collaboration constitute other major barriers identified.

Partnerships can also be strengthened by albinism organizations aligning in key advocacy areas and ensuring that critical research and policymaking protecting the rights of people with albinism is institutionalized. This is especially true at the governmental, healthcare, legal and law enforcement levels, and given shifting priorities of these stakeholders. This is why having national action plans with budgets and dedicated social services is so important.

One respondent reflected on the need for unity and joint action in the albinism community.

> ***"We need to be united as the Albinism community so that we all speak with one voice. We need many stakeholders to come on board and work with the albinism community. We also need long term activities to amplify the albinism voice." Participant from Zambia***

Others called for a need to federate and join forces so they could have a more powerful voice and greater authority, influence, and impact.

> ***"Organizations are very dispersed and compete within the same country. We should consider, if we cannot group them together, and consider specializing or categorizing them according to targets for geographical areas of action: children, women, populations of the north, the south, etc. The State, donors, and potential partners all suffer from this multiplicity of organizations in the***

Overall, across the sample, there was a fair amount of support for greater unity and collaboration, although a few respondents underscored that there needed to be strong reasons for this type of partnership or federation, and it should not be undertaken without a clear strategy. One FGD respondent suggested the creation of a regional campaign to destigmatize albinism as a strategy to share advocacy messages and to increase the visibility of the issue.

To support deeper strategizing across organizations working on albinism, other respondents recommended that civil society groups share regional advocacy strategies and successes more regularly, so that lessons could be adapted in different settings.

There is also a need to increase collaboration, integration and visibility in larger associations, movements and networks focused on other issue areas, such as disabilities in general, women and girls, etc. One FGD respondent reflected on the need for a new narrative and advocacy messages on albinism to be created that focused on connections with other relevant issues, such as existing gender inequalities in a country and COVID-19 and underscoring how albinism interacts with these issues deepening inequalities and inequities. Seeking out key actors outside the movement can help strengthen advocacy actions and amplify advocacy messages.

> ***"Albinism rights is a fight to include everyone. The movement of people with albinism should join other platforms (women, disabilities, etc..) so they are able to include albinism rights in their agenda and understand our objectives and our asks. The other movements do not even know what we are doing, and we will need their support in advance. When the albinism movement began, no other organization would support us, just a couple of agencies, and we cannot afford to stay in that comfort zone." Participant from Mozambique***

Effective advocacy also relies on lobbying, networking, and influencing with the government. Some FGD respondents expressed challenges in interacting with state actors due to a lack of knowledge and training on albinism and underlying stereotypes. This also underscores the need for dedicated resources, training and capacity development around albinism and human rights issues and the need to raise awareness of these issues with leaders and decision makers, and ultimately ensure that people with albinism are represented in leadership and decision-making bodies.

"There is a leadership problem and a lack of clear messages. There is also a problem with capacity building and training on lobbying and advocacy"
Participant from Benin

One of the issues raised in the FGDs was the importance of ensuring that people creating advocacy messages, as well as those in leadership positions in albinism organizations be more diverse e.g., ethnically, and geographically. Specifically, grassroots organizations of people with albinism and parents of people with albinism should also be represented, not just elites. Moreover, overall, it would be useful if a bottom-up approach to the work was taken where grassroot persons with albinism were meaningfully consulted on their priorities as the basis for demands and advocacy messages.

E. How governments, donors and AAN support can leverage the advocacy field for people with albinism rights to promote the enjoyment of human rights by people with albinism in Africa.

Organizations supporting people with albinism have different needs and challenges that can hinder them from fully achieving their advocacy objectives. Across Africa, these needs and challenges seem to occur in similar measures within different countries. The following areas of support were requested of key stakeholders such as governments, donors, and AAN to address these challenges (described in order of frequency):

- Funding for operations and advocacy activities
- Capacity development in resource mobilization and advocacy
- Capacity development of duty bearers, such as teachers and healthcare workers
- Need for innovation in advocacy strategies and advocacy support
- Lack of political will leading to low buy in and commitments for the implementation of the AU plan of action or any in-country policies
- Lack of unity among leaders and organizations within the network and an equally shrinking civic space
- Inadequate mechanisms to register all people with albinism within countries to track data trends
- Gaps in partnerships between governments and human rights organizations
- Lack of representation of people with albinism in decision-making processes

