



Submission in response to the call for input by UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on human rights defenders with albinism and human rights defenders working to protect and promote the rights of persons with albinism.

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Introduction

The Africa Albinism Network (AAN), Albinism Alive Initiative (AAI), Albinism Foundation of Zambia (AFZ), Divine Connexion World Wide (DCW), Organisation for Integration and Promotion of People with Albinism (OIPPA) and Swaziland Association of Persons with Albinism (SAPA), welcome the opportunity to contribute to the call for input by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on human rights defenders with albinism and human rights defenders working to protect and promote the rights of persons with albinism.

This submission will provide information on the experiences, and views of human rights defenders with albinism, albinism groups and organisations working to promote the rights and welfare of persons with albinism in Africa.



Contributing Organisation's Profile

The Africa Albinism Network (AAN), established in February 2021, is a consortium of organisations working to promote – through human rights advocacy – the dignity, rights, and welfare of persons with albinism and their family members in Africa. The Network aims to ensure that the African Union Plan of Action to End Attacks and other Human Rights Violations Targeting Persons with Albinism (2021-2031) is implemented at the national level, including through national action plans with multi-year budgets; and that the positive effects of these measures concretely advance the enjoyment of human rights by persons with albinism in the Africa region.

Albinism Alive Initiative is a game-changer Non-Governmental Organization diligently working towards the overall objective of fighting stigma and isolation, as well as creating awareness and changing the mindset of the society on albinism in Zimbabwe, Africa and the World.

Albinism Foundation of Zambia was established in 2008 as a nongovernmental organisation that works to promote the welfare of persons with albinism in Zambia. It is the first albinism organisation in Zambia. The vision of the foundation is to see persons with albinism in Zambia enjoying and exercising their rights and fundamental freedoms on an equal basis with the rest of society without any form of discrimination based on their condition.

Divine Connexion World Wide's mission is to create a world where the fear of God, Peace, and Justice is inherent in the majority. Their mission is to



promote a biblically inclusive society in Benin and throughout Africa by developing quality leadership among children and young people, providing the population with healthy theological resources, protecting and empowering the vulnerable, and planting Christocentric churches formative of disciples.

Organisation for Integration and Promotion of People with Albinism (OIPPA) mission is to promote the integration and socio-economic participation of people with albinism by reinforcing their capacities and building their autonomy.

Swaziland Association of Persons with Albinism (SAPA) was founded in 2013 by Philemon Gama and registered in 2016. It is the first Swati Association to raise awareness of the conditions of persons with albinism (PWA) in Eswatini.

Methodology

This submission is based on inputs received from human rights defenders with albinism who, in most instances, are leaders of albinism groups and organisations working to promote the rights and welfare of persons with albinism in their respective countries in Africa. These inputs were collated through one-on-one interviews as well as written submissions using the questionnaire provided by the UNIE on albinism.

The staffs at the Africa Albinism Network also shared their experiences as a regional organisation working to promote the rights of persons with



albinism in Africa through human rights advocacy with a focus on ensuring that African countries adopt and implement the AU Plan of Action on Albinism in Africa.



Response to the call for input by UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism on human rights defenders with albinism and human rights defenders working to protect and promote the rights of persons with albinism.



Region: Sub-Saharan Africa

Organisation: Africa Albinism Network

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Responses.

- 1. Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organization work on issues related to albinism. Please provide information on the work that you engage in.**

Our organization, the African Albinism Network (hereinafter the "Network" or "AAN"), is dedicated to promoting and protecting the human rights of people with albinism and their family members across Africa through the promotion of implementation of the African Union Plan of Action (AU PoA)



at the national /community level as well as through human rights advocacy at the AU, UN, National and community levels.

- 2. Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.**

We work continentally and consider the organizations of people with albinism in those countries – who we work with – human rights defenders.

- 3. Are there any laws/policies that support the work of HRDs and if so, how have they implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?**

The AU PoA refers to albinism groups/leaders of albinism groups in the prevention pillar under strategic outcome 1.2 (b), which aims to deepen the overall capacity-building of organizations representing persons with albinism. Also, under 1.6, it supports the participation and leadership of persons with albinism in public settings.

Similar references have been made in the national action plans (NAPs) in pillar 5 of Malawi, aiming at mainstreaming and empowerment of persons with albinism; on pillar 1 of South Africa sought to strengthen advocacy tools to ensure the albinism sector speaks with one voice and on draft Tanzania NAP under the fourth pillar.



4. What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work? Please specify. How can these issues be addressed and what kind of support do these HRDs need?

Resource constraints such that the needs far exceed the work to be done. With few funders in this area, HRDs compete for limited resources in a way that may hamper necessary collaboration among them. Therefore, more funding partners need to be attracted into this space. In addition, emphasis should be placed on national resources as these are relatively accessible, contextual, reduce the potential for competition and are likely to be sustainable.

The risk of toxic work environments increases because of the relatively small movement. Because few people with albinism (PWA) are qualified to work in this space, the natural processes of hiring, quitting and retrenchment, which should be expected in any workspace, can lead to toxicity that remains in the movement as the small group of qualified PWA move from one organization to the other. This, too, can hamper potential collaboration. It could be solved with the involvement of more people with and without albinism, especially at the grassroots level in these organizations, such that symbiotic learning is encouraged and skills for this field go beyond people with albinism themselves.



