



ALIVE
ALBINISM INITIATIVE



Submission in response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

21 November 2021

Submitting organizations:

The Africa Albinism Network, Standing Voice, The Albino Foundation, Source of the Nile Union of Persons with Albinism, Albinism Advocacy for Access South Africa, Divine Connexion World Wide, Associação Ze Manuel Pinto, Alive Albinism Initiative, Albinism Foundation of Zambia and Organization for integration and promotion of people with albinism (OIPPA) welcome the opportunity to jointly submit their contribution to the OHCHR study on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic.

This, the submission will provide information on the situation in 10 African countries: namely Nigeria, Uganda, Rwanda, South Africa, Zimbabwe, Zambia, Mozambique, Ghana, Malawi and Benin.

Contributing Organisations Profiles

- **Africa Albinism Network**, established in February 2021 is a consortium of organizations working to promote – through human rights advocacy – the dignity, rights, and welfare of persons with albinism and their family members in Africa. The Alliance 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.

- **Associação Ze Manuel Pinto (AZEMAP)**, legally constituted on August 25th, 2016, by order number 14. Is a civil society organization, of a charismatic and philanthropic nature, created under articles one and 4 of law 8/91 of July 18th. Its mission is to advocate for the vulnerable, with emphasis on the person with albinism. Its vision is from charity, with charity for charity, on behalf of the neediest and its values are a charity, respect for diversity, integrity, dignity, and professionalism.
- **Standing Voice** is an international non-governmental organization based in Tanzania, Malawi, and the UK. Founded in 2013, it promotes and protects the rights of people with albinism and their families across Africa. The organization works as a catalyst to amplify marginalized voices, enabling individuals to shape their own lives and futures
- **The Albino Foundation (TAF)** is an independent non-governmental/not-for-profit organization incorporated with the Corporate Affairs Commission of Nigeria. Founded in 2006, TAF is principally an organization established for persons with albinism, other disabilities, and vulnerable groups. TAF is a special focus organization that advocates for the recognition and respect of the rights and socio-economic inclusion of persons with disabilities in Nigeria. Headquartered in Abuja – Nigeria, The Foundation bears a national spread with chapters across all 36 states of Nigeria and the FCT – Abuja.
- **Source of the Nile Union of Persons with Albinism (SNUPA)** is a non-profit organization based in Jinja Uganda. It was formed by Persons living and those affected by albinism to advocate for access to quality services for this group.
- **Albinism Foundation of Zambia** was established in 2008 as a non-governmental organization that works to promote the welfare of persons with albinism in Zambia. It is the first albinism organization 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.
- **Organization for integration and promotion of people with albinism (OIPPA)** was established as a civil society organization in July 2013 after more discussion with its members on challenges faced by people with albinism in their daily life. There was a lack of social protection, very low education levels, discrimination in the community, stigma which result in poverty among

persons with albinism, skin cancer, and many other challenges. This is further exacerbated by prevailing social stigma and cultural attitudes. OIPPA advocates on behalf of its members for equal rights of persons with albinism.

- **Divine Connexion World Wide's** mission is to create a world where the fear of God, Peace, and Justice is inherent in the majority. Our 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.
- **Albinism Advocacy for Access South Africa's** focus is on learners with Albinism, as many drop out of school and attempt suicide. We push to build confidence; show they can achieve anything they desire; we assist in finding bursaries so they study further and push for independence.
- **Alive Albinism Initiative** vision is to see people with albinism rise and compete in this race of life. Our mission is to empower persons with albinism so they become ambassadors against intolerance and also change the mindsets of Zimbabwean society towards albinism.

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Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Zambia

Contributing Organization: Albinism Foundation of Zambia (AFZ) albinismzambia.com

Contact person for more information: John Chiti, Executive Director, Albinism Foundation of Zambia (AFZ); johnchiti@gmail.com

A. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: In Zambia, the population of persons with albinism may not be adequately captured. According to the 2010 Census on population and housing, the albinism population at the national level was 25,324. This was out of 13 million people. The albinism population in rural areas was higher than in urban areas at 16,937 and 8,387, respectively. Lusaka Province had the highest population of PWA at 3,495 while North-Western Province had the lowest at 1,387.

1. How many of those people are women? How many are children, as defined in your country?

A: The census records are not clear on this.

2. Please describe the overall social and economic status of people with albinism in your country?

A: Persons with albinism in Zambia still face social challenges. They do not fully interact with society because of discrimination and rejection. This in turn makes them have low confidence in themselves. For example, although the country is moving in the direction of inclusive education where schools are encouraged to enrol all people most persons with albinism still prefer to go to special schools than mainstream schools. This is because they do not feel welcome in ordinary schools but feel more confident going to special schools and interacting with persons with disabilities.

- **Very few persons with albinism are economically stable. Many are poor, unemployed, and vulnerable. The economic empowerment opportunities such as government schemes (social cash transfer, youth empowerment, etc.) are not very inclusive and have very few or no persons with albinism are beneficiaries. Persons with albinism are still being excluded from economic activities.**

3. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: Albinism falls under the Ministry of Community Development and Social Services and since albinism is categorized as a disability, it falls under Zambia Agency for Persons with Disabilities (ZAPD).

The following are some registered organizations that deal with albinism in Zambia;

- **Albinism Foundation of Zambia (AFZ)**
- **National Albinism Initiative Networking in Zambia (NAINZ)**
- **Albino Multipurpose Cooperative**
- **Light of the World Foundation**
- **Zambia Albinism Matters Organisation (ZAMO)**
- **Albinism Multipurpose Organisation**
- **Women Albinism Voice Association (WAVA)**

B. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of?

3.1. Participation in political, social, civic, and cultural life?

A: The lockdown and closure of public places during the pandemic have made persons with albinism spend more time with their families. This has had a positive impact as persons with albinism have had time to bond more with their loved ones. Many children with albinism have loved the fact that they have been spending more time with their parents during the pandemic. However, persons with albinism have participated less in political and social life during the pandemic. Zambia had its general elections in August 2021 and no person with albinism stood for elections. Although some voted, persons with albinism be still for the greater part not interested in actively participating in politics due to the stigma and discrimination they face in society.

3.2. Access to the right to health?

A: Sunscreen lotions have not been made available to persons with albinism during the pandemic. Their right to be provided with sunscreen as stated in the Disability Act of 2012 has not been fulfilled. A charity approach is still been taken where the provision of sunscreen is concerned with sunscreen being predominantly provided by NGOs. In terms of the Covid 19 vaccine. The government has made the vaccine available and free of charge to everyone including persons with albinism though they have not come out in numbers to be vaccinated. Many persons with albinism are still doubting the efficacy of the vaccine due to the misconceptions surrounding the vaccine.

3.3. Access to the right to quality education?

A: Because of the attacks that have happened during the Covid 19 pandemic persons with albinism have been living in fear. Some children are reported to have stopped going to school for fear of being attacked. Apart from that, the Covid 19 measures adopted by the government such as the closing of schools when the cases of infections increased have also affected the school curriculum and when students complete their academic year. For example, some students including those with

albinism who were supposed to finish their education in 2020 have been delayed to finish this or next year.

3.4. Access to the right to employment and the right to work?

A: The closure of schools, churches, restaurants, clubs, companies, and other public places during the pandemic has made many persons with albinism to be out of employment as they have been laid off. Most companies have only been employing essential workers so it has become harder for unemployed persons with albinism to find jobs. Thus, persons with albinism have not enjoyed their right to employment or right to work during the pandemic.

C. National Legal and policy framework

4. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: Albinism is classified as a disability so the rights of persons with albinism are protected under the country's disability laws and policies. Of particular relevance is the Disability Act of 2012. The Act requires the state to provide assistive devices for persons with albinism as well as sunscreen. Persons with albinism can also claim protection under the UN Convention on the Rights of Persons with Albinism that

Zambia is a signatory to. Outside the disability framework, there are no specific policies or laws that exclusively address issues affecting persons with albinism.

5. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Yes, albinism is considered a disability in terms of the Disability Act of 2012

D. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics and data that are available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

Some of the major obstacles for PWA to participate are;

A: The following are some of the major obstacles experienced by persons with albinism, which hinder their participation in political, social, and cultural life:

- Because of the segregation, stigma, and discrimination, they face in society many persons with albinism have low self-esteem and exclude themselves from participating in the social, cultural, political life of their communities.
- There is a non-political will from political parties to welcome and include persons with albinism in their parties.
- Persons with albinism lack the financial support to sponsor campaigns or to stand as independent candidates during elections.
- Political violence and hate speech during election periods also discourage persons with albinism from participating in politics. They would rather stay away and be safe than risk being humiliated, beaten, or attacked by political opponents.

6. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: There are no applicable laws except the general laws applicable to everyone.

Health

7. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: Many persons with albinism in Zambia die from skin cancer and sadly, many of them do know much about the deadly disease. They report late for treatment, they do not go

for medical check-ups and they still depend on sunscreen lotions (which is not available consistently) instead of taking other measures like physically avoiding the sun and wearing protective clothing. Many of them especially in rural areas are farmers, which significantly increases their exposure to the sun.

Health services such as skin cancer treatment, skin/eye screenings are only done at the university teaching hospital in Lusaka. They are not available in rural areas.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: According to the 2010 national statistics, the majority of the children with albinism attend segregated schools for children with visual impairments. This is because of two reasons:

- They experience a lot of stigmas and bullying when they are in mainstream schools;
- There is an erroneous belief that their visual impairment worsens, as they grow older until they completely lose their sight thus, they need to be introduced to Braille in the
- first grade of primary school. As a result, persons with albinism feel more confident and safer when socially interacting with persons with visual and other impairments.

The proportion of the population of persons with albinism that was currently not attending school was slightly higher than those currently attending school at 37.5 and 37.3 percent, respectively. The proportion of the albino population that had never attended school was 25.3 percent. The highest level of education attained by most of the albino population 25 years and older was primary education at 48.3 percent. However, it has been established that the first woman with albinism to graduate with a Master's Degree graduated in 2016 at the University of Zambia, School of Education. This is a landmark achievement for persons with albinism, especially women, in Zambia.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support

and reasonable accommodation, e.g., large-print material, low vision, and assistive devices?