“We value most financial support from AAN for advocacy that help people to travel to the government and meet decision makers and discuss on how to protect the needs of people with Albinism through law, budget, plans and policies” Participant from Tanzania

As mentioned, advocacy, and campaigning is underfunded according to many FGD respondents, and it is the top priority where AAN support is needed. Other priorities are in supporting advocacy and campaigning training and tool development, as well as AAN support for national advocacy efforts (i.e., through visits of governments).

“AAN should make local support, visiting organizations on the ground and national institutions to encourage them and increase visibility” Participant from Côte d’Ivoire

From FGD responses, it was clear that some of these needs could be leveraged through AAN supporting awareness of national organizations advocacy messages through networking and visibility at regional and international level. This networking, particularly that AAN might facilitate among people with albinism organizations, should aim at finding common strategies and messages to scale up advocacy for the promotion and protection of the human rights of people with albinism in the region, and to hold governments accountable for commitments to the Plan on Action on Albinism in Africa (2021-2031) in particular. As stated by one FGD respondent:

“On advocacy, in general we need to align to remain relevant otherwise there is going to be fatigue”. Participant from Kenya

Leadership and convening are other areas in which AAN can play a major role facilitating shared understanding, i.e., by convening regional thematic conferences or networking events. There is also room for convening training/workshops on, for example, how to work with online and collaborative tools or advance use of certain applications or software to address the difference in technical knowledge and technological competences.

Additional classical strategies for movement building to be scaled up (with donors’ support) which were identified in FGDs included:

- Greater mobilization and involvement of people with albinism in claiming their rights and strengthening knowledge of the mechanisms to do so.
- Federation or other forms of organizations grouping to collectively present a united front when necessary but mainly to collaborate, exchange experiences and learn from each context.
- Media engagement and collaboration with organizations defending people with albinism rights.
- Strategic programming for regional and national advocacy and campaigns, and
- Common petition creation around the Plan of Action on Albinism in Africa (2021-2031), discussed and agreed upon nationally and regionally, to advocate at all official institutions, including Governments.

AAN can take forth these recommendations and create a full work plan for several years ahead. Strategic planning and programming are at the cornerstone of advocacy successes, as signaled by several FGDs respondents. Planning for collective ways to hold governments and other national institutions accountable should be among AAN's top priorities. Doing so, will further advocacy efforts in the region and support mobilization of the movement towards a common goal. Moreover, monitoring the impact of national plans already in place to identify challenges and success stories and to replicate the latter in other contexts could foster common petitions, collective planning, and joint strategizing among albinism organizations across the region.

> ***"We will need a way to get people to understand that it is really important to work together to advance the rights. So what is needed is the tools and the strategy to get the people to support the movement and the work."***
> ***Participant from Mozambique***

Federation of the organizations working on people with albinism rights has been previously discussed (see previous section). But it is also worthy to reiterate and underscore this FGD respondent's suggestion to bridge collective work agenda and collaboration and the need for accountability to track progress through monitoring and evaluation.

AAN support in media engagement would also be useful, and could range from organizing communications, public relations, and social media workshops to a fully funded regional communications campaign on ending the stigma around people with albinism with context appropriate messages and tools for sharing.

Conclusions and recommendations

This report has provided insights on the human rights-based advocacy landscape for people with albinism in Sub-Saharan Africa. In sum, existing advocacy strategies center on developing action plans while concrete activities and services center on public education and awareness, access to health, education, employment, and access to justice. Respondent organizations point at the need to improve in all these areas through coordination among groups, improved accountability mechanisms, increased opportunities for learning and exchange within and across countries for scaling outcomes of their work.

mostly include diverse and uncoordinated efforts advocating for national action plans on albinism, and require more consistent public education and community forums, and more attention on useful research and data collection. The albinism movement points out gaps in representation of people with albinism in decision making positions and leadership. This representation would give a voice to the albinism movement to push for the adoption of the AU plan of action and development of national action plans on albinism.

