“We Are Human Too!”

What we can do about the impact of stigma on the lives of people with albinism

“An investigation into the impact of stigma on the education & life opportunities available to children & young people with albinism in Uganda and Tanzania”. A project funded by FIRAH, led by Coventry University, in partnership with Advantage Africa & Standing Voice.

Advantage Africa
pathways out of poverty

Coventry University

FIRAH
Fondation Internationale de la Recherche Appliquée sur le Handicap
International Foundation of Applied Disability Research

Albinism Research Project

The two-year research project 'An investigation into the impact of stigma on the education and life opportunities available to children and young people in Tanzania and Uganda' is funded by FIRAH and led by Coventry University in partnership with Advantage Africa and Standing Voice.

Advantage Africa was responsible for the research in Uganda in partnership with the Source of the Nile Union of Persons with Albinism (SNUPA). This document provides details of the recommendations resulting from the study.

Project Partners

Advantage Africa is a UK-based organisation which helps vulnerable children and adults in East Africa to reach their potential, overcome prejudice, work their way out of poverty and become self-reliant.

SNUPA is a non-profit organisation based in Jinja, Uganda. It was formed by persons living and affected by albinism to advocate for equal rights, inclusion and access to services for children and adults with albinism. SNUPA facilitated the research activities, conducting eight focus group discussions with participants from across the Busoga sub-region and twelve individual interviews with key informants from across Uganda.

Implementing the Research Recommendations

Research participants were open and generous in sharing their experiences with the SNUPA team and hope that the research will lead to practical and tangible outcomes to improve their lives. The recommendations are being launched at the conference 'We are Human Too!' on 24th November 2017 at the Africana Hotel, Kampala, during which stakeholders will have the opportunity to reflect on their roles in implementing them. The quotes featured in this report are from the research respondents.

"I would request to help us implement our views. I request what we have shared be worked on and implemented."

Hadiija, grandmother of a young child with albinism

Recommendations 1. Birth & Family

Stakeholders including Ministry of Health to:

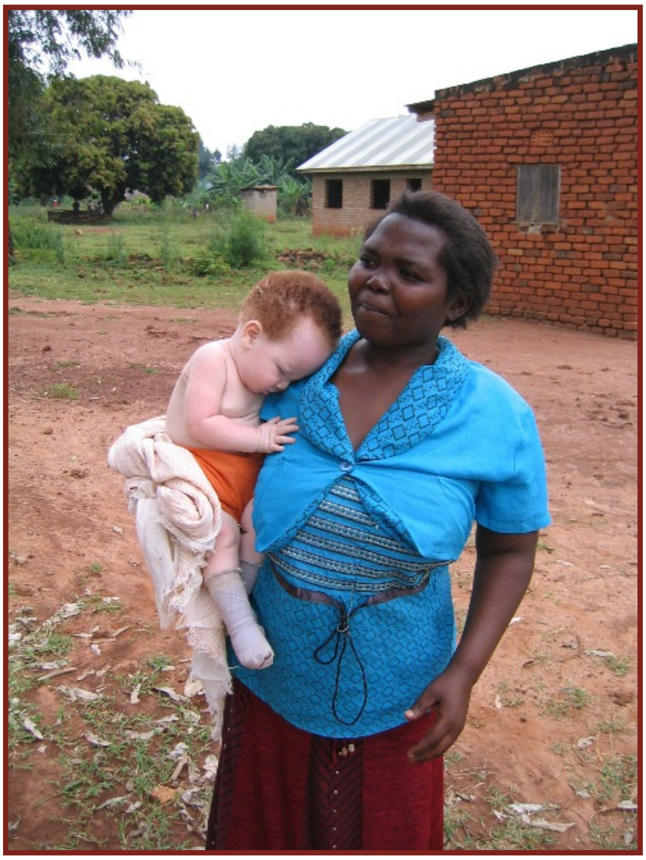
1.1 Include albinism in the curriculum for training midwives and other healthcare professionals with responsibility for childbirth and early childhood care.