A: The consideration of low vision and provision of reasonable accommodation such as large print is mostly done in special schools where you find students with albinism and those with disabilities. In these schools' teachers are trained on how to handle children with special needs. However, in ordinary schools, these provisions are not available and teachers have not trained in special education reasonable accommodation is not available and that is why most persons with albinism still prefer to go to special schools.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

A: When it comes to employment, according to the 2010 national census report, persons with albinism face the same problems faced by persons with visual impairments. This is as a result of the poor grades they get at the secondary school examination level. There are no clear statistics on the numbers of persons with albinism in formal or informal employment but the majority are in informal employment. The 2010 census indicated that the majority of the employed albino population 12 years and older was self-employed at 46.0 percent. The proportion of persons with albinism employed in the open labour market is 1.0 percent. Agriculture and animal husbandry, forestry, and fishing were the most common occupation of persons with albinism at 71.2 percent for males and 80.0 percent for females. The general situation for persons with albinism is that for those who are in formal employment, they work as school teachers or telephone operators and other low-skilled jobs in the government.

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: The main obstacle is qualifications. Most persons with albinism do not have the required qualifications for most paid jobs and this is because of poor education levels. Most of them did not complete their education so they do not have the necessary qualifications for many of the jobs.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

A: Not specifically focused on albinism but disability more broadly.

15. Are there special measures in place to promote and integrate persons with albinism in employment and the labour market?

A: I have heard of a provision of 10% jobs to be reserved to persons with disabilities in all government and private sectors according to the Disability Act. Pick n Pay has been employing deaf people in their store but I doubt many institutions adhere to this.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: Cases involving persons with albinism take long to be prosecuted and sometimes go un-investigated. This includes cases of attacks and abandonment of children with albinism. The justice system is very slow.

The other challenge faced by mothers of children with albinism is that they are unable to pay DNA tests to prove that their husbands/partners are the fathers of their

children and therefore have a duty to pay maintenance for the child. Many fathers of children with albinism reject their children when they are born with albinism citing that, as there is no one with albinism in their family and so this cannot be their child. Without

the DNA tests, mothers fail to get justice when they and their children are rejected by the biological fathers of these children.

6. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies.

A: There are no specific measures or policies on this. Cases involving persons with albinism are treated like ordinary cases. For example, when persons with albinism are attacked for their body parts such cases are handled as ordinary murder, attempted murder, assault, etc cases. There is a clear recognition of ritual killings or grave robberies as distinct offenses in law. The justice system, therefore, fails to give the necessary recognition to crimes more peculiar to persons with albinism.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: The government has put up measures such as giving covid relief grants, youth empowerment programs but persons with albinism have not benefited hugely from this.

E. Recommendations

7. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

A: Government should be more inclusive in their programs and leave no one behind including persons with albinism.

- There should be political will to effectively deal with issues affecting persons with albinism. The government must consider and be responsive to albinism issues.

F. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?

A: We are greatly concerned with the increase in attacks against persons with albinism that we have witnessed happening in Zambia especially targeting children. Government should take these issues seriously and put urgent measures in place before more lives are lost.



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Zimbabwe

Contributing Organization: Alive Albinism Initiative

Contact person for more information: Gwenlisa Mushonga Marange, Founder, Alive Albinism Initiative, tapiwagwen@gmail.com

A. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: There are no official statistics on the number of persons with albinism in Zimbabwe. According to a WHO report published in 2017, there are estimated to be 33 000 persons with albinism in the country though the accuracy of this is questionable.

2. How many of those people are women? How many are children, as defined in your country?

A: The unofficial data that is available is an estimate and is not disaggregated according to sex and age.

3. Please describe the overall social and economic status of people with albinism in your country?

A: Persons with albinism in Zimbabwe experience a lot of stigmas, segregation, and discrimination. The stigma and discrimination start at birth and continue throughout most persons with albinism's adult life. Many midwives do not fully understand albinism themselves and therefore negatively react to the birth of the child with albinism and do not provide the parents of the child with albinism sufficient information about the genetic condition to help them understand its origins leading in some cases in the rejection, abandonment, marginalization of children with albinism. Many fathers of children with albinism refuse to acknowledge the child with albinism as theirs, so most of these children are raised by single mothers or grandparents in cases where both parents' desert the child. Misinformation about albinism continues to be widespread including beliefs that it is a punishment from the ancestors and that the mother slept with a white man.

In terms of employment because of societal stigma, employers are afraid to employ persons with albinism. Persons with albinism thus live below the poverty line. They resort to begging. When our organization has events involving persons with albinism many will not attend unless we are providing free sunscreen lotion, transport, and food. This shows you the levels of desperation.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: In some instances, issues affecting persons with albinism fall under the Ministry of Health and Social Welfare.

The National disability Board should consider issues affecting persons with albinism. The sitting chairperson has albinism but the board is a toothless bulldog. Nothing has materialized since it was commissioned, they cannot carry out the programs they should.

In terms of private institutions, there are several organizations of persons with albinism. No umbrella body brings all of them together so it has been difficult for the albinism community to speak with one voice.

B. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of:

5.1. Participation in political, social, civic, and cultural life?

A: This happened to me (Gwenlisa Mushonga Marange) personally. Early last year when Covid started, I was taking my sister to the doctor. I was in the passenger seat, we were passing through a high-density suburb, some kids were on the street, and they started calling me Covid because I have albinism. They were running after the car-saying look at Covid. Because of my work as an activist, I brushed it aside but I know such an incident on someone with albinism already struggling with albinism would be devastating.

Because of this association with Covid persons with albinism in Zimbabwe avoided moving around during the pandemic. There are already so many superstitions around our lives, so persons with albinism were extra cautious and vigilant during this time. Many were afraid that new myths similar to the myth that sleeping with someone with albinism cures HIV might develop. They were fears that if some in society thought persons with albinism cause Covid then they might also think they could cure it

resulting in the development of new myths that their body parts could be used as a vaccine to prevent Covid 19 or cure it.

5.2. Access to the right to health?

A: Because of the restrictions in movement imposed by the government and many medical facilities only dealing with Covid related medical cases, getting medical attention during this time was quite challenging. Persons with albinism in need of urgent dermatological services could not access it. The huge demand for limited services resulted in persons with albinism not equitably accessing Covid 19 treatment. Access to government hospitals for treatment depended on knowing someone working there or being able to pay a bribe. For persons who were already living in poverty, this meant it was out of reach. If the ordinary Zimbabwean was having problems, what more those considered lesser humans even before the pandemic.

5.3. Access to the right to quality education?

A: When the lockdown measures were put in place, some education institutions started teaching online, via WhatsApp, using the radio. Persons with albinism who live below the poverty line with no access to smartphones, radios, laptops, and computers thus missed learning during this time. Even when schools resumed, they are still struggling to catch up because of sharing of textbooks with small fonts and teachers writing illegibly on the board.

5.4. Access to the right to employment and the right to work?

A: The lucky people who had jobs, given the high unemployment rate in the country many lost jobs during that time, many people including those with albinism resorted to vending and other informal employment. This was difficult when hard lockdown measures like staying at home were imposed.

C. National Legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: There are not any specific policies or laws focused on persons with albinism. Recently to government enacted a Disability Policy but not an Act.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: The problem in Zimbabwe is that albinism is not legally defined as a disability so we as persons with albinism struggle to figure out where we belong. Some in the disability community discriminate against persons with albinism because they view albinism as a medical condition and not a disability. We constantly have to justify that albinism is a disability according to the UN Convention on the Rights of Persons with Disabilities understanding of disability. Persons with albinism, therefore, do not always benefit from measures put in place by the government and others for persons with disabilities, for instance, persons with disabilities can import accessible vehicles duty-free but persons with albinism struggle to access this benefit. In shops, if someone with albinism tries to use the queue for persons with disabilities and the older persons, they are accused of unjustifiably jumping the queue. Whether albinism is considered a disability or not tends to be contextual, and can be used in a way that empowers or disempowers persons with albinism.

D. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics and data that are available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

A: It does not matter whether you are educated and qualified people do not expect much from you when you have albinism. They do not believe you can make a tangible contribution. Therefore, in the end, you end up looking down upon yourself and do not even try to participate in society because of the stigma you experience. Even when opportunities to participate are presented, you do not take them. The biggest barrier to persons with albinism in Zimbabwe is attitudinal barriers.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: No specific ones.

Health

9. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: Civil Society Organisations do much of the information dissemination on albinism and health on radios, TVs, and social media platforms. The people in remote and rural areas don't always access this information.

The dermatology services in private health institutions are exorbitant, there are however, a few private institutions that offer free services for persons with albinism but they can't cater for everyone. City Med Hospital is one such institution. They treat and operate persons with albinism who have skin cancer free but the person must pay for radiology and some other smaller. Dr. Wazara, Dr. Mutandadura, Dr. Bandason who run private practices offer their services free.

To access dermatology services free of charge without any co-payment at a government hospital you have to go to the Department of Social Welfare first to get a letter saying that the government will pay for your treatment. The Department of Social Welfare was failing to pay the hospitals for these services rendered so this arrangement has been scrapped off. Many people with albinism are dying of skin cancer. Every month we lose one or two people. If there is a merciful doctor then you may be admitted without paying at a government hospital. In most cases, you have to make co-payments. A general CT scan costs USD36. To get radiotherapy for 3 or 4 sessions you need USD 500. Most people just can't afford it. Sometimes well-wishers raise funds for treatment for persons with albinism and then divert the funds for their use.

In terms of ophthalmology services, the process to get an appointment for an eye exam takes forever in public hospitals. You wait at least 6 months to get just the eye exam done because they are fully booked. People end up not going there. You still need to pay.

Sunscreen is not available in public hospitals and clinics; you have to buy it yourself. We don't manufacture it, it is imported. A bottle is USD25 depending on where you are getting it.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: Our schools claim to be inclusive but this is true. Teachers are not taught about albinism at training colleges. The schools lack information on how to deal with students with albinism. Children with albinism are at times turned away from mainstream schools because the school says that they are not capacitated to teach people like them. There are cases reported to our organization where teachers do not want to mark books of students with albinism, make the student stay at the back of the class, and generally exhibit a negative attitude towards them. Not surprisingly several children with albinism drop out of school. There has been no large-scale research done to quantify the problem.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, e.g., large-print material, low vision, and assistive devices?

A: No. The only time provisions are made is during the national public exams where students can get more time and large print, but day to day learning there is nothing in place.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

A: Unemployment among persons with albinism in Zimbabwe is high. No, matter how educated you are likely to struggle to get employment, especially in the formal sector. Employers are concerned that you will scare away customers. There is also the issue of bullying from colleagues. Even when applying for low-skilled jobs such as domestic

worker and gardener once they see you have albinism, they turn you away. However, there is no data to quantify this.

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: See the previous answer

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

A: The normal labour laws apply but there is no specific reference to persons with albinism.

15. Are there special measures in place to promote and integrate persons with albinism in employment and the labour market?