AAN’s input is particularly important for the capacity development of organizations on resource mobilization and advocacy, actively encouraging unity and collaboration among albinism groups, and supporting national advocacy efforts.

Key capacity development needs for these organizations are centered around resource mobilization, advocacy, and managerial training for leadership. Additionally, there is a need for increased funding for the advocacy and campaign for the upholding of human rights of people with albinism. The main national advocacy priorities organizations highlighted included access to quality healthcare and education.

To address the organizations’ needs better support the work of albinism organizations and the regional movement to promote the enjoyment of human rights of people with albinism in Africa, and capacity areas, the following recommendations have been made to AAN, donors, albinism movement, and other stakeholders by the respondent organizations. have been made.

Recommendations

A. On organizational strengthening for implementing advocacy and campaigns:

1. Build the organizational and resource mobilization capacity of organizations supporting people with albinism to ensure sustainability.
2. Create and fund training strategy for albinism organizations which do not only focus on advocacy but also training in management, human rights frameworks, fundraising, and monitoring & evaluation.
3. Call upon international organizations, INGOs, private donors and international development agencies to fund people with albinism organizations in order to follow through with the African Plan of Action as this is essential to advancing the 2030 Agenda for Sustainable Development.
4. Provide core support that enables organizations to address issues like barriers to their effective work such as getting office space, appropriate transport, cover volunteers expenses, or pay staff.
5. Boost leadership Support training skills on advocacy and put in place processes for the leadership to reflect intersectionality among people with albinism.
6. Set up monitoring and evaluation frameworks for advocacy and campaign impact, in a manner that facilitates learning.

B. On Movement Building:

1. Reach out to other civil society organizations and movements with a human rights agenda and connect advocacy demands to broaden the impact of the messages of albinism organizations and to jointly hold governments accountable for their duty to promote and protect human rights.
2. Fund innovative coalitions and collaborative advocacy across the region on the AU plan of action.
3. Fund mobilization strategies to systematically engage people with albinism on any advocacy, policy, campaign, and decision-making process designed to guarantee their rights.
4. Reflect on organizing a general assembly of organizations to draft a resolution and launch a campaign to be supported by African states.
5. Map allies and engage with them in meaningful ways.
6. Call upon African states to fulfill the AU Plan of Action on Albinism (2021 to 2031) under which strategic objective 2.4 clearly compels states to increase resource mobilization. Priority actions suggested for African states are: “(a) Provide funding for work on albinism, including to strengthen the governance, operations and activities of organizations representing persons

with albinism. (b) Allocate and monitor specific budgets to facilitate the implementation of program interventions on albinism, with a focus on gender mainstreaming. (c) Engage bilateral donors to allocate resources towards work on albinism. (d) Lobby for adequate funding for statistical data on albinism to improve strategic planning"[29].

C. On AAN support to scale up advocacy:

1. Build stronger relationships amongst albinism groups network members and push for more collaboration and learning among them.
2. Facilitate dialogue among partner organizations to reach consensus on a common policy and advocacy agenda and goals.
3. Increase visibility for the movement by leading a consistent media strategy, and support partners to engage with it.
4. Lead fundraising efforts towards creating and implementing a regional advocacy and campaign strategy that includes research, messaging and tools that are context appropriate and support across countries.
5. Map and track state efforts to improve national disaggregated and intersectional data collection of the needs of people with albinism, including the need for a proper vital registration, and the adequate tracking of violence against them is stated on strategic outcome 3.4 of the African Action plan on Albinism. This provides AAN with the legal grounds to advocate States to: "(a) Produce comprehensive periodic reports on the situation of persons with albinism in the country, including progress on implementing the targets of this Plan of Action. (b) Produce comprehensive reports on how this Plan of Action on albinism has been implemented using the indicators provided and include persons with albinism in all data-gathering processes that concern them"[30].
6. Map and compare National Action Plans on Albinism and specific laws, as well as countries with laws on people with disabilities that include people with albinism in the implementation of those disability measures. Use best practices and lessons learned from the comparative analysis to advocate and dialogue with African governments to improve their legislations, budgets, and services for people with albinism.