1.2 Equip traditional birth attendants and village health teams with knowledge about albinism.

1.3 Provide counselling and simple information to families with new-borns with albinism about how to care for their child.

"When I was producing that child, the nurse saw the child coming out and shouted, "What's this lady producing!" I almost ran off the bed but decided to be strong."

Amina (mother of child with albinism)



"…the father of the child has never surfaced ever since I delivered, I look after the child myself."

Lydia (mother of child with albinism)

"I faced many challenges since my day one, I am told that when my mother gave birth to me like this, they told my daddy that your wife has produced an albino so he also told the grandfather, he was so annoyed. He called the community members then said "I have called you here to witness when am sending this son of mine with his curse away from my home," while referring to me being a curse in a family."

Sharik (teenage boy with albinism)

“I started doing some small business to support my children since the husband had abandoned me and had stopped supporting my children. My brothers and sisters couldn’t interact with me in family matters, they distanced themselves from me and I remained alone.”

Hasifa (woman with albinism)

“A mother gives birth to a child with albinism and the parents separate because the father of this child keeps saying the woman has the genes to produce albinism but the truth is both parents must be carriers so that they can produce a person with albinism.”

Sherry (woman without albinism)

“Giving birth to a person with albinism is hereditary; the mother and the father must have the gene of albinism. It’s not as a result of laughing at a person with albinism.”

Wilberforce (man with albinism)

“Many people misunderstand albinism; they always tell us after giving birth to children with albinism, “You have to do some ritual ceremonies to be cleaned from that curse.”

Amina (mother of child with albinism)

“Her mother was too scared because of the words people used to talk that “she has given birth to a ghost”, “she’s a misfortune”, “a pig”, so she really never felt well about that.”

Elizabeth (woman with albinism, a mother of a child without albinism)

“After getting that child, I got shocked because by then, there was no other child like that on the entire village…community members always said I gave birth to lubaale [a ghost]. After getting him, I took him to hospital, the doctors told me the child has no problem but his genes brought that colour.”

Moses (father of boy with albinism)

> ***“My parents were God fearing people and God helped them and they loved me as I was.”***

Peter (man with albinism)

> ***“You might see the person [with albinism] isolated or on other occasions students surrounding this one, because, they see he or she is very different. Surrounding them all the time because, it’s like a sport. So that really affects them; but save for those who have been born and bred in home that give them space, gives them opportunity to exercise their potential, those families where father, mother and siblings who tell them that they are not different from them. You will find a few like that who have grown and they are very assertive; you find a few of those.”***

Julius (Equal Opportunities Commission)

Recommendations 2. Education

Stakeholders including Ministry of Education to:

2.1 Train teachers in the educational, health and social needs of children with albinism.

2.2 Include albinism in school science syllabus to help children understand the condition.

2.3 Promote existing booklets and information on albinism to inform and raise awareness of the condition.

2.4 Allow pupils with albinism to wear sun protective clothing including long-sleeved uniform, sunglasses and wide-brimmed hats as part of their national school policy.

2.5 Allow extra time for learners with visual impairment (including children with albinism) to undertake tests and examinations as part of their national school policy.

2.6 Produce educational materials including text books and exam papers in larger print, to benefit pupils with visual impairment.

2.7 Liaise with parents and the entire community to protect the safety of children with albinism walking to school through security measures including ‘walk to school peer groups.’

"Then some students were fearing me. They could fear sitting with me on the same seat, sharing things with me but there was one teacher...He could tell them "he is like you regardless of the colour" and he helped me well to study…I still remember that guy though he died. He encouraged me that though you're different in the colour, we shall be with you."

Paul (man with albinism talking about his experience at school)

"Now when I could drink water in a cup my fellow pupils couldn't use the same cup again, if I eat food they could restrict them from using the same plate."

Betty (teenage girl with albinism)

"The Headmaster strongly told my daddy that they will not allow me in school, rather he should look for albino school or any other schools. My daddy was stranded and one of the teachers felt sorry for us and told the Headmaster "Mr. Headmaster, why don't you allow this boy to study, he is also a human like us?""