A: There is general affirmative action for persons with albinism; employers get tax exemption when they employ someone with a disability.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: Even if their rights are violated, persons with albinism do not know where to go, whom to ask for assistance. Police can tell you when you report a violation that, that is not a crime. Do not bother to report because they know nothing will materialize out of it.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: Not that we know of.



ALIVE
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E. Recommendations

19. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

A: There is a need for a clear-cut policy on issues affecting persons with albinism it will make life easier. The laws, policies there for persons with disabilities do not always benefit persons with albinism. If we get something tailor-made for the albinism community that will ensure that all the government departments and sectors pay attention to albinism issues in the execution of their mandates.

F. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?

A: There is a need to do a lot of self-awareness and empowerment for persons with albinism to take their rightful place, to stand up for themselves, to know it is a condition, not a limitation.

Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Ghana

Contributing Organization: Kwame Andrews Daklo is an Albinism Rights Activist and Albinism Programs Coordinator at Engage Now Africa. He is an Obama Leader and a YALI RLC Alumni.

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A. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: There are no national disaggregated statistics on albinism. The recent population and housing census 2021 does not have information or data on albinism. The disability statistics collected also do not provide a clear picture to draw from. However, organizations such as Engage Now Africa, Ghana Association of Persons with Albinism estimate that there are 3 600 persons with albinism in the country. Field data has been collected by these organizations over the years.

2. How many of those people are women? How many are children, as defined in your country?

A: There are no concrete statistics on this.

3. Please describe the overall social and economic status of people with albinism in your country?

A: It is not encouraging; many persons with albinism live in situations of poverty because of the deeply rooted discrimination they experience. They struggle to find proper work; their employment opportunities are limited to public service jobs such as nursing and teaching.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: There are no specific public institutions or agencies dedicated to persons with albinism; however, the National Council of Persons with Disability is responsible for all persons with disabilities including those with albinism. Persons with albinism are represented on the board of the Council. The current President of the Council is a person with albinism. The Council falls under the Ministry of Gender and Social Protection. The Department of Social Welfare is responsible for distributing at the district level common funds dedicated to persons with disabilities including those with albinism.

The Ghana Association of Persons with Albinism is a private institution, which represents the albinism community and engages in advocacy and public sensitization on albinism.

The Ghana Federation of Disability Organisation is an umbrella body for the disability community in Ghana, made up of member organizations of persons with disabilities with different impairments.

Engage Now Africa also works to promote the rights of persons with albinism primarily through its educational art programs, skin cancer treatment clinics and engaging in public education activities, community sensitization, and advocacy.

B. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of?

5.1. Participation in political, social, civic, and cultural life?

A: The Covid 19 pandemic affected persons with albinism in the same way that it affected everyone else. However, due to pre-existing misconceptions surrounding the condition, and the hypervisibility of persons with albinism in a society with predominantly dark pigmented members, persons with albinism felt the pandemic harsher and experienced it differently from others. There was a belief at the start of the pandemic that since the disease originated in China anyone who looked Caucasian including persons with albinism was a carrier. The pandemic, therefore, increased the stigma around persons with albinism. I experienced this on 3 occasions described below.

(1) In the first instance it was in the evening around 11 pm. I was walking down the street looking for transport when a man came running down the street calling me Mr. Corona virus man. I did not do anything about it.

(2) During lockdown I went into a supermarket to get some groceries before the curfew period started as I was sanitizing my hand's a guy walked up to me and asked in a local language if I was Chinese. I replied that I was not in vernacular. He went on to say if I had been, he would have prevented me from going into the shops because Chinese people are spreading the virus.

(3) I was sitting in the front seat of a minivan taxi. There was a traffic jam so the cars were moving slowly. A driver on a motorbike stopped next to be minivan and asked the driver why he was letting me ride in the taxi when people like me were spreading the

virus. He became confrontational and demanded to know whether I was Chinese and if so, I should go back and stop spreading the virus.

5.2 Access to the right to health?

A: Access to health care was already a problem for persons with albinism even before the outbreak so the pandemic worsened it. Someone I know was suffering from skin cancer when the pandemic broke out. We were in the process of helping him get treatment but, when the Covid 19 pandemic hit the hospitals shifted all their focus to those affected by the virus. The person's treatment was put on hold for a whole year. His skin cancer worsened considerably, it got quite bad. When the public hospitals reopened there was such a huge backlog of patients waiting for treatment that in the end, he resorted to getting treatment from a private hospital, which was costly.

Organizations such as Engage now Africa used to go to the communities and distribute sunscreen lotion and sunglasses for persons with albinism. Due to the restrictions put in place during the pandemic, they could not do such community activities. This has affected the health of those beneficiaries as no alternative measures were put in place. Without access to sunscreen lotions, there was a marked deterioration of skin condition amongst the albinism community.

5.3. Access to the right to quality education?

A: During the pandemic, all schools closed down and everyone stayed home for about 7 months at all levels of education from basic to tertiary education. The Ministry of Education came up with TV and Radio programs where teachers taught various subjects. The problem with this was that it excluded persons with albinism in rural areas who have no access to gadgets like TV and Radio thus denying them access to education during that time. Those with access to TVs could not adequately see what was being displayed on the TV screen because not much thought was given to making programs accessible to those with low vision. The Ministry of Education did not try to reach students with albinism so that they could share material being taught on TV in large print. Therefore, students with albinism just sat in front of their TVs during these lessons but could not see, especially maths lessons, which involve a lot of writing on board. These are some of the challenges students with albinism faced during the Covid 19 pandemic. At the tertiary level, Universities were running courses on zoom and google classes but failed to take into account the fact that some of the students with albinism from poor households have no access to smartphones, personal computers, and other devices for them to participate in online learning. There is a second-year

undergraduate student with albinism I know from a remote village with no smartphone or laptop, limited access to the internet who could not take part in the classes and ended up dropping out.

5.4. Access to the right to employment and the right to work?

A: Honestly getting employment has always been problematic for persons with albinism. Those who work for the government were fortunate that the government still paid them whether or not they went to work during the pandemic. Those persons with albinism employed in the private sector were affected the most by the pandemic. Many private school teachers were laid off, those who sold in markets could not go to work and were forced to stay at home with no source of income, and their source of income was based on their daily activities. Persons with albinism were considered to be spreading the virus and so people did not want to engage their businesses in the case of entrepreneurs during this time.

National Legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: Not exactly, there is nothing if you scan through all legal and policy documents there is no single mention of persons with albinism. However, if you consider or take albinism to be a disability then there are the Persons with Disability Act (2006). Though albinism is not mentioned, the definition of disability is wide enough to encompass persons with albinism. The Disability Act is not in line with the UNCRPD and is currently under review. The process has been slow but the government says it is committed to seeing the revision through. The review is a great opportunity to clarify and bring certainty to this question.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Practically speaking yes but in terms of the legal framework, there is nowhere in says in our laws explicitly that persons with albinism are persons with disabilities though they tend to be integrated into the disability programs.

C. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics that that data is available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

A: The obstacles faced by persons with albinism are fuelled by myths and misconceptions that surround the condition. The discrimination, stigma, social exclusion, and marginalization that ensues, as a result, create the biggest barrier to persons with albinism participating in the political, cultural, and social life of their communities. Because of the myth and belief systems built over the years, this group is believed to be supernatural. They are called *Ofri* this name means someone in borrowed skin or living in a state of confusion. Persons with albinism because of their skin colour are therefore not viewed as full or equal members of the society whose views in political, economic, and other matters count. This lack of recognition in turn causes a person with albinism to lack self-confidence, self-esteem and withdraw from society. Many are not confident to speak on any issues.

The level of education of the albinism community is very low, the recent data collection of about 300 individuals with albinism revealed that only five individuals from that sample size had progressed to a tertiary level, which is worrying. This is because of the challenges they face within the education system. It shows that persons with albinism are not empowered in terms of education to participate at their community levels this pattern is replicated at the district, national level.

Another reason that prevents persons with albinism from fully participating in the political, economic, and cultural life of their communities is that Ghana is very hot.

Without access to sunscreen and without sun-protective behaviours the sun causes persons with albinism to develop skin conditions. 99% of persons with albinism have some discoloration on their skin, while others have sores, skin lesions, and cancer. This disfigurement lowers the self-confidence of persons with albinism and contributes to them shying away from engaging in communal life. Many are taunted, jeered at, and receive comments that discredit them because of their physical appearance so they choose to stay in their houses and not engage.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: No. Not specific to albinism.

Health

9. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: The situation is bad because firstly persons with albinism themselves do not have adequate information about their condition and therefore they expose themselves to the sun especially in the course of trying to earn a living. Some of them do not have anyone to talk to about their condition, their parents or guardians do not understand the condition fully either. Many when they develop skin cancer do not even know the sores of their bodies are skin cancer and need to be addressed.

There are no health facilities that specialize in addressing the needs of persons with albinism in terms of skincare, eye care, and psychosocial support. Persons with albinism use the same services as everyone. The country has three skin cancer treatment centers two of them belong to the government (Accra: Korle-Bu Teaching Hospital and Komfo Anokye Teaching Hospital) and one is privately located in (Kumazin Sweden Ghana Medical Centre). Even if one is on national health insurance, skin cancer is not covered so one has to pay for all costs related to the consultation. It is worrying that some health workers do not understand the condition of albinism so they treat it like an ordinary skin condition so people with albinism do not get an accurate

diagnosis for their skin condition. There are about 23 dermatologists in the entire country. 70% of them are based in Accra, Kumasi, and Tamari, which are urban areas. Ophthalmologists are about 300 or so and are mostly urban-based. People in rural areas do not have access to these services because of the cost of travel from the village to urban areas to access where these services are. To put this in context last year a foreign doctor who had come to assist with the pandemic discovered a hole in the head of a 17 years old boy with albinism. The boy could not get help from the facilities in the North so he had to be driven 13 hrs to the South to get treatment.

Sunscreen is regarded as a cosmetic product, therefore is, and not covered under the health insurance program. It is not on the benefits package for essential drugs. As it is not provided free of charge to persons with albinism, they have to buy it themselves. It is very expensive in Ghana. The average cost price of a sunscreen 75ml bottle is USD9. You can only get good quality brands in selected supermarkets in the city. You find that persons with albinism living in villages do not even know about sunscreen. Some sunscreen is being distributed by NGOs but the quantities are limited. In some instances, it is the only source of sunscreen people have. Engage Now Africa has been able to work with some partners to start producing sunscreen locally at a very small scale.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: There are no statistics on enrolment and attendance of children with albinism. However, students with albinism struggle in the classroom because of low vision, and teachers seem not to be aware of this. The major obstacle experienced by children with albinism at school is discrimination and stigma, which leads to bullying. Other children do not like to play with them or even sit close to them because of the stigma surrounding them. The teachers do not know how to position them in the classroom and at times sit them in the back. Students are unable to see what teachers write on board because they use light-coloured chalk or write in small letters. This is a particular problem when teachers demonstrate math equations on the board. There are no large font textbooks allocated to students with albinism in most schools.