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[29] African Union Plan of Action (2021-2031). 2021. p. 23-24. https://africaalbinismnetwork.org/?post_type=resource&s=matrix

[30] Ibid, p.31-32.

7. Conduct regional evidence-based research on emerging issues impacting people with albinism rights (such as COVID-19 impact on people with albinism).

Acknowledgements

The Africa Albinism Network is proud to have commissioned this survey with an independent consulting organization, ImpactMapper. The AAN is equally grateful to all survey participants for their participation. We are also grateful for the support of our advisory board and ultimately our funders and other supporters. Finally, the AAN is reassured that its working methods – using the AU Plan of Action – to guide its advocacy support to albinism groups, continues to be a reliable means to transform societies, laws, hearts, and minds for the day-to-day enjoyment of human rights by people with albinism.

Appendices & Annex

Appendix A: A Summary of Key needs for better advocacy, FGD responses

- Training on:
    - Monitoring and evaluation skills
    - Advocacy skills
    - Leadership and management
    - Policy analysis
    - Evidence-based research
- Office needs:
    - Office space
    - Furniture
    - Car/vehicle for mobility during advocacy activities and reach out for mobilization purposes
- Staff
    - Paid staff
    - Volunteers (and ways to deal with overturning of volunteers)
- International and regional networking with people with albinism organizations for shared learnings and support
- Funding for national and regional advocacy and campaigning

Appendix B: Survey and FGD Respondents

#	Organization	Survey	FGD
1	Africa Albino Foundation (AAF)	X	X
2	African Albinism Ambassadors (AAA)	X	
3	ALBIMOZ	X	
4	Albinism Foundation of Zambia (AFZ)	X	X
5	Albinism Society of Kenya (ASK)	X	X
6	Albinism Society of South Africa (ASSA)	X	X
7	Albinism Umbrella	X	X
8	Albinos Sans Frontieres (ASF)	X	X
9	Alive Albinism Initiative (AAI)	X	X
10	Amor a Vida	X	X
11	Association pour la Protection et le Développement de la Personne Albinos (APRODEPA)	X	X
12	Associação de Apoio a pessoas Albinas (ALPA)	X	
13	Associação de Apoio de Albinos de Angola (4As)	X	
14	Association Albinos Madagascar	X	X
15	Association Malienne pour la Protection des Albinos (AMPA)	X	X
16	Association Mondiale pour la Defense des Interets et la Solidarité des Albinos (ASMODISA)	X	X
17	Association Nationale des Albinos du Niger (ANAN)	X	X
18	Association Nationale des Albinos du Togo (ANAT)	X	X
19	Association of People with Albinism of Malawi (APAM)	X	X
20	Association pour la Promotion des Albinos au Cameroun (APAC)	X	X
21	AZEMAP	X	X
22	Bien-être des Albinos de Côte d'Ivoire (BEDA-CI)	X	X
23	Butterfly Foundation (BF)	X	X
24	Corbetta RDC	X	X
25	Divine Connection Worldwide	X	X
26	Fédération des Associations et Organisations pour le Bien-Être des Albinos de Côte d'Ivoire (FAOBEACI)	X	
27	Fraternidade Albinista (FALB)	X	X
28	Ghana Association of Persons with Albinism (GAPA)	X	X

29	Government Official		X
30	Missão Kanimambo - Associação de Apoio ao Albinismo	X	
31	National Albinism Taskforce (South Africa)	X	X
32	Organisation pour le Bien Être des Albinos au Congo (OBEAC)	X	X
33	ONG Valeur Albinos	X	X
34	Organisation des Personnes Albinos du Burundi (OPAB)	X	X
35	Organization for Integration and Promotion of People with Albinism (OIPPA)	X	X
36	Positive Exposure Kenya	X	X
37	Solidarité pour l'Insertion des Albinos du Mali (SIAM)	X	X
38	SOS Albinos	X	X
39	Source of the Nile Union of Person with Albinism (SNUPA)	X	X
40	Standing Voice - Tanzania	X	X
41	Standing Voice - Malawi	X	X
42	Stuki Motsa Foundation	X	X
43	Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA)	X	X
44	Swaziland Association of Persons with Albinism (SAPA)	X	X
45	Tanzania Albinism Society (TAS)	X	X
46	The Albinism Foundation (TAF)	X	X
47	The Albinism Network Association (TANA)	X	X
48	Zambia Albinism Matter Organization (ZAMO)	X	X
49	Zambia Albinism Taskforce	X	X
	TOTAL	**48**	**43**