Sharik (teenager with albinism)

"When I was at school, many children used to run away from me and they feared me a lot. They couldn't eat with me, they could just throw me food or eat and leave for me the remains."

John (man with albinism)

"We had a teacher who used to chase me out of class whenever I entered; saying "you're not supposed to be here", one day she beat me and chased me out of class."

Eunice (woman with albinism)

"People with albinism face a number of challenges, one, most of them are short sighted, so they…can't clearly see on the blackboard. Two, they are discriminated; some children tease them. Some of the children with albinism feel out of place while at school, they lose self-confidence because their fellow children don't involve them in their activities."

Fred (Religious leader, without albinism)

"The teacher also called the boy weird names like a ghost."

Joel (father of two children with albinism)

"In our communities, most the of schools are primary and the secondary schools are few…This forced us to look for those schools where they are of long distance from our homes, yet I fear to move alone early in the morning because of much threat attached to albinism condition - and at the end of the day you reach late and you are punished."

Paul (teenage boy with albinism)

"I am a day scholar, ever since my Daddy lost his job...Long distance from school to home… I was walking one day going to school then I heard a whispering sound saying "She is there, catch her, I will trap her this side". I started to run away but in the process of running away, I knocked myself and fell down, this was due to short sightedness. With God's mercy they did not see where I had fallen...I reported to my Dad but he was like "what can we do now my daughter? There is no way. God must just help us with such situations".

Betty (teenage girl with albinism)

Recommendations 3. Health

Stakeholders including Ministry of Health to:

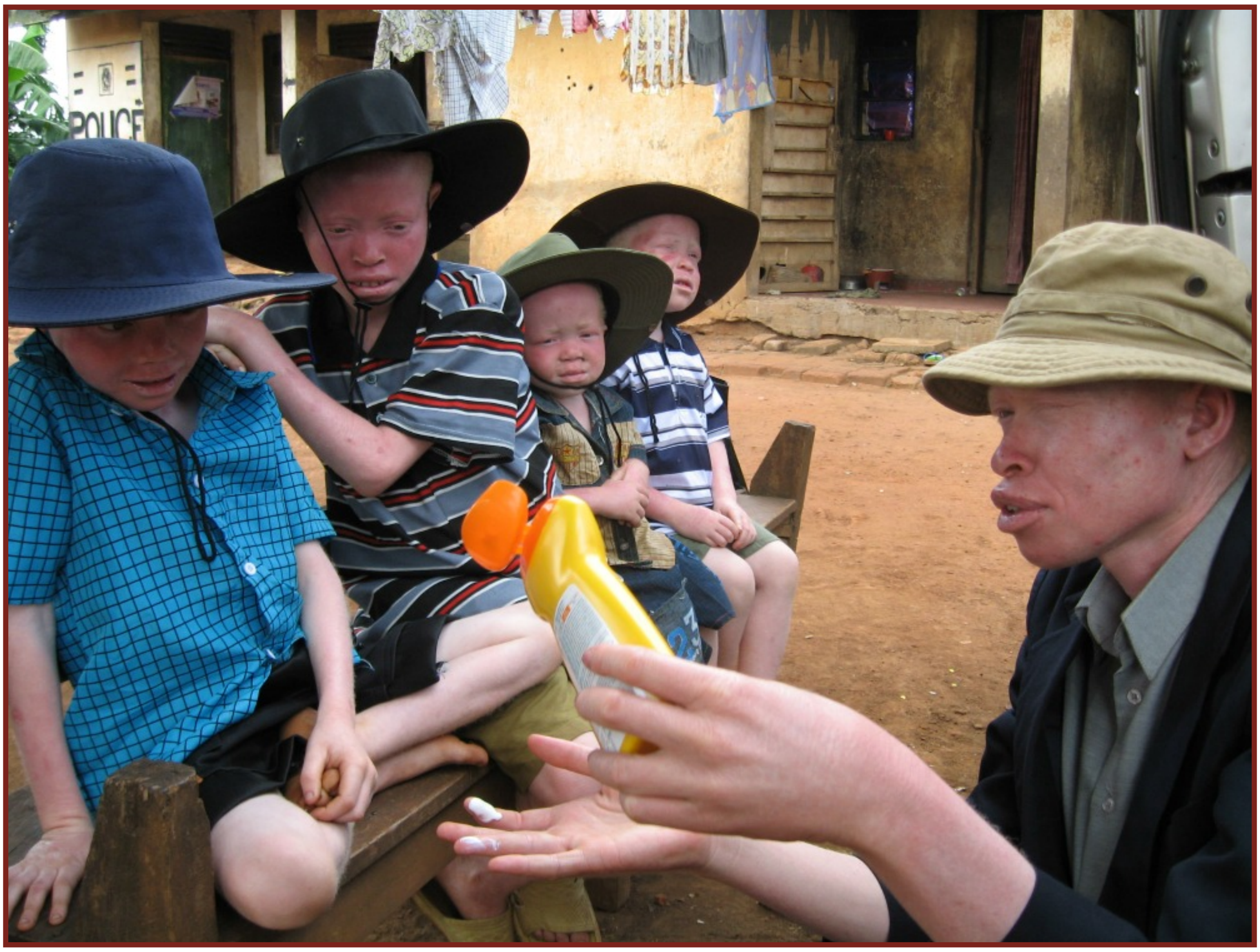
3.1 Include albinism in the training of all health care professionals.