I grew up in a remote part of Ghana. It was difficult for me to accumulate what was being taught. I repeated grades several times at a junior secondary level. It took me 6 years to complete the first three grades of junior secondary school. The first attempt at junior secondary was a total failure because I could not write notes and read the textbooks well. The school did not provide textbooks in large font and most of the material was written on the board so I had to depend on what teachers said in class to follow what was being taught. Things only started to change when I started adopting coping mechanisms like asking friends to write notes for me. If I did not use these strategies, I would not have made it to university. For one to progress to the second level you have to pass the primary/junior level first. Many persons with albinism do not make it to the secondary level and those who go to the second level fail to process to the tertiary level because of the same challenges.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, e.g., large-print material, low vision, and assistive devices?

A: No. Only in special schools, such as schools dedicated to the blind and deaf that are where you find assistive devices being used by students. In many mainstream schools where persons with albinism go there are no such assistive devices provided. There is an inclusive education policy but it is still not rolled out fully which means it is not making a difference in the lives of persons with albinism.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

A: There is a total lack of data collected on albinism.

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: The lack of reasonable accommodation. Some of those employed in the public sector are not given meaningful work that allows them to gain experience. They are just employed to fulfill government quotas. They are not given any work to do, they just go to work and come back home.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

A: Not exactly, the Person with Disability Act provides incentives for employers who employ persons with a disability.

15. Are there special measures in place to promote and integrate persons with albinism in employment and the labour market?

A: The government is working on the Affirmative Action Bill but the Bill is targeted at women and not people with albinism.

16. What obstacles exist for persons with albinism in having access to justice?

A: Persons with albinism do not report the crimes committed against them to the police because of the fear of reprisal and attacks if they report. They are afraid that they are going to be victimized so they just take the abuse.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies.

A: In general, terms, the Constitution has the provision of free and fair trials for everyone, and the Disability Act speaks to access to justice for persons with disabilities.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular, regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: At the height of the pandemic, the government distributed relief items such as food parcels, PEE to persons with albinism and person with disabilities. The majority of persons with albinism in the rural areas did not benefit, as efforts were concentrated in urban settings.

Recommendations

19. Please provide specific recommendations for further action to be taken by your Government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

A: I recommend that they adopt legislative and policy measures to address issues affecting persons with albinism. They should start with amending the Disability Act to make specific mention of persons with albinism so they benefit from all the disability programs in the country.

- Ghana should adopt a National Action Plan on Albinism, which mirrors the Africa Union Plan of Action on Albinism.
- Institutions that promote, protect the rights of persons with albinism must be strengthened.
- The NHS must be amended to make adequate provision for persons with albinism in terms of their specific needs including skin cancer treatment and sunscreen.

Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?

A: Ghana has ratified the Marrakesh treaty but we do not see it in action.



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Rwanda

Contributing Organization: Organization for integration and promotion of people with albinism (OIPPA)

G. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: Last year the National Council of Persons with Disability and the Ministry did a survey of persons with albinism and found that they were 1238.

2. How many of those people are women? How many are children, as defined in your country?

A: Male 522 and Female 716. We do not know the exact number of children.

3. Please describe the overall social and economic status of people with albinism in your country?

A: It is not good. Persons with albinism are not considered persons with disabilities and therefore do not benefit from socio-economic programs in place for persons with albinism. The Rwandan community has negative beliefs about albinism, which causes discrimination so socially the albinism community still faces stigma and discrimination, which hinder the enjoyment of their basic rights. Most persons with albinism are not educated nor able to access employment.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: The National Council of Persons with Disabilities oversees issues affecting all persons with disabilities.

Organization for integration and promotion of people with albinism (OIPPA) is one such organization.

H. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of?

5.1. Participation in political, social, civic, and cultural life?

A: Even before the onset of the pandemic persons with albinism did not participate much in the political, social, and cultural life of the country. When the pandemic broke out the government in Rwanda distributed food parcels and other essentials to vulnerable groups, sadly the local officials in charge of the distribution discriminated against persons with albinism because of negative attitudes towards them.

At the start of the pandemic, there were rumours that the virus would not attack black people but white people. Persons with albinism were considered vulnerable to contracting the virus because of their white skin colour. There was a belief that they would more easily succumb to the virus due to their supposedly weaker immune system. These rumours and unfounded beliefs affected persons with albinism psychologically. It made them afraid and isolated from society. Many did not leave their homes for fear of contracting the virus and dying from it. The government did not dispel the myths they kept quiet.

5.2. Access to the right to health?

A: In 2020 at the start of the pandemic in March, it was not easy for persons with albinism to get sunscreen lotion. Civil Society Organisations used to provide these lotions but they were mandated to shut down and stop all activities and so we are unable to provide sunscreen to their members. Even hospitals did not provide it.

5.3. Access to the right to quality education?

A: The pandemic affected education of learners with albinism. During the pandemic, schools were closed. The government resorted to teaching students at home through radios and TVs. Students with albinism from poor families who could not afford TVs and radio missed a lot of learning. Some schools provided courses using social media, whatsapp again students with

albinism from poorer families could not afford the data required. Students with albinism have low vision and as a result, even when they had a TV available it was not an effective medium to teach them. Even now, that schools have reopened it's not easy for them because now, they are not able to sit in the front of the classroom as before so they see the board more clearly because of social distance regulations nor can they consult their peers when they struggle to see the board. There is also the issue of staying for long in the sun whilst waiting to wash hands before school. Children with albinism are getting sun damage from spending a long time waiting to wash their hands.

5.4. Access to the right to employment and the right to work?

A: Even before the pandemic persons with albinism struggled to access work so the unemployment of persons with albinism was not caused by the pandemic.

I. National Legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: No specific law or policy, even the sunscreen lotion provision is not governed by policy.

The disability law is there but does not mention PWA 2007. However, today in process of reviewing the law, have requested to include albinism.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Verbally it is considered a disability but it is not written in any law or policy. This affects us because when claiming rights, they say it is not easy to plan for a group not recognized by law. The National Council of Persons with Disability has started to include persons with albinism in their activities.

J. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics and data that are available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

A: As mentioned, persons with albinism do not participate in politics because of negative cultural beliefs, which result in them being discriminated against. In Rwanda most other groups historically excluded from politics such as women, youth are now politically represented at district and sector levels but because of myths surrounding them, persons with albinism are not included. Politicians say gates are open for all persons to enter any party. The channels to participate in politics are not as inclusive. Persons with albinism also aren't willing to stand for elections because of the discrimination they face.

Socially even families of persons with albinism are discriminated against, some community members do not want to associate with them or work with them. Most of this is connected to culture. Persons with albinism are not seen as normal human beings, they are called names. They do not enjoy equal human rights.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: The same laws that apply to all Rwandans also apply but persons with albinism do not benefit as much from this protection.

Health

9. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: In its concluding observations to Rwanda the CRPD Committee in 2019 made several recommendations including that the government of Rwanda must take specific measures to safeguard the health of persons with albinism. The government has been working towards implementing this obligation. The government through the Ministry of Health has availed sun lotions. There are not enough measures in place yet to address skin cancer. The government cares more about other cancers such as breast cancer but not skin cancer. As an organization, we supported 100 persons with albinism to be screened for cancer about 38 showed symptoms of skin cancer. Rwanda has hospitals that can do skin cancer screening e.g., the Rwanda

military hospital but those hospitals are expensive and persons with albinism are not able to access them, they also work on referral system Skin cancer preventative programs, which focus. Ophthalmology services are also very expensive. Health insurance does not cover eyeglasses.

We have lobbied the government to include sun lotion on public health insurance. They have approved it. It is now cheap to access it; the problem is it is not widely distributed.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: There are still many issues; some families do not send children to school because they have negative misconceptions about the educability of children with albinism. Poverty also hinders children from accessing school. When children go to school, they have challenges. Classroom setup that makes it hard to see the board is one common one. Learning material is not printed in large font, teachers do not consider the low vision challenges they experience. They do not consider them as students who have special needs.

In school, students with albinism are bullied and called names. Schools do not permit students with albinism to wear hats and long-sleeved clothes, which are not part of the school uniform. There is also a shortage of books in class where students have to share books. In national exams, students with albinism need additional time and large font exam scripts, which sometimes are not provided.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, e.g. large print material, low vision, and assistive devices?

A: Most teachers do not know about albinism. Need to include in teaching modules. Some schools provide front desks; many do not provide any support for students with albinism.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

A: Most people work in the informal sector. It is too hard to access employment; employees do not want to employ persons with albinism in their company & institutions. The number of educated persons with albinism is also low.

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: When persons with albinism are interviewed for jobs and mention they have a low vision, they don't get recruited. Their sensitivity to the sun does not permit most persons with albinism to work outdoors extensively this limits the low-skill outdoor jobs they can do.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

A: None.

15. Are there special measures in place to promote and integrate persons with albinism in employment and the labour market?

A: No special measures in place.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: Most of the obstacles are connected to culture. When persons with albinism are not independent and do not have control over their lives, they are in danger of being victims of violence and abuse. They do not report it because sometimes the perpetrator is a family member and at other times, it would disgrace the family.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies.

A: No.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: None

K. Recommendations

19. Please provide specific recommendations for further action to be taken by your Government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

- Request that the government put in place a program for skin cancer screening, testing, and treatment and increase the number of dermatologists.
- Recommend that government adopt specific measures aiming to improve the living condition of persons with albinism, including improving their access to employment, education.
- The government should conduct more social awareness campaigns aiming to promote the rights of persons with albinism and combat the stigma and discrimination faced in the community.
- Political parties should take a lead to include persons with albinism in the political spheres to improve their participation in politics. There should be a person with albinism in the National Council of Disabled People.

L. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Uganda

Contributing Organization: Source of the Nile Union of Persons with Albinism

Contact person for more information: Peter Ogik; founder and chairperson of Source of the Nile Union of Persons with Albinism, a non-profit organization in Jinja; ogikpeter17@gmail.com

A. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: There are no official statistics on the number of persons with albinism. Estimates from NGO's put the number at between 4500-5000. The Eastern part of the country has the highest number of persons with albinism at 2 300. The estimates are based on membership of organisations working on albinism and data collected in the course of program work as well as from data collected at entry points of key services. Last census did not count persons with albinism.