Appendix C: Survey Questionnaire

2022 Survey on Human Rights and Advocacy Priorities

Part 1: About your organization

Q1. Data collector's name (Name of the person filling out this form)

Q2. Full name of the respondent organization

Q3. Respondent Name (Person responding to questions on behalf of their organization)

Q4. Respondent Title (role within their organization)

Q5. In what country is the organization based?

Q6. In how many states or provinces or regions in your country does your organization work in?

Q7. What is your organization's working language?
- English
- French
- Portuguese
- Other (please specify)

Q8. What year was your organization registered?

Q9. For how many years has your organization been actively involved in advocacy initiatives for the protection of people with albinism?
- Less than 1 year
- 1 – 5 years
- 6 – 10 years
- 10 – 15 years
- 15 years or more

Part 2: Personnel

Q10. Leader of organization
- Name of the organization's leader
- Title of the organization's leader

Q11. Deputy Leader of the Organization
- Name of the organization's deputy leader
- Title of the organization's deputy leader

Q12. Has anyone in leadership in your organization received human rights advocacy training?
- Yes
- No
- I am not sure/ Don't know

Q13. How long ago did they receive human rights training?
- Less than 1 year ago
- 1- 3 years ago
- 4 – 6 years ago
- 6 years or more ago
- Don't know
- N/A

Q14. How many (paid) staff work for your organization?
- Less than 6
- 6 – 15
- 16 – 25
- 25 – 50
- 51 or more
- N/A

Q15. Approximately what percentage of your (paid) staff work full time for your organization?
- Less than half (<50%)
- About half (~50%)
- More than half (51% - 99%)
- All staff (100%)
- N/A

Q16. Approximately how many volunteers work for your organization?
- Less than 5
- 5 – 15
- 16 – 25
- 26 – 50
- 51- 100
- 101 or more

Part 3: Partnerships

Q17. Which of the following partners does your organization engage with to implement your activities?
- Government
- Intergovernmental Organizations (e.g., African Union, United Nations)

- International Development Organizations (e.g., Embassies, UNDP office)
- Regional Economic Communities (e.g., ECOWAS, SADC, EAC)
- Law Enforcement Authorities (e.g., Police)
- National Human Rights Commission
- Academic Institutions
- International NGOs (e.g., Amnesty, Open Society Foundations etc.)
- Legal Institutions and Legal Experts
- Teachers
- Healthcare professionals
- Traditional healers
- Traditional leaders
- Religious leaders
- Media
- Private corporations (e.g., Airtel, Safaricom, Carrefour)
- Other (please specify)

Q18. What is your organization's *estimated annual* budget?
- Less than $5000 USD
- $5001 - $10,000 USD
- $10,0001 - $25,000 USD
- $25,001 - $50,000 USD
- $50,001 or more

Q19. Have you ever received funding from any entity?
- Yes
- No
- Don't Know

Q20. From what type of entity have you received the largest sum?
- Government
- Intergovernmental Organization (e.g., UN Agencies)
- International NGOs (e.g., Amnesty International)
- Community (e.g., religious organization)
- Private corporation
- Individual / Membership Dues
- Other (please specify)

Q21. Select the largest sum your organization has received from one funding source
- Less than $5000 USD
- $5001 - $10,000 USD
- $10,001 - $25,000 USD
- $25,001 - $50,000 USD
- $50,001 and above
- Don't know

Part 4: Activities

Q22. Which of the following activities does your organization do?

- Public awareness
- Media advocacy
- Lobbying government for policy, law, and action plans
- Capacity Development and Training for people with albinism
- Capacity Development and Training for key stakeholders (e.g., Teachers, family members of persons with albinism)
- Promoting employment of persons with albinism
- Health Services
- Provision of adaptive devices for low vision
- Protection and support services for victims of attacks
- Other (please specify)

Q23. Please estimate, how many *people with albinism and/or their family members* receive your services annually?