3.2 Include the specific needs of people with albinism within the national Minimum Health Care Package (MHCP), with national budget allocation for high SPF sunscreen and low vision aids.

3.3 Include the needs of people with albinism in the state cancer policy. This should include making cryotherapy available across the country to treat early stage cancers and ensuring that hospital equipment is working and increasing the number of dermatologists nationally.

3.4 Co-operate with the Uganda Revenue Authority to continue tax and duty waiver on sunscreen imports for people with albinism and ensure this agreement is long-term.

3.5 Endorse and support in-country production of high SPF sunscreen.



ALBINISM ACTIONS for CHANGE

HEALTH

- Ministry of Health to include needs of people with albinism within the **national minimum health care package** and **train health workers**
- Uganda Revenue Authority to make permanent the **sunscreen tax and duty waiver**
- Include the needs of people with albinism in the **State Cancer Policy**
- Ministry of Health to endorse local production of **high protection sunscreen**

BIRTH

Provide **simple information and support for families** of new-borns with albinism

Train **midwives** and **other health workers** in albinism awareness

Equip **traditional birth attendants** and **village health teams** with albinism knowledge

EDUCATION

Ministry of Education to train **teachers** in education, health & social issues concerning albinism

Include albinism in school **Science syllabus**

Allow learners with albinism to **wear sun protective clothing**

Safeguard learners with albinism when **walking to/ from school**

Provide **visually impaired learners** (inc. those with albinism) with large print materials and more time in examinations

EMPLOYMENT

Promote **employment** for people with albinism, accommodating their visual impairments and need for indoor work

Take action against **employers** who discriminate against people with albinism

Ensure people with albinism have equal access to **economic empowerment** and **social protection programmes**

CAMPAIGNS AND PUBLIC AWARENESS

Work with people with albinism to **raise awareness** of albinism nationwide through public information and media campaigns

Promote the **rights** of people with albinism with reference to national and international laws and resolutions

JUSTICE & SECURITY

- Ugandan Government to state publicly that **perpetrators of violence** against people with albinism will be **brought to justice**
- Implement **laws and regulations** relating to violence against people with albinism including in relation to witchcraft and traditional medicine
- Enable people with albinism to access justice by provision of **legal aid, training police / judiciary** and **publicising prosecutions**

“The biggest challenge we face in our lives; the sun affects us, it affects our eyes, the skin.”

Emma (woman with albinism)

“With hot sunshine my skin went bad with many wounds.”

Latifu (teenage boy with albinism)

“If it’s farming, I cannot over stay in sunshine the way other people do, actually it can cause skin cancer to me. Actually if I go to dig at 7am, I take 2 hours, I make sure at 9:00 am, I’m leaving the garden.”