2. How many of those people are women? How many are children, as defined in your country?

A: The difference between the genders is not that much from the data we have. The ratio of men and woman is almost the same. Women 49%, Men 51%. Children under 18 constitute 55% of the population of persons with albinism whilst youth 18-35 are 35% of the population and adults 35yrs and above 10%.

3. Please describe the overall social and economic status of people with albinism in your country?

A: Persons with albinism are marginalised though things are starting to improve. Their socio-economic status is quite low. Few are economically stable; few participate in politics and social aspects of life. Many are under privileged and are simply surviving. Most persons with albinism are self-employed and live hand to mouth trying to make ends meet. This is because most were not educated, even those educated find it hard to get job. A number end up doing menial work

like gardening, fetching water, selling clothes. These doors are outdoors resulting in them getting burnt in the sun and increasing their risk of skin cancer. They are now officially recognised as persons with disabilities by Disability Act. The Act now gives them access to disability grants which is starting to improve the situation somewhat.

Regarding social status it's hard to change perception of people in rural areas, they still largely exclude persons with albinism because of myths and superstitions about albinism. Parents refuse for their daughters to marry someone with albinism. Others are forced to attend special schools because they are turned away from mainstream schools. Some struggle in their business because people do not want to buy from someone with albinism.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: Ministry of Gender, Labour and Social Welfare are responsible for albinism. There is a state minister for Disability who also champions disability rights.

The National Council for Disability is an institution of government that monitors the implementation of issues affecting persons with albinism. Persons with albinism represented.

The National Union of Disabled People is umbrella body of all organisations working on disability. In the board of Directors there is a person with albinism.

B. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of:

5.1. participation in political, social, civic and cultural life?

A: There is a report from Uganda on impact of Covid 19 on persons with albinism. Gatherings were not allowed so most political campaigns done through TV's. This limited people's participation overall. Not having money for campaigns precludes persons with albinism from standing for elections. Some people fail to participate because information passes them by. Persons with albinism were excluded from participating in Ginja, they were not recognised as candidates. Many councils have persons with disabilities because organisations mobilised participation but only 5 persons with albinism are in elected positions.

The total lockdown measures and not socialising traumatised some people. This is because the different gatherings where they normally would meet which provided much needed social support and celebrations like international albinism awareness day were banned during this time. There was a lot of fear psychologically, people with albinism thought they were going to die. Our organisation began to connect people with albinism through video and teleconference

so they felt less alone. People had no food during this time and no one to reach out for help. They didn't have opportunity go and work so for many who lived daily hand to mouth and those who had family to feed this period was particularly distressing. NGO's working on albinism were not allowed to work in the community in the 6 months of lockdown. Some myths came up tried to connect it to albinism more in villages not so much in towns.

5.2. access to the right to health?

A. Access to the right to health was affected to a large extent. We have seen higher number cases of skin cancer after lockdown. Our organisation has a programme where we run quarterly skin clinics in 5 to 6 districts in the country. We provide skin cancer screening, sun screen lotion, and if anyone who comes to our clinic is diagnosed with skin cancer, we assist them to go for therapy and surgery. But with the lockdown restrictions put in place by government and related restrictions on movement and gatherings we had to pause our programme. This meant persons with albinism who dependent on our programs were not accessing sun screen lotions and got sun burnt. The government in its health centres was not distributing sunscreen at the time. They also could not get skin cancer screening services. The number of cases of skin cancer has increased as a result. 3 people we are aware of passed on from level 4 skin cancer which can't be treated. There are no specific eyecare services for persons with albinism. It costs more than USD30 to test individually. With vaccination roll out persons with disabilities have been given due consideration.

5.3. access to the right to quality education?

A: The government resorted to provide teaching through radios and TVs. This approach was not effective for students with albinism. The families of most persons with albinism live in poverty and so do not own TV's and radios. Those who own then struggled with the small letters projected on the TV. They had to stand close to the TV which wasn't good. As people lost their source of income even buying batteries for radios was hard for many.

The government tried to print reading materials for distribution to children studying remotely but the font was small so organisations of persons with albinism had to reprint them for children with albinism. We tried as organisations to come up with some way forward. We got families of children with albinism mini solar systems/ panels and radios so students with albinism could follow classes done on radio. In urban areas hired teachers to teach children at home and provided data for university students as data tends to be expensive. We have raised these issues with government and made some recommendations for the future. The country is still under partial lockdown but children are back in school now.

5.4. access to the right to employment and the right to work?

A: Most persons with albinism self-employed. They are living hand to mouth, so Covid restrictions affected them. For teachers with albinism things are still terrible. They have not

been working for the past 1 and half years and are at home sitting and waiting. Some lost jobs and some only get a small portion of their salary.

The impact of Covid has also been felt by the NGO sector. Many lost funding had to stop projects as money was rerouted to fighting Covid 19. Lots of programmes were disrupted because of the new restrictions in movement and only those NGO's that were able to quickly adapt survived.

C. National legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and source of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: There was no specific policies or legislation on albinism. The Constitution has a non-discrimination clause that prohibits discrimination on the basis of disability and any other ground. Albinism is included in the Disability Act 2020. There is a National Action Plan on Albinism that has been drafted but has not been adopted yet.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Yes, it is now under the new Disability Act 2020.

D. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic and cultural life? Please provide statistics and data if available. Are there any obstacles for persons with albinism to participate in political, social, civic and cultural life, and if yes, what are the major obstacles?

A: Even though we now have a law that more explicitly protects the rights of persons with albinism there is not a lot of awareness around it amongst persons the public. There a lot of unrefuted myths and erroneous beliefs about persons with albinism. There are beliefs that they

should go to school, can't study and can't do anything which is very demoralising for persons with albinism. There are also beliefs that albinism is contagious, that those with it are either less human or super human which excludes them from society.

Some persons with albinism grow up in homes with unsupportive families where they are called degrading names and are hidden when visitors come not surprisingly even when grown up, they don't participate in society. The way society perceives persons with albinism as ghost makes them fear themselves and jump at your own shadow.

Persons with albinism are afraid to stand for election but also do not have the resources to. You have to pay money to stand for elections, have to travel the whole country campaigning. You need a campaign team; you need to facilitate people to come to your meetings. Hire venue, snacks, transport costs. Persons with albinism who are not economically stable are unable to do this.

Discrimination is often hard to prove.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic and cultural life? If yes, please provide details and source of the major laws and policies.

A: No particular laws. Same laws applicable to everyone else.

Health

9. How would you describe the health situation of persons with albinism? Are dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: The health services are not designed for persons with albinism in particular but for everyone. There is a huge demand for health services offered by the national referral hospital in some districts. These hospitals are understaffed. 10 000 people need services so you take months without being attended to meantime you are getting worse. These hospitals also tend to be far so NGO's working on albinism who implement health programmes, don't have stable funding to reach the number of people they need to. The NGO's run these programmes to show government how it can be done. Sun screen is not available free of charge in public hospitals.

Access to health information remains a big challenge. In one case shared with us when the baby was delivered the doctor ran out screaming. Training of midwives, nurses to counsel mothers of children with albinism is needed. Some mothers are young, they need to be supported psychologically to support their children. Youth don't learn about albinism in school.

NGOs are trying to fill the gap by disseminating health and other information on albinism on radio shows, dramas, television shows, edutainment, research, writing, conferences, community gathering.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: The situation is improving. Some parents do not send their children with albinism to school because they believe they are incapable of doing well in school. Parents also don't send their children because of they can't afford to pay fees. Other parents are protective of their children and don't send them to school for fear of attacks especially where the child needs to walk a long distance to get to school. Children with albinism are also deterred from going to school where they have to walk long distances in the sun and get sun burnt. The burns take a few weeks to heal and they miss school whilst attending to them leading to poor performance.

Children with albinism of school going age drop out of school mainly because of being bullied and called names by peers and teachers alike. Other students don't want to sit next to them. Teachers are often not supportive and fail to help them be well accommodated at school. This is partly because teachers lack knowledge on how better to accommodate children with albinism. Some teachers wont even allow children with albinism to wear wide brimmed hats, long sleeved clothing to protect themselves where these are not part of the normal school uniform.

Children with albinism are short sighted which in the absence of support can lead to low writing and reading levels. When I was at school, I was not seeing so well the black board. I had to go close to the board several times so I could see letter by letter. Teachers have a responsibility to teach the students in their class to be supportive, understanding and to counter the myths around albinism. We started a teacher training, and have seen positive results in the schools the training is run with more students graduating school.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, for e.g. large print material, low vision and assistive devices?

A: Not provided for but the Disability Act and manual for its implementation will hopefully change things.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning employment and unemployment rate of persons with albinism, if applicable?

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: The low employment rate of persons with albinism is a result of a number of interrelated factors. Few attained an education because of factors discussed. Mis perception by the employers about the capabilities of persons with albinism lead them to believe they are incapable of doing some of the tasks performed by their peers. Some believe that they will bring bad luck to their business and scare customers away.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and source of the major laws and policies.

A: Labour law prohibit discrimination in labour practice.

15. Are there special measures in place to promote and integrate persons with albinism in employment and in the labour market?

A: There is affirmative action, tax break and waivers when you hire someone with a disability. This doesn't always lead to full integration as some employers just employ persons with albinism to do menial work so they can get the tax benefits.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: Some persons with albinism don't know rights, when mistreated don't know where to report and are afraid of reprisal from the community. They are also not provided with the reasonable accommodation and support they need in pursuing justice. In one case a person with albinism went to report an incident at the police station and was told by the police if he wanted then to go and arrest the perpetrator, he must provide the fuel.

Some things not clear in the law so police don't know how to file the case. For instance, when someone forcefully cuts the hair of a person with albinism. Sometimes the perpetrator has power and money and therefore evades justice. In 2017 there was a case of a man that had

forcefully cut the hair of child for ritual purposes and injured the skin on their skull in the process, when we followed up, we heard case withdrawn.

The lenient sentences those perpetrators get also discourage persons with albinism from reporting cases. There was a man who invited the father of a child with albinism to sell their child. The father of the child sends his wife and child away for their protection following the incident. The man then killed the father of the child with albinism. He was tried but to our surprise after one year released. It did not make sense for us and demoralised people from trusting courts. We could not understand what circumstances lead to his release.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and source of the laws and policies.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding the participation in political, social, civic and cultural life; health; education and employment?

A: Nothing specific on albinism. The government came up with food relief programme. Many people didn't get food, not enough.

E. Recommendations

19. Please provide specific recommendations for further action to be taken by your Government and other stakeholders to address challenges to the full and equal participation of person with albinism in society and development?