Unwillingness on the part of the government to engage. This appears to stem from three fundamental problems. First, the misunderstanding that working on the issue of PWA may impact their work on disabilities in general. The government appears not to be aware of how to continue the general work on disabilities while carrying out specific measures for the particular problems faced by people with albinism, such as by developing medium-term national action plans on albinism with funding, as called for by the AU PoA. Second is the lack of knowledge about the AU PoA, which is pervasive among many governments in several countries, given the little references they make to it in their speeches when they engage in the issue, e.g., little to no reference to the AU PoA in the draft NAPs of DRC and Kenya until stakeholders such as the AAN pointed out these crucial omissions. Thirdly is the issue of numbers. Governments have a habit of working with large aggregates or large numbers of people. Work with smaller numbers, such as PWA, may seem administratively inefficient for government. This shows that governments need support when engaging with marginalized groups, vulnerable groups, and minority groups in general. They also need to be adequately informed on how to address the matter of marginalized groups in a manner that is administratively efficient.

An example is South Africa, where a directorate is set up for marginalized and vulnerable groups in one ministry. This approach helps to give a type of simultaneous aggregation and disaggregation necessary to meet the Sustainable Development Goals and its core principle of "leaving no one



behind". It is not surprising that South Africa – while slow in adopting its NAP and yet to do so – was among the first to act on the issue of PWA. Governments should be supported in understanding that small groups, in particular, need support as they may fall by the wayside in aggregations. In addition, they need to understand the problem of proportionality: even if there are 50 people with albinism in a village, an attack on 5 of those is an attack on 10 per cent of their population in that area, leaving the rest of them in dire fear of attack among other high risk-related human rights violations. Promotion of the NAP or use of action plans in general, which are based on the human rights approach, can help governments to overcome the numbers issue, the disability "conflict" issue, and the need to take the necessary action to protect people with albinism.

5. Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

Reprisals. For instance, we are aware that in Tanzania, a coalition of civil society organisations who issued a press release on the case of attacks against a person with albinism last year appeared to have received some blowback from the government, causing them some hesitation in issuing a similar release after another attack was reported in November 2022.

Also, in Tanzania, there appears to be a general block in the media to report cases of attacks. We have noticed that cases are hardly reported on in the mainstream or local press. They are often found only on obscure websites



such as blogs and from civil society organisation leaders. We have reason to believe that the media fear reprisal in reporting these cases in Tanzania.

6. Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

Yes, in the course of our work, we are witness to attitudinal barriers toward women human rights defenders, including against members of our staff, a majority of whom are women. In meetings across Africa, women are easily shut down during discussions or ignored on their points, only for a man to repeat the same point later and be heeded. Women are also prone to sexual abuse and other forms of exploitation. Given that most PWA groups in the region are nascent, short on funds and tend to be led by people with modest personal means, it is safe to conclude that these are conditions favourable to exploitation. We have received serious allegations of exploitation in one country, leading us to re-strategize our interventions there. Allegations range from grave sexual exploitation to exploitation in the form of money in exchange for political support within the albinism movement.

While women bear the brunt of sexism and gender-based violence, we have reason to believe that men with albinism face a certain degree of added exposure to exploitation due to the compound effect of low confidence from stigma and social attitudes toward albinism as well as poverty.



7. What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

We know that civil society members from Mozambique, Malawi, and Zambia, among others, must attend to the homes of victims of attacks and the police to participate in various work, from victim support to the investigation. Often these are carried out without protection from the government or their organization which is often under-resourced. This puts albinism leaders at significant risk.

The potential of sexual and other forms of exploitation of people with albinism who are often in dire need both organizationally and personally need to be addressed, including through awareness training and the use of mentorship programs whereby more experienced human rights-based groups coach and support up-and-coming PWA groups. Above all, these albinism organizations need to be outfitted with the necessary resources and organizational infrastructure, including political checks and balances.

8. Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.



In some countries, such as Malawi and Mozambique, the government is working on updating their NAPs. However, Tanzania, Kenya, and South Africa are yet to adopt their draft NAPs. These NAPs sometimes have provisions to protect or support albinism leaders. For instance, draft NAP under the first pillar of protection in Tanzania aims to improve the security and safety of persons with albinism. It expands to provide security in the home setting, schools and the community from the village level to the national.

9. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

Risk assessments: whether brief or extensive, are often considered before staff are sent to the field. Once in the field, all efforts are made to put both staff and local interlocutors in safe hotels/accommodations (recommendations are made based on internal risk-assessments, although these can be jettisoned if – upon consultation – they are not desired or considered inappropriate by local interlocutors).

AAN consults with a security company with regional experience to consider the security situation in several African countries. These assessments are taken into consideration with the security assessment of our trusted national partner, who is pre-identified based on a history of credibility and reliability.



Digital security is in place through service providers. So, we have the basics in this regard. Plans are in the works to review and extend these. Note, though, that this often comes at a cost, so we are working with the basics for now.

Also, regarding digital security as it relates to our work. For example, details of home addresses or locations are often hidden, initials are used in reporting the names of victims of attacks, even if the names are already in the public domain. This is to infuse a trauma-informed approach into our work and to respect victim rights as best as possible, including the need to protect survivors or relatives of the victims who may be witnesses.

10. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical and psychological well-being.

For physical well-being, please see our response at number 10. In addition, private vehicles are often enlisted to transport staff when doing fieldwork.

Psychological well-being is supported by an annual vacation period with pay that can be taken at any time. A team/collaborative approach is also taken in general, and particularly in instances whereby any staff is facing bullying, verbal abuse or toxicity from a partner or interlocutor. In such cases, other staff may step in to support or give the original staff respite and support. AAN also hopes to engage staff in ongoing professional



development, including temperament analysis skills to provide them with psychological understanding, which in turn builds resilience when facing or working with diverse personalities.

11. Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organizations or civil society organizations?