Paul (man with albinism)

“They have continuous challenges of the skin, and not wanting to be under the hot sun and then wanting the sun glasses of course, and the lotions that are supposed to protect their bodies against the sun.”

Julius (Equal Opportunities Commission, without albinism)

“So the government I think needs to do some more, maybe providing tax waivers and incentives to organisations that make cosmetic products in Uganda to begin to manufacture those protective gear that people with albinism need (such as sunscreen).”

Joseph (Country Director ADD International-Uganda, without albinism)

“Their skin is not good when they live under the sunshine. So I learnt that persons with albinism all the time must be under the shade so that their skin is protected well and they must put on long sleeved clothes so that the sun doesn’t heat them hard especially the skins. They must put on wide brimmed hats such that their skins around the neck, the ears are protected. “

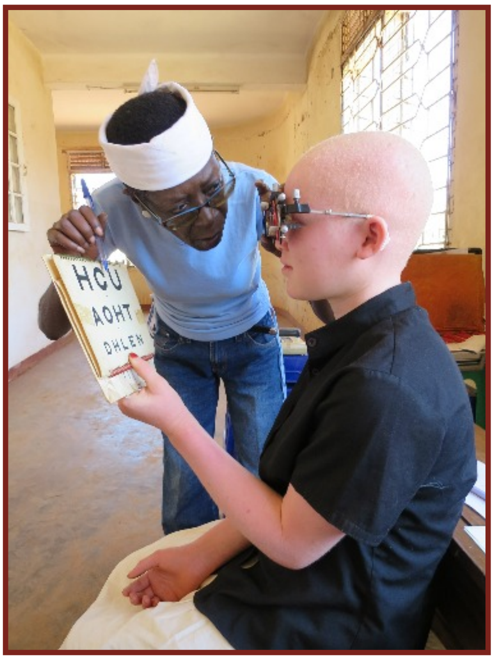
Sherry (woman without albinism)

“In the hospitals, once, the nurse feared to inject one of the boys with albinism. About three nurses kept on asking each other how they would inject the boy. His father called me and told me the whole story. When I reached them I told them that the only difference with the albinos is that their skins are somewhat hard. But if you’re a real nurse, just go on injecting them. “

***Councillor representing persons
with disabilities in local government***

"I had a problem of short sight. … I think short sightedness has caused a lot of deterioration towards my education. Sometimes teachers can draw on a chalk board to show an experiment, but due to short sightedness, this made (me) to perform poorly in such subjects."

Paul (teenage boy with albinism)



"They [the Medical School] never had that in the syllabus….I gave them some tips on albinism and am spreading it to some other medical students. Otherwise it's not in their syllabus."

Ngobi Manson (Dermatology Officer and Medical School Lecturer)

Recommendations 4. Justice, Security & Public Awareness

Stakeholders including relevant Ugandan Government Ministries to:

4.1 Issue an immediate, high-profile statement expressing determination to ensure that the perpetrators of acts of violence against persons with albinism are brought to justice.

4.2 Review legal and regulatory frameworks to ensure they encompass all aspects of attacks against persons with albinism, including in relation to witchcraft and traditional medicine.

4.3 Enable victims of attack to access justice. This should include educating persons with albinism on their rights, provision of legal aid, educating law enforcement and judicial professionals on albinism and publicising prosecution to deter offenders.

4.4 Work with organisations of persons with albinism to raise awareness of albinism nationwide, through public information and media campaigns.

4.5 Promote rights of people with albinism through existing provision in the UN's 2013 Resolution on the Rights of Persons with Albinism, the Uganda Constitution, Children's Act and Local Government Act which calls for 'affirmative action in favour of marginalized groups'.

”On the side of witchdoctors, they surely hunt these people so we must take serious note on this.”

Jamal (father of child with albinism)

“Previously there were accusations that children with albinism are witch hunted, most of the families keep their children with albinism at home. The insecurity around children with albinism is the major problem.”

Paul (local councillor)

“People just suspect and want to use body parts of persons with albinism for traditional practices but…those people are the same as I am.”