- Less than 50
- 51 – 100
- 101 – 250
- 251 and above

Q24. Please estimate, how many people *without* albinism receive your services annually? (e.g., Teachers trained, healthcare professionals trained etc.)

- Less than 50
- 51 – 100
- 101 – 250
- 251 and above

Part 5: Priorities

Q25. Of the following, which are currently TOP THREE priority advocacy areas for your organization?

- Access to Health
- Access to Education
- Access to Employment (including Entrepreneurship)
- Access to Justice
- Women Impacted by Albinism
- Children with Albinism
- Other (please specify)

Q26. Of the following issues related to HEALTH, which do your organization consider to be the TOP THREE priorities?

- Access to and affordability of skin care/dermatological support
- Access to and affordability of eye care/ophthalmology support
- Train healthcare professionals

- Provide psychological support for people with albinism
- The provision of rehabilitation services for victims of violence
- N/A
- Other (please specify)

Q27. Of the following issues related to <u>EDUCATION</u>, which do your organization consider to be the <u>TOP THREE</u> priorities?

- Eliminate sociocultural barriers to accessing education for people with albinism (e.g., bullying)
- Inclusive Education
- Teacher and non-teaching staff training
- Promote reasonable accommodation and access to adaptive devices for low vision
- N/A
- Other (please specify)

Q28. Of the following issues related to <u>EMPLOYMENT</u> which do your organization consider to be the <u>TOP THREE</u> priorities?

- Access to information about employment opportunities
- Reasonable accommodation at work
- Vocational training programs for people with albinism
- Promote safe and favorable working conditions for people with albinism
- Train current and potential employers on the inclusion of people with albinism
- N/A
- Other (please specify)

Q29. Of the following issues related to <u>ACCESS TO JUSTICE</u> which do your organization consider to be the <u>TOP THREE</u> priorities?

- Mitigating the lack of knowledge of laws, experts, cost of lawyers
- Train judiciary and law enforcement authorities (e.g., Police)
- Strategic litigation (e.g., Bring a case to make a point)
- Record cases of attack
- Follow-up with court proceedings and advocate for speedy judicial proceedings in cases of attacks
- Psychosocial support to victims and family members
- N/A
- Other (please specify)

Q30. Of the following issues related to <u>WOMEN IMPACTED BY ALBINISM</u> which do your organization consider to be the <u>TOP THREE</u> priorities?

- Eliminate harmful practices against/towards women with albinism
- Eliminate gender-based violence and discrimination in employment
- Access to information for women with albinism
- Access to sexual and reproductive healthcare

- Protection of women with albinism against sexual and gender-based violence
- General health services for women impacted by albinism
- Psychosocial support for women impacted by albinism
- N/A
- Other (please specify)

Q31. Of the following issues related to CHILDREN WITH ALBINISM which do your organization consider to be the TOP THREE priorities?

- Harmful practices which fail to protect children with albinism
- Improve access to information for children with albinism (e.g., child-friendly publications)
- Improve access to inclusive education
- General health services for children with albinism
- Psychosocial support for children with albinism
- N/A
- Other (please specify)

Q32. Thinking of your advocacy and protection work, what are your organization's TOP THREE target audiences?

- People with albinism and their families
- People with albinism who live in "hotspots" or areas of reported attacks
- Government
- NGOs
- Teachers/educators
- Healthcare professionals
- Media
- Intergovernmental Organizations (AU, UN)
- Other (please specify)

Q33. Considering your organization's advocacy work, please indicate whether each strategy is a low priority, medium priority, or high priority.

- Research and Data Collection
- National Action Plans on Albinism
- Public Education and Community Forums
- Traditional Media Engagement
- Digital Advocacy / social media
- Workshops, Trainings, Seminars
- Other (please specify)

Part 6: Advocacy Knowledge & Capacity

Q34. Is your organization aware that the African Union has adopted a Plan of Action on Albinism from 2021 to 2031?