AAN proudly collaborates actively with other HRDs such as Amnesty International, the UNIE on albinism, and the National Human Rights Institutions in some of our priority countries such as Kenya, Malawi and Zambia. We also engage in varying degrees with other CSOs in the albinism community, in particular ranging from national partners in our priority countries (eight of them (in random order): Malawi, Togo, Tanzania, Mozambique, South Africa, Kenya, Zambia and Uganda), to international partners such as the Global Albinism Alliance.

12. In relation to the previous question, please specify any challenges you face in working or collaborating with other organizations and how these can be addressed.

Resources: The AAN and some groups are willing but unable to support/engage due to resource limits – human, time and financial.



Different priorities: for instance, one group may be interested in a scientific approach to PWA, whereas we take on a more human-rights-based approach.

North-South dynamic: Sometimes, we struggle with earning the trust of fellow global South CSOs, whereas the same trust easily goes to relatively wealthy organisations, i.e., mostly organizations from the global north. This can impact South-South collaboration and opens room for (in) advertent relationship distortion or manipulation due to real or perceived power. Cross-cultural awareness and a proper training/understanding of the role of power dynamics in post-colonial societies, how funding works etc., could reduce this dynamic and increase both SS and NS collaboration among HRDs working on albinism.

13. Are there any good examples or practices in relation to the protection of HRDs?

Zambia appointed an influential PWA-HRD to its police commission. This offers PWA in the country a sense of security or protection since they now have a contact to reach out to when they are in jeopardy. In addition, the PWA can influence police protection policies for PWA.

AAN's work with Amnesty International is an excellent example of mentorship between a new and not-so-new human rights defender. This relationship gives AAN access to other CSOs who already know and trust Amnesty International. Moreover, AAN can consult with Amnesty



International on how to deal with issues that may be new to AAN, such as governmental threats of reprisal, exploitation allegations and so on. We strongly encourage this type of organization-mentorship approach in the albinism movement, which as a whole, is relatively new. However, good faith and measures to address other issues, such as those highlighted at number 12, would be necessary to ensure that such partnerships work well.



Country: Eswatini

Organisation: Swaziland Association of Persons with Albinism

Contact: Philemon Gama, Founding National Director. Email: albinismd@gmail.com. Phone: +26876791886

Responses.

- 1. Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organization work on issues related to albinism. Please provide information on the work that you engage in.**

I am a person with Albinism and the founding National Director for the Swaziland Association of Persons with Albinism working specifically on protecting and promoting the human rights of persons with albinism. Since the organisation's founding, I've advocated for the rights of persons with albinism in the country. Some of my activities are awareness campaigns and public education about the plight of persons with albinism in print and



electronic media. We have also advocated for the commemoration of June 13.

- 2. Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.**

Groups of persons with albinism are considered human rights defenders partially. This is because some people sometimes regard us (persons with albinism) as persons who do not need special attention because of our able bodies.

- 3. Are there any laws/policies that support the work of HRDs and if so, how have they implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?**

The government of this country does have some policies that support human rights defenders, e.g., the National action plan for persons with disabilities 2017 to 2022 and the Persons with Disabilities Act of 2018. In addition, the country ratified the UNCRPD in 2012. All these legal documents have provisions for protecting persons with disabilities. Unfortunately, however, they are not implemented to their fullest expectations.

- 4. What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work?**



Please specify. How can these issues be addressed and what kind of support do these HRDs need?

The main challenge our advocates face in pursuing their work is financial constraints that hinder them from delivering to their fullest level for their organizations

These challenges can be addressed by establishing a principal fund for organizations working to promote the rights of persons with albinism. This fund will cater to the needs of these organisations' day-to-day work. When established, the fund will significantly impact the work of the albinism movement.

5. Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

We do have persons with albinism who work for other organizations that do not subscribe to the Albinism philosophy. Seemingly they are doing well, except for the fact that they are discriminated against in some instances.

6. Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

We have women with albinism as human rights defenders who face double tragedy. First, they are considered inferior compared to men because they



are women. Secondly, the Albinism condition makes them prone to discrimination and stigmatisation.

7. What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

The main security issue is safety when travelling to communities, especially in rural areas where most myths and misconceptions come from. For example, some traditional Healers who reside in rural areas believe that the body parts of persons with albinism, when used in ritual potions bring good omen. Therefore, they harvest body parts of persons with albinism for such purposes. This creates security concerns for human rights defenders travelling to such areas.

They are also prone to rape as some people have a primitive belief that mating with a person with albinism is a curative measure for HIV/AIDS.

8. Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.

N/A

9. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender



working on the rights of persons with albinism, or your organization take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

I do not travel during the night. In addition, I am cautious about interacting with suspicious strangers who may harbour evil intentions. I do not follow suspicious links on digital platforms

10. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical and psychological well-being.

I have decided to undergo a trauma healing training course. I am using that expertise to heal the broken souls of others. For my psychological well-being, I also undergo counselling sessions sometimes, and if possible, I go for some sporting activities.

11. Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organizations or civil society organizations?



Our organization welcomes any collaboration with other Albinism organizations since we share information with others about issues affecting our people.

12. In relation to the previous question, please specify any challenges you face in working or collaborating with other organizations and how these can be addressed.

N/A

13 Are there any good examples or practices in relation to the protection of HRDs?

N/A



Country: Benin

Organisation: Divine Connexion World Wide (DCW),

Contact Person: Franck Houètèhou C. Hounsa; Executive Director and Founder; Divine Connexion Worldwide; connexionworldwide1@gmail.com. Phone: +22997895528.

Responses

1. Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organization work on issues related to albinism. Please provide information on the work that you engage in.

Yes, I am a person with albinism working on the rights of persons with albinism in Benin. We raise awareness of albinism through my organisation. We also take care of the needs of children with albinism. Currently, we have 15 children with albinism receiving mentorships for over six years now. We support the payment of school fees and provide assistive devices such as monocular for these children and take care of their health expenses.



2. Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.

Yes, they are considered human rights defenders

3. Are there any laws/policies that support the work of HRDs and if so, how have they implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?

To the best of my knowledge, no specific laws or policies support human rights defenders' work. However, some laws protect human rights in general but are not specific to human rights defenders.

4. What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work? Please specify. How can these issues be addressed and what kind of support do these HRDs need?

The main challenge human rights defenders face is the risk of kidnapping. I have received phone calls that seemed to have been set up to kidnap or kill me because of my work as a human rights defender. In addition, our security is always at risk of physical attack.

There should be a law promulgated to protect human rights defenders. Furthermore, the perpetrators of crimes against human rights defenders



should be strictly enforced with stricter and harsher punishment to deter others from engaging in the same or similar offences.

Human rights defenders need protection from state security operatives to deliver on their work as defenders of human rights effectively. Also, human rights defenders need financial support to work effectively. That notwithstanding, they also need governmental support in terms of listening to their plights and ensuring that government agencies meet their requests.

5. Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

I know people with albinism who work as lawyers and administrative staff at the National Human Rights Council. However, their work is not focused on the rights of persons with albinism.

6. Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

I do not know any woman with albinism who works as a human right defender. However, I know others without albinism are working to promote the rights of persons with albinism. However, I am unaware of any challenges they might be facing aside from the challenges associated with being an African woman who is mainly seen as inferior to their men counterparts.



7. What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

The main security concern affecting human rights defenders with albinism is reprisal attacks, especially from perpetrators of attacks against persons with albinism. For instance, we risk being attacked by those who believe that the body parts of persons with albinism possess magical power. So, when we speak publicly to demystify these notions, they think we are destroying their business in the body parts of persons with albinism. Similarly, we receive threats from the government when we speak up since they are not focusing on issues affecting persons with albinism. Still, we try to force them to do so. However, this may create tension between government and human rights defenders with albinism and others working to promote the rights of persons with albinism.

8. Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.

No. We have reported several cases of missing persons to the police. Still, they have not taken any action on such issues. In all cases, they only paid lip services to our reports with no effort.



9. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

To guarantee my security, I make sure I move with someone while giving as much information to others about my whereabouts. I also ensure I am in the office with someone because my office is a bit isolated. So, I ensure I am in the office with my secretary or wife. In addition, I follow strict administrative protocols, especially in collaborations involving moving out of the office to the field. All communications are channelled through my secretary, and necessary security checks are done before I embark on out-of-office engagements.

I activated the two-step verification on Facebook to ensure hackers could not access my account. Unfortunately, my website has been hacked, and I am working on a more secure one to prevent future occurrences. Fortunately, I now have the skills to develop a website. So, I will ensure the new website is well secured from being hacked. Additionally, I block people who abuse me through social media channels. I take these measures to guarantee my digital security.

10. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender



working on the rights of persons with albinism, or your organization take to guarantee your physical and psychological well-being.

Refer to point nine on physical well-being. Psychologically, I am facing many challenges and do not know what to do. Sometimes, I am depressed and cannot figure a way out. Therefore, I cannot pinpoint any particular measure to take care of my psychological well-being.

11. Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organizations or civil society organizations?

We have collaborated with several organisations, and I am also working on joining the National Federation for persons with disabilities. In addition, we work with the National Human Rights Council, sharing information to assist their work.

12. In relation to the previous question, please specify any challenges you face in working or collaborating with other organizations and how these can be addressed.

One challenge I faced while working with one organisation in the past was information flow issues. As a result, we were not getting the correct information on the project as it was supposed to be. As a result, we did not



get any feedback on the project in the long run, which was very unfortunate at the time.

13. Are there any good examples or practices in relation to the protection of HRDs?

N/A



Country: Ghana

Contact Person: Adam Abdul Wahab. He is a person with albinism, and disability rights advocate working as the Programmes Officer, Health and Civic Participation of persons with disabilities at the Ghana Federation of Disability Organisation.

Contact: Email: wabjemada@gmail.com Phone: +233244739094/+233206603388

Responses.

- 1. Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organization work on issues related to albinism. Please provide information on the work that you engage in.**

I am an individual who has worked on the rights of persons with albinism. I also work for an organisation that promotes the human rights of all persons with disabilities, including those with albinism. We have done much work to protect the rights of persons with albinism. For example, I started working as an advocacy officer with the Ghana Association of Persons with Albinism. I have visited many places and spoken with many persons with albinism and their families. We also had the opportunity to engage law enforcement agencies to ensure that they take cognisant of the rights of persons with albinism to protect their rights. In addition, I have had engagements with



radio, television, and media. I have written a lot about promoting and defending the rights of persons with albinism.

2. Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.

Yes, they are considered human rights defenders. They are referred to as human rights defenders because they do advocacy to influence the programmes and policies of the government at the national level in the interest of the people they are pushing for. In that case, they see to it that the rights of individuals with disabilities, including persons with albinism, are not violated. Therefore, since they protect individuals' rights from being violated, they are referred to as human rights defenders.

3. Are there any laws/policies that support the work of HRDs and if so, how have they been implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?

Yes, Ghana has a disability act (Persons with Disability Act 715 of 2006) which seeks to promote and protect the rights of all persons with disabilities, including albinism. Besides that, there is the national constitution (The 1992 Constitution of the Republic of Ghana) which make specific provision in article 29 to address issues relating to disabilities. These tools or legal systems guide the works of human rights defenders pushing for the rights



of persons with albinism. In addition, Ghana had also ratified the United Nations Convention on the rights of persons with disabilities, an international treaty seeking to promote and protect the rights of persons with disabilities. These are instruments based on which human rights defenders operate.