Fred (religious leader)

“We came up with communicational manual which we gave a title, “No magic, no witchcraft, just albinism”… People think that their condition is contagious, others (that it) involves witchcraft…some think that their body portions have magic in them that they can possibly bring more wealth and that is appalling.”

Julius (Equal Opportunities Commission)

“I learnt from a family of five children (with albinism)…that they were having sleepless nights because bad people wanted to steal these children and sacrifice them and get body parts. They are lied to that these body parts have magical powers to give wealth, to help you become important in society and all these things.”

Gertrude (journalist)

“They are also at risk [family members of people with albinism]…The witchdoctor directly confronted this parent, “sell us your child, we can give any amount you want”. He said, “No I cannot give you my child”. After knowing their plan to kidnap his 3 year old daughter with albinism, he took his family away from that village for their safety and he came back to protect his home and also to go on with his activities. So within few days the witchdoctor came with some people who helped in killing. The following day community members found him slaughtered and the blood was in a bucket and it was also spread around his banana plantation beside his house. His head was missing, the remaining body was buried.”

Peter (man with albinism)

“A traditional practitioner came to my home...My wife came and told me someone wants the hair of my children…He was giving me 30,000 Uganda shillings in return for the hair. I reported the issue to police and he escaped as the police tried to chase him...I was willing to invest anything to see justice prevail…It’s a pity some policemen don’t intervene in such issues. I didn’t get annoyed because he [the traditional practitioner] wanted my child’s hair but because he instilled fear in my child. “

Joel (father of children with albinism)

“These men would just use them and leave them there with a myth that when you have sex with an albino person, you get rid of HIV…this has caused the young girls to get HIV and have unwanted pregnancies.”

Sherry (woman without albinism)

“I met girls who had been raped and defiled. Young girls living with albinism because their tormenters think they have magical powers, if they sleep with them, they would probably get cured of HIV, they will get rich.”

Gertrude (journalist)

“I urge the community to love these people, we produce them, we marry them and produce children with them, we keep them, so they need to be cared for. We need to love them as we love the rest of the people because if we don’t stop the isolation, we have cases to answer before God…Some people segregate and we really want to tell people in our country that God created everyone in his own image and all people created no matter how he/she looks, is an image of God.”

Fred (religious leader)

“I started understanding the cause. I realised they lack melanin but I knew in my understanding that they are normal people, only lacking that pigment. So it’s only the colour of the skin that differs. … . In Islam, one with albinism is not different from other people.”

Adam (religious leader)

“The difference is the skin, not anything else. They have an upright mind, they have feelings like any other person…Secondly, parents of children with albinism please treat the children the way they are because these children are like any other children in the community, love them.”

Sherry (woman without albinism)