A: Collaborate more closely with organisations working on albinism. Better solutions are formulated, designed and implementing when co created.

F. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?





Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country focus: Mozambique

Contributing Organization: Associação Ze Manuel Pinto (AZEMAP)

Contact person for more information: Flavia Pinto, President, Associação Ze Manuel Pinto (AZEMAP) associacaozemanuelpinto@gmail.com

M. General

3. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: Mozambique has around 30,000 people with albinism, according to the report presented by the government on June 13, 2020, on the international awareness day for people with albinism.

2. How many of those people are women? How many are children, as defined in your country?

A: Data on albinism is currently not disaggregated according to gender and age.

8. Please describe the overall social and economic status of people with albinism in your country?

A: The social situation of people with albinism remains worrying. Persons with albinism are widely discriminated against, stigmatized, often in the community where they are living and sometimes by their own families. They struggle to overcome barriers such as insecurity, bullying, and the lack of reasonable accommodations to enable their full inclusion and participation in society.

Economic situation: From consumption-based poverty assessments which look at the monetary value which can allow a household to obtain a basket of goods corresponding to an acceptable basic standard of living, it was noted that persons with albinism live far below the poverty line. Persons with albinism are likely to live in poverty due to a combination of factors including discrimination, stigma, human rights violations, and struggling to access resources.

9. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: Public Institution: Ministry of Justice, Constitutional and Religious Affairs

Private:

- ✓ Associacao Zé Manuel Pinto (AZEMAP) in Tete.
- ✓ Albimoz- Maputo
- ✓ Amora Vida- Maputo

N. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of?

5.1. Participation in political, social, civic, and cultural life?

A: our government has always ignored the situation of persons with albinism in our country. This group even before the onset of the pandemic was always marginalized and disadvantaged. Several factors hinder their effective and efficient participation in

society. Opportunities are rarely given for persons with albinism to actively participate in political, social, civic, and cultural life.

5.2. Access to the right to health?

A: The Government of Mozambique is still far from creating basic health care conditions for people with albinism. In hospitals, there is a shortage of dermatologists for skin cancer screening, testing, and treatment. There is also a short supply of ophthalmologists to provide eye care and undertake eye operations that may be needed by persons with albinism. Health professionals always treat pregnant women who give birth to children with albinism with contempt when they give birth due to erroneous cultural beliefs around albinism.

5.3. Access to the right to quality education?

A: Non-existent, as the Ministry of Education and Human Development has not yet created optimal conditions for learners with albinism. Children with albinism face numerous obstacles in school, including bullying by other students, and sometimes by teachers; little or no accommodations suitable for their low vision and requirements to participate in outdoor physical education classes without proper protection from the sun.

5.4. Access to the right to employment and the right to work?

A: Another obstacle exists in our country. The right to work intersects with many other human rights, which if not fulfilled can hinder access to employment. In our country, people with albinism cannot secure a job in the formal sector because they do not have the required qualifications for the job because of the challenges, they faced in accessing education. Illiteracy and lack of qualifications or training is huge hindrance to accessing employment opportunities for this group.

0. National Legal and policy framework

8. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: In Mozambique, still no national legal framework adapts an effective approach to discrimination against people with albinism

- 8.1. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Albinism in Mozambique is considered a disability. So far, there is no legal provision that defends the interests of people with albinism.

P. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

9. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics and data that are available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

A: We referred in the previous paragraphs: limited opportunities to participate in activities or actions of greater importance or prominence. The multiple social and economic obstacles also invariably reinforce the serious obstacles to their political, civic, social, and cultural participation. In Mozambique, the phenomenon of “Discrimination” still prevails.

10. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: Does not exist

Health

11. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: As we mentioned in the previous paragraph, the Ministry of Health has a shortage of medical personnel for the areas of dermatology and ophthalmology.

Education

12. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: The educational situation of people with albinism in the country is still a great challenge; few children have access to school education, attendance is low, and school-age completion remains the seven-headed beast. Obstacles: The right to education has been systematically denied to people with albinism. Obstacles experienced by children with albinism include discrimination, social stigma, superstitions and myths, violence, poverty, lack of appropriate infrastructure, the location radius of school facilities is too long, sometimes schools are 5 to 10 km away, consequently, insecurity is greater; learning materials and methods, as well as a lack of sufficiently trained staff. All these contribute significantly to low school attendance and high dropout rates among persons with albinism.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, e.g., large-print material, low vision, and assistive devices?

A: Unfortunately, our government does absolutely nothing.

Employment

13. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

A: The employment situation of people with albinism in Mozambique is less than ideal, as many people with albinism are unable to access work in the formal sector because most of them do not meet the required requirements or qualifications required for formal work, because of the challenges that face in accessing quality education.

14. What obstacles exist for persons with albinism in seeking paid employment in the open labor market?

A: obstacles are many: discrimination, stigmatization, unacceptable work environments, and fear of attacks, illiteracy, and lack of qualifications or training. Therefore, most companies are not interested in employing people with albinism. Because of these barriers, many people with albinism are unemployed or poorly employed, many of them being forced to work in low-paying, short-term jobs in the informal sector. The informal sector consists of economic activities that are not regulated or protected by the government. This means that people employed in the informal sector do not have full access to laws and systems that protect workers' rights.

15. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

A: In Mozambique, there is no law or policy on the employment of people with albinism.

16. Are there special measures in place to promote and integrate persons with albinism in employment and the labour market?

A: NO

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: Existing obstacles: not having effective access to information and communication to be able to know and defend your rights.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies. R: There are no policies.

A: There is no specific policy. There is a Multi sectoral action plan that we are not sure what they are doing.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: On the Government side. No, it does not exist.

Q. Recommendations

19. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

- A: Persons with albinism should be provided with a means of survival to ensure a decent life through the “social support” or “Microcredit” program. The neediest persons with albinism and their families would benefit immensely from such inclusion. They would receive some money to start small businesses locally, such as “making homemade bread or cookies, selling agricultural products” and within six months once their businesses are profitable, they can return the initial capital to benefit other families too.
- The government should support persons with albinism interested in farming and those already farming with agricultural inputs such as hoes, machetes, and seeds, watering cans to increase production and productivity, and self-reliance.
- For single or abandoned mothers whose child is a person with albinism, who are helped with building material, e.g., zinc sheets, cement, nails, beams, burnt wire, to improve their homes.
- For the most deprived families who were helped with domestic instruments e.g., aluminium pans, plates, enamel cups, buckets, knives, spoons, clothing, shoes, and blankets, etc.
- Allocate funds to support victims with albinism about legal proceedings, medical expenses, including mental health, and psychosocial support.
- Ensuring access to psychological support for professionals who work very closely on this issue, being exposed to a high level of stress resulting from this context of extreme violence.
- Support victims in the social reintegration process to avoid victimization.
- Conduct more awareness-raising lectures on the prevention of trafficking, involving health professionals, the Police, religious leaders, and including the various case management perspectives.

- Develop manuals for case management to be used by entities that are part of the Reference Group, as well as for the education sector. Be used as a crosscutting subject in the curriculum, and by community leaders to identify cases of violence.
- Continuously train the employees of the various institutions (agents SCENIC, PRM, Migration at the borders and Social Action) as well as community leaders on the phenomenon of trafficking (concepts, outlines, referral system, support for victims, issues related to ethics and deontology);
- Publicly disclose examples of good practices, such as the "Diana" case that drew the public's attention to the outcome of the case, highlighting the functioning and effectiveness of the Justice, to discourage the practice of trafficking.
- Use the various digital and media platforms available for prevention, whether these are applications, social networks, WhatsApp groups, antenna space in radios (focusing on community radios), or others, always using a language accessible to the target population.
- Strengthen collaboration with AMETRAMO to carry out in-depth studies on the use of organs and parts of the human body of people with albinism to better understand the phenomenon.

17. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?

- There is a support scheme called "sponsorship for children" which consists in offering a "scholarship" both for the acquisition of school material and for the payment of tuition fees up to higher education or vocational training.



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Benin

Contributing Organization: Divine Connexion Worldwide (www.dcw.bj)

Contact person for more information: Franck Houètèhou C. HOSA; Director and Founder; Divine Connexion Worldwide; connexionworldwide1@gmail.com;

R. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: We do not have any official census on persons with albinism. There are no statistics. We estimate 2000-2500 based on the census we did 6 to 7 years ago. The census was done in four of the communes, which constitute the biggest divisions of the country, which gave a percentage.

2. How many of those people are women? How many are children, as defined in your country?

A: The data from the census showed that we have more children than adults.

3. Please describe the overall social and economic status of people with albinism in your country?

A: Very low. Health challenges experienced by persons with albinism mainly vision impairment and skin problems are not addressed. We struggle to access education leading to us working in low-paid jobs and doing odd jobs like selling in the market. We live hand to mouth. Few persons with albinism have indoor jobs. Very few have fixed jobs.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: The Disability Unit of the Ministry of Family and Social Affairs handles all affairs related to persons with disabilities but their actions show they don't plan for persons with albinism and do not closely consult them. It took them a while to openly affirm that albinism is a disability.

There are a few local organizations that work on albinism, 3 are nationwide (ONG Valuer Albinos, Albi International, and Connexion Worldwide) not all of them registered.

S. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of?

5.1. Participation in political, social, civic, and cultural life?

A: Persons with albinism were affected the same way as others and did not have jobs. Since the pandemic, we have had elections. Persons with albinism participated; no person with albinism was a candidate in the elections.

5.2. Access to the right to health?

A: There was no official health plan on how to take care of the health needs of persons with albinism during the pandemic. No structure was in place. Even before the pandemic health, service delivery was in general terrible. When the pandemic broke, our organization could not do our dermatology and ophthalmology program, so the services we render to persons with albinism were disrupted.

5.3. Access to the right to quality education?

A: Even before the pandemic, this was a big problem. Our organization has been training teachers on teaching children with albinism. We have trained 500 teachers to date. The government stopped classes for 4 to 5 months after the outbreak and schools moved to online learning, which was a disadvantage to those without access to technology.

5.4. Access to the right to employment and the right to work?

A: Persons with albinism were affected, many who had small businesses their businesses closed. People were forced to stay at home and their businesses went broke. Those in the entertainment industry like musicians could not perform as all gatherings were banned and struggled to survive.

T. National Legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: There is a general law on disability the Disability Act that came into force 3 years ago. It does not mention albinism specifically. Persons with albinism were not consulted in the drafting of the bill. Amnesty is supporting the development of some form of legal and policy framework pioneering for the protection and promotion of persons with albinism.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: They say it is but waiting to see what this means in action. No law or policy says this. It is just the government's standpoint when they speak.

U. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics and data that are available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

A: They participate in social and cultural life anyone else the only thing that is a problem for them is they are stigmatized in school and mocked but awareness raising by NGOs is helping to reduce the stigma. Persons with albinism are considered Gods in some

cultures in Benin. They are worshiped and respected. We do not accept being seen as Gods nor us being seen as less than human either just because of the colour of skin. We do not need over revered above other people this creates myths and superstitions around us. We just want to be treated as equals.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: No specific laws or policies just laws of general application.

Health

9. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: Most people do not have access to the healthcare services they need because these services are expensive; the government provides them free. There is no access to sunscreen in public hospitals to my knowledge. Dermatologists are not well trained on albinism. There are no government-led programs to provide information about albinism. Mothers of children with albinism go home after giving birth to children with albinism without knowledge on how to take care of the child. NGOs are the ones who normally provide this health information. Persons with albinism are very vulnerable because of their economic situation.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: I have been to school with only 4-5 people with albinism. A reasonable accommodation is not provided. Most parents do enrol their children in schools but the school does not accommodate them. The teachers do not know how to teach a person with albinism.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, e.g. large print material, low vision, and assistive devices?

A: No, except those schools whose teachers we train. They are more aware and try to find accessible devices for their students. Many schools just think students with albinism are such a small number so why should they put so much effort.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

A: There are no statistics.

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: Access to education means they are not qualified for the job. People are rejected for jobs simply because they have albinism but they are not told it is because of albinism. People also do not believe people with albinism can deliver.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

A: No. General labour laws apply.

15. Are there special measures in place to promote and integrate persons with albinism in employment and the labour market?

A: Nothing.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: No knowledge on this.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies.

No. General laws apply.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: The government told people with small businesses to be registered for them to get grants to mitigate the impact of Covid 19. For the business to be considered it needed to be registered. Taxes are high in Benin so people do not want to register their businesses and be liable for tax so many did not apply for this grant.

V. Recommendations

19. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

A: The first responsibility of the government is to protect everyone in the country; people with albinism are not less deserving because they are fewer.

- The State must create adequate conditions for persons with albinism to thrive. They are not lesser human beings and do not deserve to be stigmatized.
- The State should teach teachers how to teach persons with albinism in classroom settings.

W. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country focus: *Malawi*

Contributing Organization: STANDING VOICE | Malawi

Contact person for more information: Bonface Ophiyah Massah; Country Director; bon@standingvoice.org

A. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the Covid 19 on the situation of persons with albinism in terms of:

5.1 Participation in political, social, civic, and cultural life

A: When it comes to political, social, civic, and cultural life people with albinism are affected the most. They did not enjoy their right to justice due to the Covid 19 restrictions in the country. Courts in the country are no longer operating at a normal scale due to working on shifts arrangement as a preventive measure for COVID-19. Access to courts is pivotal to the enforcement of human rights. The delay in resolution of cases occasioned by the working on shifts arrangement has had a great negative impact on the person with albinism. The ongoing cases of attacks against persons with albinism several of which are still pending in the courts. The delay may affect the quality of evidence which may deteriorate over time and affect the outcome of the cases. With limited movement due to restrictions, it has been difficult to access the courts of law, coupled with the courts also operating in shifts and on appointed days. In addition, cases of gender-based violence have increased on women and girls with albinism. Most women and girls with albinism have experience difficulty reporting such incidences as law enforcement officers are also adhering to preventive measures, whilst other stakeholders who rely on donor funds, have been affected with most donors pulling funding. Consequently, a few cases on gender-based violence on women and girls with albinism cases reported in

various courts by FEDOMA on behalf of its affiliates under the Spotlight Initiative being implemented in Dowa, Ntchisi, Nsanje, and Mzimba.

5.2 Access to the right to quality education.

A: The government of Malawi ordered for the closure of schools as a way of containing the spread of the Covid 19 pandemic and opted for online learning it did not consider persons and children with albinism. Online learning is conducted through radio or the use of smartphones by sending materials. This arrangement sidelined children with hearing impairment and those who are blind respectively. It was hard for the children with albinism to have access to the needed learning material for them to participate. Most institutions where learners access braille materials are boarding schools. The materials can be accessed during the times when the schools are in session. The closure of schools meant that such children were sent home without any materials to read. This put them at a disadvantage with their able-bodied students or learners who had all the materials and could continue studying whilst in their homes. No special needs teachers were assigned to assist learners with disabilities during the lockdowns and the prolonged school holidays. More so, inadequate assistance devices expose most learners with albinism to the virus as they cannot protect themselves. For example, those that are paraplegic and those using white canes a device used by many people who are visually impaired often have challenges washing their hands and sanitizing regularly as buckets and soap are not placed in a disability-friendly manner.

5.3 Access to the right to health care services.

A: The Covid 19 pandemic forced the Malawian government to change its health care system and put more effort into the COVID-19 pandemic. This has resulted in directing many resources towards COVID-19 which on the other hand leads to other health care services either receiving very little attention or being neglected. It was reported that with COVID-19, most health services facilities were overwhelmed, as such not able to attend to certain issues affecting persons with albinism. COVID-19 patients become a priority in this case. In addition, health care services have been struggling to give good quality services because of the pressure on their financial and human resources. Despite the already existing supply chain challenges in accessing sunscreen lotion, the availability of the lotion had dwindled in supply since the coming of the COVID-19 pandemic. COVID-19 pandemic has negatively affected the provision of health care services in the country. Moreover, Access to Sexual and Reproductive Health (SRH) services were more challenging for women and girls with albinism and compared to other persons due to lack of adaptability in the equipment and facilities in the SRH settings. In addition, stereotyping in terms of their bodies, intimate relationships, and sexuality, and lack of transport to health facilities have been a hassle for women and girls with albinism to access health services, and the Covid 19 pandemic has worsened the situation.

5.4 Access to the right to employment and the right to work

A: Persons with albinism have been directly affected by the Covid 19 pandemic in economic terms. Most of them lost their work and income due to the imposed Covid 19 regulation in the country. There is no comparative data on the rates persons with and without albinism are losing work and income. The evidence available shows that persons with albinism who are working informal sectors and those who are already experiencing extreme poverty have been particularly severely impacted. The livelihood activities of people with albinism have been impacted by the COVID-19 pandemic and several persons with albinism are facing challenges to travel to their workplace due to the imposed covid 19 regulations in the country. The majority of persons with albinism are small-scale, business operators. 37% reported experiencing reduced demand for goods and services due to customers' fear of contracting the virus and restrictions on travel and movement. The negative effects of the closure of COVID 19 are most felt in urban environments, where there are no alternative ways of surviving. The government's lockdown measures disrupted livelihoods, and this significantly increased gender-based violence on people living with albinism and various social problems, poverty levels have increased. The majority of persons with albinism do not know how to adapt their business practices to protect themselves and their customers and prevent the spread of COVID-19. This, therefore, trickles down to their economic welfare. Most businesses for persons with albinism have almost closed as the conditions are not conducive for running businesses due to restrictions in movement and other measures put in place by the government. For instance, Mzuzu Disabled Organization runs a knitting and sewing business and due to the pandemic, their production and sales have hit rock-bottom as their members and customers stay at home. The Malawi Council for the Handicapped (MACOHA) has not been spared either. It has scared down its operations as the staff is now working in shifts to achieve social distancing.



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: South Africa

Contributing Organization: Albinism Advocacy for Access South Africa

Contact person for more information: Mpho Tjope, Founder & Director of Albinism Advocacy for Access South Africa & Chairperson of the South Africa Albinism Taskforce, mpho@actiononalbinism.org

B. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: It's very difficult to say. South Africa promised that in the next census they will include a question on albinism. Due to Covid the census has been moved to next year. Emigrants with albinism also inflate the numbers. There is a need to look at persons with albinism who are asylum seekers.

2. How many of those people are women? How many are children, as defined in your country?

A: We don't know.

3. Please describe the overall social and economic status of people with albinism in your country?

A: Economic: The majority of work going age are not fully employed. There are on one-year learnership or internships, the afterwards the go back to unemployment. The denial of education has meant persons with albinism don't have a qualification; many did not finish school so getting a job becomes hard. We still get cases of children being rejected from mainstream schools.

Social: There are improvements though. We have seen the increase in visibility of persons with albinism in media spaces and greater participation in society. More still needs to be done to dispel existing myths around albinism.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: Albinism falls under the Department of Women, Children and Persons with Disabilities.

There is the National Task team on albinism, an umbrella body of organisations of persons with albinism.

C. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of:

5.1. participation in political, social, civic and cultural life?

A: When food parcels were being distributed last year to persons with disabilities and other vulnerable groups. Persons with albinism were not given because many who were giving out food parcels felt that persons with albinism were not disabled. Most persons with albinism were home during the pandemic. NGO's working on albinism saw an increase in cases of gender-based violence against women with albinism.

5.2. access to the right to health?

A: Some were unable to go to the hospital to get sunscreen. Hospitals closed. Children with albinism experienced emotional and mental strain during lockdown. They felt alone. School provided companions they could talk to about things that were bothering them.

5.3. access to the right to quality education?

A: Learners moved to remote learning for some time during the pandemic. That was a challenge particularly to those with albinism with no access to the devices to connect to online learning. Those with laptops didn't always have or know how to navigate assistive programmes. With University learners, no consideration was given to the need for extra time during assessment. There was not enough planning or consultation done to ensure inclusive remote learning.

5.4. access to the right to employment and the right to work?

A: It was more difficult if not impossible to get a job during this time.

D. National legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and source of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: There are no specific laws in. A National Action Plan on Albinism is currently being developed.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Yes. Though there is confusion about this amongst the different government departments. The driving licensing department considers persons with albinism as visually impaired and thus unable to drive. SASSA does not consider persons with albinism disabled so they do not qualify. The definition disability in the white paper on disability is so broad it can include albinism.

E. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic and cultural life? Please provide statistics and data if available. Are there any obstacles for persons with albinism to participate in political, social, civic and cultural life, and if yes, what are the major obstacles?

A: It depends where you are, it's not universal. In the rural areas persons with albinism are referred to using derogatory names in vernacular. Being uneducated affects how persons with albinism are perceived in social spaces and how much influence they have. More effort is needed to include persons with albinism in all aspects of society.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic and cultural life? If yes, please provide details and source of the major laws and policies.

A: No.