When we talk about implementing these legal instruments, we may say a challenge or a gap exists. Human rights defenders have been pushing for these laws to be implemented; however, implementation has not been very effective. We believe that when these instruments are effectively implemented, it will create an opportunity to protect HRDs. For instance, the UNCRPD call for the involvement of the organisation of persons with disabilities in the implementation process of the convention.

4. What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work? Please specify. How can these issues be addressed and what kind of support do these HRDs need?

One of the barriers human rights defenders with albinism face is usually the societal perceptions and understanding of albinism as a disability condition. For instance, some people still do not know that albinism is a disability. Therefore, it becomes difficult for people to accept that when you push for the inclusion of people with albinism in the disability community, they do not want to accept. Therefore, people tend to see that laws that protect and



defend the rights of people with disabilities exclude persons with albinism. This is a challenge for human rights defenders with albinism.

Again, people believing in themselves present another challenge to HRDs with albinism. For example, a famous lawyer with albinism in Ghana categorically stated publicly that he is a person with albinism but not a person with disabilities. These situations make the work of HRDs with albinism very difficult.

These challenges can be addressed by constant engagement, education and sensitisation. Therefore, HRDs would need capacity development programmes to enable them to have a better understanding of the relationship between albinism and other disabilities.

5. Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

I can use myself here as an example of a human rights defender with albinism whose work is not explicitly focused on albinism. My work also involves advocacy around general disability, gender and media freedom. One challenge we sometimes face is the misunderstanding between organisations of persons with albinism and individuals defending the rights of persons with albinism. For instance, if I decide to talk about rights violations of a person with albinism, maybe an albinism organisation would think that I should seek permission from them before I go ahead to address



some of those issues. They feel that issues about the rights of persons with albinism are solely their mandate. I think this is a challenge that needs to be addressed.

6. Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

Women human rights defenders generally face some challenges. In Africa and specifically Ghana and within the disability movement, women, for some times now, have not been given a voice or even if they are, it is not recognised. This makes it difficult for women human rights defenders to succeed as human rights defenders. Connecting that to women human rights defenders with albinism, they have particular issues of discrimination and stigmatisation based on their albinism. Again, being a woman with albinism creates a situation of intersectionality, which significantly impact their work as women human rights defenders with albinism. This situation makes it difficult for them to defend their rights and that of others.

7. What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

The security challenge I can discuss concerning human rights defenders with albinism is the traditional beliefs and perceptions that persons with albinism



are not allowed to visit some communities in Ghana. There are some communities in Ghana where if you are a person with albinism, you do not have the right to be there according to their traditional authority. In these situations, the right to residence, freedom of movement and security of persons with albinism is severely violated. Even though there is no evidence of physical attacks or killings of persons with albinism in such communities, these communities pose severe security threats to persons with albinism moving into such communities to engage in human rights defence.

Let me cite an example of a personal experience I encountered with other human rights defenders with albinism in our attempt to engage a community. In 2019, the Ghana Association of Persons with Albinism tried to engage a community in the Eastern region of Ghana, that is, 'Akwamufie', to be precise. I was part of the team that was to visit the community. But unfortunately, we got there, and we were made to sit in the bus for more than an hour and were never allowed to step on that community's land. The belief was that it was taboo for us (persons with albinism) to walk around the community, especially near the chief's palace. It is believed that the gods of the land do not permit the presence of persons with albinism near its shrine.

8. Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.



I cannot confidently say there has been a response to addressing the security concerns faced by human rights defenders with albinism. However, the Commission on Human Rights and Administrative Justice (CHRAJ) started working on measures to remove some of those barriers affecting human rights defenders and persons with disabilities, including albinism, to have the freedom to operate in every part of the country. Notwithstanding, I have not seen any published responses or any sanctionable action taken against some of these communities. I can hardly say there is a response, but there is an attempt to respond.

9. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

Some of the steps that we have taken as human rights defenders is seeking support, guidance and protection from the state security agencies, especially the police service. In most cases, we write to these security agencies to ensure they are involved in whatever we do. In addition, there is a push for implementing some policies and legislations that seek to allow human rights defenders to operate without any hindrance. For instance, the review and implementation of the revised Disability Act allow organisations of persons with disability, including albinism and individuals with a disability, to operate. However, the same act also gives security agencies and the judiciary



responsibility to support the advocacy of persons with disability, including albinism.

Concerning digital security, Ghana has a Data Protection Act which seeks to protect the data of every individual. Since the data protection act is in place, we can assume that our digital data is protected. However, security agencies or the judiciary may call for your data upon a violation or wrongdoing for investigation purposes. At the organisation, we have some cyber security software we use to secure our individual, and organisational data, for example, the data of our beneficiaries.

10. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical and psychological well-being.

There are organisational protocols such as guidance and counselling, and information sharing, especially when embarking on fieldwork. At the individual level, we use these administrative protocols in our dealing. For instance, I always share information with close relatives during field visits.

11. Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organizations or civil society organizations?



The Ghana Association of Persons with Albinism (GAPA), an advocacy organisation for persons with albinism in Ghana, have had several collaborations with other organisations at both national and international level. For example, GAPA is a member organisation of the Ghana Federation of Disability Organisations (GFD), an umbrella organisation of all disability groups in Ghana. Automatically, GAPA is in collaboration with all disability groups in Ghana. GAPA also works collaboratively with Engage Now Africa and OSIWA, among others. These organisations provide all kinds of technical and funding support for their human right defence work.

12. In relation to the previous question, please specify any challenges you face in working or collaborating with other organizations and how these can be addressed.