- Yes
- No

- A little bit and I don’t know what that means for us
- A little bit and I don’t know how to use it to our advantage

Q35. Has the African Union Plan of Action on Albinism been adopted in your country?

- Yes
- No
- In Process
- I am not sure

Q36. What legislative and policy frameworks exist to protect people with albinism in your country?

- Specific law on albinism
- Specific policy on albinism
- Specific action plan on albinism
- Disability laws and policies
- Other (please specify)

Q37. What best describes your organization’s comfort level with human rights advocacy?

- Expert
- Very Comfortable
- Comfortable
- Uncomfortable
- Totally new to this
- Other (please specify)

Q38. Select what you think are the <u>TOP THREE</u> barriers to effective Civil Society and Government collaboration on the protection of people with albinism in your country.

- Varying and multiple objectives
- Differences in perspectives and framework
- Difference in technical knowledge and competences
- Linguistic barriers
- Competition for resources
- Problems with leadership
- Other (please specify)

Q39. Select what you think are the <u>TOP THREE</u> barriers to effective Civil Society collaboration on the protection of people with albinism in your country.

- Varying and multiple objectives
- Differences in perspectives and framework
- Difference in technical knowledge and competences
- Linguistic barriers
- Competition for resources

- Problems with leadership
- Other (please specify)

Q40. From your organization's perspective, please name the countries that have done well on human rights advocacy or the protection of people with albinism and why? (Please specify countries) ***(Optional)***

Q41. What else should the Africa Albinism Network know about needs, trends, and priorities that your organization faces? Please specify. ***(Optional)***

Annex A: Interpretation by the Africa Albinism Network

Upon review of the survey response data, we see three crucial themes emerging.

Theme 1: Holistic and Cross-Cutting Advocacy Strategies are preferred
Nearly all albinism groups are conducting awareness-raising or public education activities as a key advocacy strategy. This is not surprising given that belief-based stigma remains an issue. Moreover, this strategy is relatively low-cost with potential for high impact. It is also transferrable to various domains whether health, education, police or judiciary, meaning impact can be multi-sectoral and holistic to tackle discrimination and exclusion in all areas of life. Another key strategy of choice is using the National Action Plans. These too are multi-sectoral and hold potential to support sustainable interventions to advance the protection of people with albinism from various sectors in society, in a more sustained and systematic manner.

Theme 2: The Right to Life appears to drive the advocacy priorities of albinism groups
"Priority" areas are better understood as the areas where most albinism groups currently work. The top four areas were health, education, access to justice, and employment. That these are currently the areas of most intervention for albinism groups is reasonable since:

- Health, particularly prevention, and treatment of skin cancer is a key priority for albinism groups given that it is a fundamental aspect of survival/the right to life and without which the other rights cannot be accessed.
- Education is a key priority given that without it, the right to life of people with albinism can be compromised. People with albinism who have low literacy may end up working outdoors and contracting skin cancer which remains a deadly force in many parts of the continent.
- Access to employment and justice are also indirectly tied to the right to life since both can facilitate access to a decent livelihood, health, and security.

The prioritization of health and education confirms the longstanding hierarchy of needs illustrated by the psychologist, Abraham Maslow, whereby, the most primordial needs linked to survival are the foundation of the other needs.

This also suggests that the priorities not highlighted by a majority such as psychosocial concerns or particular concerns of women and children may in the future become a priority, once the current priorities linked to the basic right to life have been met or improved. This is further supported by the fact that the albinism organizations with the higher budgets were the majority organizations working on issues pertaining to women and children impacted by albinism as well as “other” priorities not identified by other respondents.

Theme 3: The Survey Results Affirm the AU Plan of Action on Albinism

The key advocacy strategies and priorities identified by albinism groups strongly align with the measures that make up the AU Plan on Action on Albinism in Africa (2021-2031). This is not a surprise given the participation of albinism group leaders in the development of that Plan of Action. This consistency should reassure potential supporters of the movement that there is a clear and consistent unity of vision among albinism groups in the region.

Further Insights

The above themes are based on the basic collation of responses alone. We look forward to conducting further (comparative) analysis of the data to get more insights.

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