Health

9. How would you describe the health situation of persons with albinism? Are dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: Part of the challenge has been persons with albinism not knowing about the services. For instance, the Chris Baragwanath hospital offers the skin cancer treatment but not a lot of people with albinism know. There is need for more knowledge dissemination on albinism by government in accessible and easy to understand formats. The medical information about albinism is currently scientific and academic and not easy to understand. Persons with albinism and their families have started various wats app group to share information with each other. The requirement to produce an ID number when collecting sunscreen has the effect of excluding migrants with albinism.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: The enrolment rates are high, but some mainstream schools discourage children with albinism from attending. Last year our organisation had to intervene to assist where a school as refusing to enrol a child with albinism.

70% or more of students with albinism drop out. This is mainly because of the bullying and abuse they face in schools and fear of attacks. There are cases of parents not taking their child with albinism to school because of fear of attacks in areas were attacks or attempted attacks have been reported. The long walks to school also discourage some students. In some places students have to walk through areas with dense vegetation, so safety is an issue of safety. The exposure to the sun in the long walks and resultant skin damage also discourages some learners from going to school. Most drop out in high school where they have more power to resist going to school.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, for e.g. large print material, low vision and assistive devices?

A: Most people prefer taking their children to special schools. In mainstream schools' students with albinism literary on their own. There is need to educate teachers. They don't know what to do. They can do so much but not aware they can.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning employment and unemployment rate of persons with albinism, if applicable?

A: Many youths with albinism are on internships. They hop from one to another without getting permanent employment.

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: Various obstacles exist. Lack of education. Myths around albinism. I went to an interview and someone asked if I burn when I get in the sun. In another interview someone asked to touch me. They are curious because there are so many myths surrounding you.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and source of the major laws and policies.

A: No, general laws.

15. Are there special measures in place to promote and integrate persons with albinism in employment and in the labour market?

A: None besides the ones that speak on disability inclusion.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: In recent research my organisation did 99% of people with albinism said they didn't know that South Africa has Equality Courts as a result they do not use these courts. Persons with albinism are often subjected to hate speech and other human rights violations but they don't know what remedies they can obtain and what services are there. The government can do a better job of bringing services to the people.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and source of the laws and policies.

A. No.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding the participation in political, social, civic and cultural life; health; education and employment?

A: Yes, they were like food parcels but the implementation was poor. Persons with albinism were seen as not having a disability and thus not qualifying for the parcel.

F. Recommendations

19. Please provide specific recommendations for further action to be taken by your Government and other stakeholders to address challenges to the full and equal participation of person with albinism in society and development?

A: Speedily approving the draft National Action Plan. The plan has a detailed strategy to improve the lives of persons with albinism and address the economical, health, education, and other

challenges they currently face. The plan was written by rights bearers so solutions came from the ground up.

G. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?

A: There is need to consider persons with albinism who are asylum seekers and emigrants.



Response to call for input by the OHCHR on Social development challenges faced by persons with albinism, including the impact of the COVID-19 pandemic

Country: Nigeria

Contributing Organization: The Albino Foundation, Nigeria

Contact person for more information: Jake Epelle, CEO/Founder of The Albino Foundation Nigeria; epellejake@gmail.com

A. General

1. How many persons with albinism live in your country according to the most recent national statistics? Please provide numbers or estimates and the source of information?

A: We do not have any credible and thoroughly researched statistics. There have been some attempts by civil society organizations to get these statistics. My organization did a baseline survey in nine states but the sample size is too small to make it conclusive. For now, we know there are more persons with albinism in the North and Central part of the country than in the South.

2. How many of those people are women? How many are children, as defined in your country?

A: There is no data. The rough estimate is 60% women, 40% men.

3. Please describe the overall social and economic status of people with albinism in your country?

A: It is not commendable. Many live 70% below the abject poverty threshold. The poverty levels are alarming. Most require transport to go back home when they attend events organized to discuss their issues. Many of them struggle with low self-esteem and lack the confidence to participate fully in society due to the rejection they face from society.

4. Are there any public or private institutions in your country responsible for persons with albinism? If yes, please list the most important institutions.

A: Because of our advocacy, persons with albinism are integrated into the disability framework. The National Disability Commission under the Ministry of Humanitarian Affairs is responsible for issues affecting persons with disabilities.

Now formed a community-driven association albinism association of Nigeria, umbrella body for both individuals and organizations

B. Impact of the COVID-19 pandemic on the situation of persons with albinism

5. What has been the impact of the COVID-19 pandemic on the situation of persons with albinism in terms of?

5.1. Participation in political, social, civic, and cultural life?

A: Covid has hurt persons with albinism particularly in light of narratives that connected Covid and albinism, which further fuelled existing discrimination against persons with albinism. As organizations of persons with albinism, we reacted quickly and raised our voices to change the narrative. When I was infected, I went public.

The positive aspect is that the pandemic created greater dialogue and consciousness around the need for social integration and inclusion. Organizations working on albinism used this space to stress the need for more inclusive interventions.

5.2. Access to the right to health?

A: We fought as an organization for conditions related to albinism to continue to be prioritized even during the pandemic. We were partly successful. On one hand, we had doctors go to attend to persons with albinism in their communities where there was a high demand for services. However, had skin cancer services were severely disrupted? They were no doctors to attend to this. Many doctors were diverted to isolation centers, care centers focusing on Covid 19 patients.

5.3. Access to the right to quality education?

A: The effect on students with albinism was tremendous. Many had to stay at home; it took the Nigerian government a lot of time to devise a method of ensuring continued learning during this time. The methods the government came up with TV, radio, social media were not fully accessible to persons with albinism. TV lessons are not great for people with low vision. The Albino Foundation came up with an initiative rethinking education amidst and beyond covid 19, which brought together the Ministry of Communication, and Education to discuss innovative ways to ensure inclusive learning when children were not in schools.

5.4. Access to the right to employment and the right to work?

A: There was limited effect, as many are not employed, to begin with. Some of the people with albinism who were working lost their jobs many of them not paid during this time. Organizations working on albinism raised funds to give those in destitute situations some food.

C. National Legal and policy framework

6. Are there any national legal or policy frameworks concerning the issues of persons with albinism? If yes, please provide details and sources of the relevant laws and policies? Also, please describe if and how these laws and policies take a non-discriminatory approach towards persons with albinism?

A: There is a National Policy on Albinism (2019-2020), that policy is being reviewed.

6. Is albinism counted as a disability in your country? If yes, please provide details about specific provisions and key laws or policies on this issue.

A: Yes.

D. Activities to address the socio-economic concerns of persons with albinism

Participation in political, social, civic, and cultural life

7. How would you describe the situation of persons with albinism in terms of participation in political, social, civic, and cultural life? Please provide statistics and data that are available. Are there any obstacles for persons with albinism to participate in political, social, civic, and cultural life, and if yes, what are the major obstacles?

A: See response above in three.

8. Are there any applicable laws or policies concerning the participation of persons with albinism in political, social, civic, and cultural life? If yes, please provide details and sources of the major laws and policies.

A: No, the general laws apply.

Health

9. How would you describe the health situation of persons with albinism? Are our dermatology and ophthalmology services readily available to them? Is there information made available to them about health risks linked with albinism? If so, how is this information disseminated and communicated?

A: It is not great, to be honest. We were getting free skin cancer treatment before but the current administration has stopped it, the reason is that we are few in numbers. Therefore, our people are dying it's either you find the money to get medical help or you are left to die. Sunscreen lotion is not available free of charge in public hospitals and is quite expensive to buy from shops. I recently noticed that sunscreen is disappearing from the shelves of shops.

Education

10. What is the educational situation of persons with albinism? Please provide statistics or other information regarding school enrolment/attendance/completion of persons with albinism of schooling age? Are there any obstacles for children with albinism to access education, and if yes, what are the major obstacles?

A: This generation of persons with albinism are making every effort to go to attain an education. Despite challenges, their school attendance and completion rates are good.

11. Given the low vision issues present in most persons with albinism, does the school system in your country recognize such special needs and provide the required support and reasonable accommodation, e.g. large print material, low vision, and assistive devices?

A: The government is not providing these devices, on our own as persons with albinism we are collaborating with Clinton Foundation and others to provide the low vision assistive devices and technology to students with albinism.

Employment

12. What is the employment situation of persons with albinism? Please provide statistics or other information concerning the employment and unemployment rate of persons with albinism, if applicable?

13. What obstacles exist for persons with albinism in seeking paid employment in the open labour market?

A: When it comes to employment, qualifications are an issue; many organizational policies refuse to acknowledge the barriers people with albinism faced in the education system that precluded them from getting the qualifications required. The type of qualifications they studied for is not marketable oftentimes. Some universities do not give equal opportunity to students with albinism to study courses of their own choice where accommodating them in these programs may be inconvenient. Other times parents do not even allow their children with albinism to even go to school because they do not think they will live long. Misconceptions about albinism such as that people with albinism are blind also deter employers from employing persons with albinism. The majority of Nigerians are employed in the private sector, but the participation of persons with albinism in this sector is limited.

14. Are there any applicable laws or policies concerning the employment of persons with albinism? If yes, please provide details and sources of the major laws and policies.

15. Are there special measures in place to promote and integrate persons with albinism in employment and the labor market?

A: No such measures. What we are trying to do as organizations is to ensure persons with albinism benefit from the measures put in place for persons with disabilities.

Justice

16. What obstacles exist for persons with albinism in having access to justice?

A: It's not an issue that is discussed a lot but the truth is that many of the judges and magistrates don't know much about albinism and issues affecting persons with them and so when they have to adjudicate on such issues, they do not always issue progressive judgments. The Albinism Foundation has started training judges and magistrates on various issues related to access to justice for persons with albinism as part of its disability inclusion project.

17. Are there any applicable laws, policies or other measures to ensure that persons with albinism have access to justice? If yes, please provide details and the source of the laws and policies.

A: No.

COVID-19 pandemic

18. Are there any measures in place to mitigate the impact of the COVID-19 pandemic on persons with albinism, in particular regarding participation in political, social, civic, and cultural life; health; education, and employment?

A: NGOs mobilized funds that benefited persons with albinism.

E. Recommendations

19. Please provide specific recommendations for further action to be taken by your government and other stakeholders to address challenges to the full and equal participation of people with albinism in society and development?

A: The Nigerian government needs to reinstate the skin cancer treatment program and ensure that it continues.

- The government must ensure that persons with albinism are given equal opportunities with others and included in all the thematic areas especially emerging issues.
- Albinism should be considered by development partners as a standalone issue, not subsumed in disability. A twin-track approach must be used in funding albinism. Some dedicated funding must be provided as well as included in funding for disability.
- There is a need to support entrepreneurs with albinism.
- The government must invest in data collection and research on albinism.

F. Further remarks

20. Would you have any further comments on the social situation of people with albinism in your country?