One of the challenges is understanding the mandate of each organisation. Also, conflict of interest and the power dynamic is a challenge, especially between smaller organisations and much bigger and well resource ones.

To resolve these challenges, we need to build a network of like-minded organisations to educate each other to understand our mandates better.

13. Are there any good examples or practices in relation to the protection of HRDs?

A TV station invited me to discuss an issue surrounding persons with disabilities. While on air at the TV station, I received a text message warning me about what I was discussing. At the same time, the producer of the show



received the same warning message. Upon sensing danger and security threats, I was given a place to rest for about an hour after the discussion. Later, the TV station drove me straight to my doorstep. This measure was taken to protect me from harm.

Other Remarks

I want to recommend that countries have specific policies or laws addressing the needs of people with albinism. We can assume that the disability act covers persons with albinism as persons with disabilities. However, relating to this mental health which falls within the disability movement, persons with albinism have peculiar needs, just as persons with mental health disabilities need to be addressed. It is high time countries adopt specific policies and programmes to address the peculiar needs of persons with albinism. in addition,

I would also recommend adopting and implementing the Africa Disability Rights Protocol and the AU plan of action on albinism in Africa.



Country: Rwanda

Contributing Organisation: Organisation for Integration and Promotion of People with Albinism (OIPPA)

Contact Person: Nicodeme HAKIZIMANA, Executive Director of the Organisation for Integration and Promotion of People with Albinism (OIPPA). Email: oiippa2012@gmail.com. Phone: +250 785 636 049 / +250 786 149 961

Responses

- 1 Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organization work on issues related to albinism. Please provide information on the work that you engage in.**

I am a person with albinism and the executive director of an organization of persons with albinism. Our mission is to promote the integration and socio-economic participation of people with albinism by reinforcing their capacities and building their autonomy.



2 Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.

Yes, the groups and individuals work to advance the rights of persons with albinism; however, most of these groups are mainly groups of persons with disabilities.

3 Are there any laws/policies that support the work of HRDs and if so, how have they implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?

There are no specific laws or policies that support the work of HRDs; however, there is a particular law, Rwanda: Law No. 04/99 of 1999 establishing the National Human Rights Commission that governs the National Human Right Commission in Rwanda.

4 What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work? Please specify. How can these issues be addressed and what kind of support do these HRDs need?

In Rwanda, the law protecting persons with disabilities (Law N° 01/2007 of 20/01/2007 Relating To Protection of Disabled Persons In General) does not mention anywhere that albinism is a disability like any other



type of disability. This affects the advocacy work of HRDs in most ministries and other public institutions. It is too hard to allocate a budget or include persons with albinism in planning when this category is not mentioned in the law.

The government should address these issues by reviewing the disability law of 2007, which protect persons with disability in Rwanda and include persons with albinism as a particular category of disability.

5 Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

There is no particular challenge.

6 Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

The challenge they face is that the community and decision-makers are unaware of albinism, and most have negative beliefs about albinism. Others do not even know about albinism, which brings resistance to change. The misconception associated with the condition affects their advocacy work leading to no positive impacts.

7 What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights



defenders working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

No security challenges.

8 Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.

n/a

9 Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

Generally, the government has measures to protect its citizens, including persons with albinism. There is no specific way reserved to protect persons with albinism.

10 Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical and psychological well-being.

There are no specific measures.



11 Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organizations or civil society organizations?

In Rwanda, we have an umbrella organization of different types of disabilities which work together to advocate for persons with disabilities. There is also a national council of persons with disabilities, human rights commission and a platform for civil society organizations. All these platforms are connected to raise the voice of persons with disabilities

12 In relation to the previous question, please specify any challenges you face in working or collaborating with other organizations and how these can be addressed.

The issues are that these organizations have the same understanding and perceptions about albinism as the general public. Therefore, it takes effort to explain yourself and your disability in order to give them a correct understanding of albinism and for them to support you in your advocacy work.

13 Are there any good examples or practices in relation to the protection of HRDs?

N/A



Country: Zambia

Organisation: Albinism Foundation of Zambia

Contact Person: John Chiti, Technical Advisor, Albinism Foundation of Zambia. Email: johnchiti@ymail.com. Phone: +260977977026

Responses

1 Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organisation work on issues related to albinism. Please provide information on the work that you engage in.

I am a person with albinism working on the rights of persons with albinism in Zambia. I am the technical advisor to an organisation working on albinism issues. I am an activist advocating for the rights of persons with albinism and other disabilities in Zambia. I am also an artist and use my music to advocate for the rights of people with albinism and other persons with disabilities.



2 Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.

The term "human rights defenders" is not common in Zambia, especially among people with albinism. Many do not understand the term. The common terms here are social workers, activists and advocates. So most persons with albinism or individuals working to promote the rights of persons with albinism would instead call themselves activists or advocates.

3 Are there any laws/policies that support the work of HRDs and if so, how have they implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?

I am not aware of any law specifically for human rights defenders. However, I am aware some laws guide organisations. For instance, the disability act of Zambia talks about the organisation of persons with albinism. However, the disability act does not address individuals but organisations of persons with disabilities.

The implementation of the persons with disabilities act is not very effective. Most of the rights stated in the act have not been actualised. However, some of the measures in the act that cover organisations do exist in the act. However, implementation is deficient. Therefore, I can give a 30% implementation rate for the disability act.



4 What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work? Please specify. How can these issues be addressed and what kind of support do these HRDs need?

Lack of funding to support the work of human rights defenders. As a result, most human rights defenders depend on organisational support to do their work. This is compounded by the fact that institutions do not fund individuals, so individual human rights defenders with albinism find it challenging to get funding to support their work.

Lack of training: Very few human rights defenders with albinism are trained. Most of them work because of their passion for promoting the rights and welfare of persons with albinism. In these cases, most human rights defenders depend on their personal experiences and stories. Still, they lack professional training and the use of appropriate advocacy tools to advance their work.

Lack of recognition for individuals who are human rights defenders. To be recognised as a human right defender, you must belong to an institution and speak from the institutional point of view, not as an individual. The work of individual human rights defenders is mostly politicised, and such persons are labelled politicians. For instance, when you speak publicly against the government or an institution, you will be quickly judged as a politician instead of a human rights defender. This makes it difficult for individuals to



be established as human rights defenders because of a lack of support and politicisation of their work.

To address these issues mentioned above, we need to recognise the work of individual human rights defenders and provide them with the necessary support to defend and promote the rights of persons with albinism. Therefore, human rights defenders need funding support. Therefore, there should be some funding to support the work of human rights defenders. In addition, more training programmes for human rights defenders should be held to train these individuals. For instance, I received three months of training as a Mandela Washington Fellow. As a result, we were trained to be human rights advocates. This kind of training should target human rights defenders.

5 Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

I do not know anyone with albinism who advocate for other conditions apart from their own. The challenges human rights defenders with albinism face are issues of security concerns. Human rights defenders with albinism who speak openly in public become target for physical, mental or verbal threats. The most concerning security threat have to do with witnesses of ritual attacks. Because of the fear of reprisal attacks from the perpetrators, witnesses to such attacks do not open up to assist police investigations. Some



of these witnesses may be family members who are unsure of their protection when they open up to speak about the attacks.

In the same way, human rights defenders with albinism fear reprisal attacks. This affects their level of confidence to participate and speak on issues of attacks and the rights of persons with albinism publicly. Similarly, they are not sure their safety is guaranteed by the security agencies, which generally affect their approach to work as human right defenders.

6 Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

First of all, a few women human rights defenders with albinism are working to promote the rights of persons with albinism. I know about three or four ladies with albinism actively involved in the advocacy. In contrast, others lead organisations of persons with albinism. Generally, women human rights defenders are very few. The challenge they face mostly is sexual harassment from men. Men always take advantage of women because of their sexuality. Also, because they are women, they are not given an equal opportunity to operate as their men counterparts just because they are women. They face criticism and discrimination based on the fact that they are women with albinism. Therefore, it is a double discrimination for women human rights defenders with albinism.

7 What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights defenders



working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

The urgent security issue affecting human rights defenders is physical security. Human rights defenders become targets for reprisal attacks exposing them to security threats. The other security issues have to do with legal capacity and support. You could be faced with a legal case as a human rights defender. For instance, either you sue, or you are sued. These situations require legal support, and some defenders do not know where and how to access legal aid to provide their legal services at no cost.

8 Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.

There have not been any national responses to the security issues faced by human rights defenders that I know about. What I know is that the human rights commission comes in on specific issues of human right nature. For instance, the recently launched film on albinism was initially entitled "The Mwabi", meaning Albino in Chichewa. The albinism community was unhappy about the film's title and spoke against it. However, the public began to attack us verbally, saying we were ungrateful for not appreciating the movie about us. On this issue, the National Human rights commission and other institutions supported the albinism community on changing the name of the film to "Can you see us."



9 Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organisation take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

Working with the media is one measure I take as a human rights defender. Being in the media space is a sort of guarantee to our physical security since the media reports on all that we do. In case of any threat to us, the media will quickly pick it up. In addition, we also inform others about what we are doing and where we are at a particular time. Other measures include making sure we stay in a well-secured house. For example, where I stay is well secured with security guards. But this comes at a cost, and many cannot afford it. My position as a police commissioner gives me the privilege of having access to state security for my protection. Also, when I perform as a musician, I hire security to protect myself while on stage, which comes at a cost. Other instances include engaging the police to protect us when conducting community sensitisation programmes on the field.

10 Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organisation take to guarantee your physical and psychological well-being.

For information on physical well-being, refer to the point above in 9.



I have mentors who provide the necessary support I need psychologically. They advise me on how to handle issues and how to go about things. These individuals are long-standing human rights defenders. I go to them for advice and, mentorship, legal and psychological guidance. This exposure has allowed me to mentor and advises other human rights defenders.

11 Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organisations or civil society organisations?

First of all, networking among human rights defenders is very poor. Most human rights defenders are confined to their issues and areas of concern to them. Aside from these, we have collaborated with several organisations, including Amnesty International, Africa Albinism Network and Under the Same Sun. We have also worked with the media, other disability organisations, and local institutions to promote the rights of persons with albinism in Zambia.

12 In relation to the previous question, please specify any challenges you face in working or collaborating with other organisations and how these can be addressed.



The most common challenge I can discuss is financial challenges, where we do not have much funding to facilitate collaborations and partnerships effectively.

These challenges can be addressed through financial support to the organisation working to advance the rights of persons with albinism. Also, training in resource mobilisation and capacity development will be essential to the organisation working to promote human rights.

13 Are there any good examples or practices in relation to the protection of HRDs?

It is essential to know the tricks and tactics of the perpetrators of attacks against persons with albinism. For that matter, we have a project focussing on engaging the perpetrators of such attacks. To achieve this, we engage prison inmates who were prosecuted because of their involvement in such crimes. This engagement provides us with the necessary information on the measures used by the attackers. This way, we can understand how these attacks happen to be able to guard against them.



Country: Zimbabwe

Organisation: Albinism Alive Initiative

Contact Person: Gwen Mushonga. Founder, Alive Albinism Initiative.

Email: tapiwagwen@gmail.com. Phone: +263 77 347 8907

Responses

1. Please indicate if you are a person with albinism working specifically on the human rights of persons with albinism, a person with albinism working on other human rights issues, or you or your organization work on issues related to albinism. Please provide information on the work that you engage in.

Yes. As the founder of Alive Albinism Initiative, my work raises awareness about albinism and human rights education for persons with albinism and the general public.

2. Are groups and individuals working to advance the rights of persons with albinism in your country considered human rights defenders? If not, please explain why not.

On a personal note, it is we persons with albinism working to promote the rights of persons with albinism who consider ourselves human rights



defenders. However, In Zimbabwe, there are a lot of stigma and other issues surrounding albinism, including discrimination, so we are not recognised as human rights defenders since there is no law categorising albinism as a form of disability in the country.

In Zimbabwe, a disability is when someone is blind, physically disabled or deaf. Also, persons with albinism are not considered human rights defenders because there are no laws and policies on albinism recognising their disabilities.

3. Are there any laws/policies that support the work of HRDs and if so, how have they implemented? Are they implemented in a way that take into consideration the needs of specific groups, i.e., HRDs with disabilities?

No specific policies or laws protect human rights defenders working on the rights and welfare of persons with albinism in Zimbabwe. However, we have the disability act (Disabled Persons Act of 1996), which I am not sure gives protection to human right defenders. The implementation of the disability act has not been effective. In that regard, we cannot say the act's implementation considers the needs of human rights defenders with disabilities, including albinism.

4. What are the main challenges, barriers, or restrictions that human rights defenders with albinism and human rights defenders working on the rights of persons with albinism face in their work?



Please specify. How can these issues be addressed and what kind of support do these HRDs need?

In Zimbabwe, we can speak of financial resources as a significant restriction affecting the work of human rights defenders with albinism. In addition, we do not get the necessary support from the government as human rights defenders. Mostly we are on our own trying to support ourselves and our organisations. Because of funding issues, we cannot reach out to all persons with albinism in the country. We knock on doors and try to engage our community leader and get no response from them. People assume that albinism is just a condition, so we should not expect much from the government. Also, the issue of sunscreen lotion for persons with albinism is another challenge. Sunscreen lotions are costly in the country, and many cannot afford them. As human rights defenders or advocates, we try to run around to get these essential items to persons with albinism. However, our requests, in most cases, have fallen on deaf ears.

Human rights defenders need financial support to be able to work more effectively. Aside from that, people with albinism need a lot of education to understand their condition and prevent sun exposure and skin cancer. Persons with albinism need to be trained to fight for their rights and take up positions, be it political or others. Training more community members to become human rights defenders who can work to advance the rights of persons with albinism. The fight for the right of persons with albinism



should not be left only to persons with albinism. Others need to be trained and become ambassadors for the rights of persons with albinism.

5. Please provide information on human rights defenders with albinism who are working on issues that are not focused on albinism. Do these HRDs face particular challenges?

I know one person with albinism who is a friend. He is into business and youth advocacy in Zimbabwe. The challenge he faces in most cases is discrimination, where his colleagues tend to undermine him due to his condition.

6. Are women human rights defenders with albinism and women human rights defenders working on the rights of persons with albinism facing particular challenges? Please, specify.

I would say we face double or triple jeopardy as women human rights defenders in Africa, where women are looked down upon. Having another condition on top of being a woman, people would think, what good can come of it? In most cases, men would take advantage of me as a woman with albinism when I try to create contacts and networks. I face resistance from the opposite sex when I try to approach. When I succeeded in creating that professional relationship with the opposite sex, it does not end there. They always want to move beyond the professional relationship into something else, which I find most challenging and unacceptable.



7. What are the main/most urgent security issues affecting the work of human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? Please specify any particular security challenges facing women HRDs.

In Zimbabwe, we do not have many security issues besides stigmatisation and discrimination.

8. Have there been any response by national and local authorities to the security issues faced by human rights defenders with albinism and human rights defenders working on the rights of persons with albinism? If so, please specify.

N/A

9. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender working on the rights of persons with albinism, or your organization take to guarantee your physical security. Please also provide information on steps taken to guarantee digital security.

Depending on the type of work or where I am going, I inform people around me to know my whereabouts. For instance, if I meet the local leaders, I inform my office and home about the particular community I am visiting and the kind of people I expect to encounter.

10. Please provide information about the measures that you, as a human rights defender with albinism/human rights defender



working on the rights of persons with albinism, or your organization take to guarantee your physical and psychological well-being.

On my physical well-being, refer to question 9 above. Psychologically, I have a family support system. My children understand what albinism is all about. So, they provide the necessary support by staying positive and well-behaved. As human rights defenders, we receive many issues, especially people coming to you with problems thinking you have a solution. These situations get to us psychologically, and I try to handle them in my way. What I do in most cases is avoid negativity. I try to stay positive at all times.

11. Please provide information on the relationship and collaboration between the work of human rights defenders with albinism/ human rights defenders working on the rights of persons with albinism in your country and other national or international human rights defenders, non-governmental organizations or civil society organizations?

We had several partnerships and collaborations with some international organisations like Amnesty International. We have worked with these organisations on international albinism awareness day, day of the girl child and international disability day.

12. In relation to the previous question, please specify any challenges you face in working or collaborating with other organizations and how these can be addressed.



At one point, we faced a challenge with an international organisation. It was issues of power dynamics where we did not have much power to influence the decisions of these multinational organisation

To address these security issues, stakeholder consultation is paramount to understanding the needs of the beneficiary individuals and groups. For instance, organising conferences in the cities do not benefit those in the rural areas who need the most assistance. Therefore, through proper consultations, the needs of the groups will be well understood and taken care of.

13. Are there any good examples or practices in relation to the protection of HRDs?

N/A