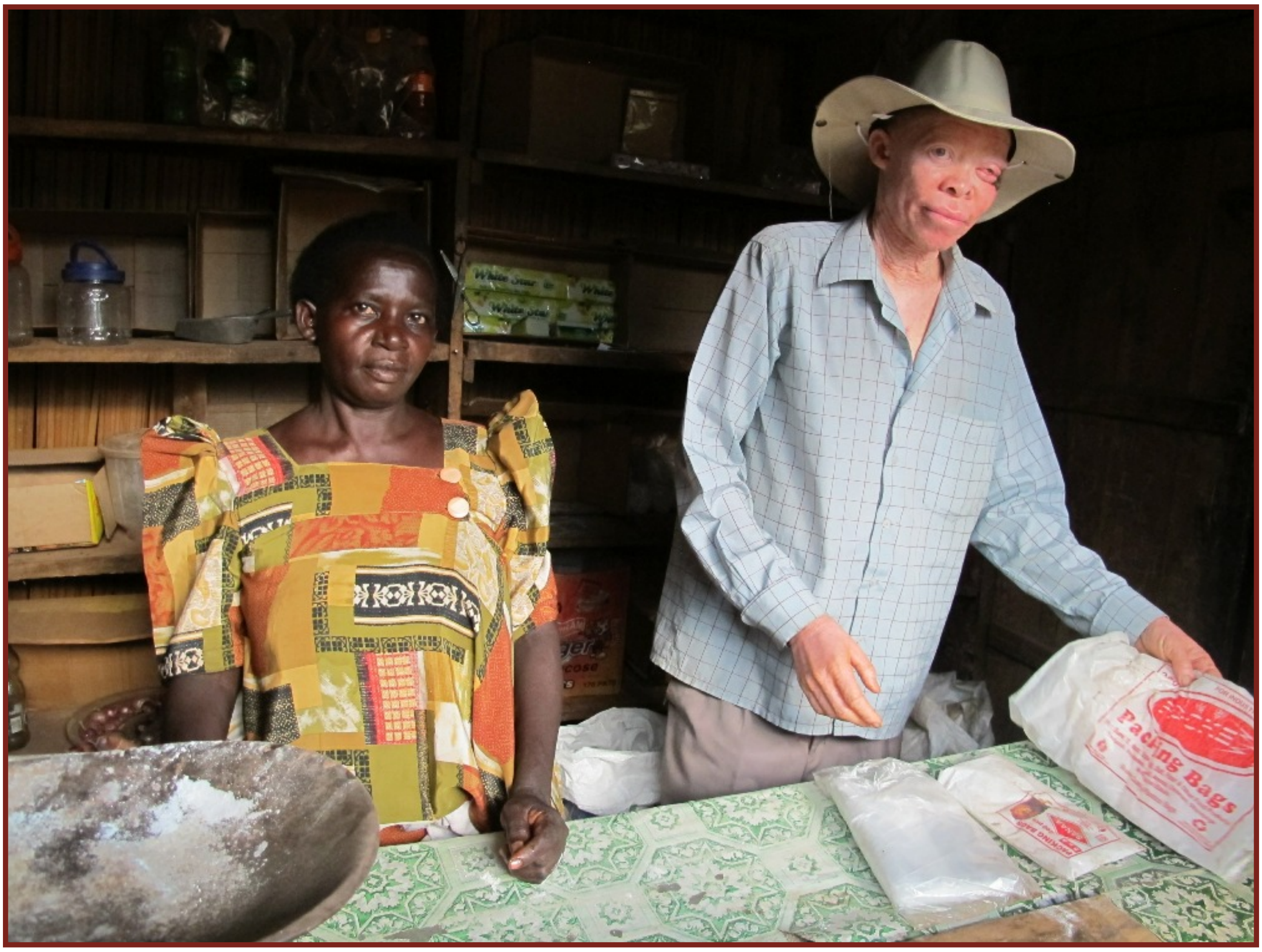
<u>Recommendations 5. Employment</u>

Stakeholders including relevant Ugandan Government Ministries to:

5.1 Promote access to employment for people with albinism, including accommodating their need for indoor work and access to disability grants, in line with the Government's goal 'To ensure that all Ugandans enjoy better standards of living, especially the disadvantaged and vulnerable groups'.

5.2 Take legal action under the Persons with Disabilities Act when employers discriminate against persons with albinism.

5.3 Ensure that persons with albinism have equal access to economic empowerment and social protection programmes such as the Uganda Women Entrepreneurship Programme, the Uganda Youth Livelihood Programme, the Disability Special Grant, and the national health insurance scheme. This should include disseminating information through organisations of persons with albinism, training employers and officials on the rights of persons with albinism and monitoring representation of persons with albinism.



“People living with albinism live in so much poverty. People don’t give them jobs because they think you (PWA) cannot work. It’s not true.”

Gertrude (journalist without albinism)

“The biggest challenge I have faced is most albinos never got the chance to go to school and it means they don’t have good jobs or white collar jobs.”

Elizabeth (woman with albinism)

“People with albinism often lack opportunities to take part in economic activities on an equal basis with other Ugandans, because of frequent discrimination from employers and others in the local economy. Many live in poverty.”

Peter (man with albinism)

“Discrimination at work place, like once there was a school we went with John [who has albinism] seeking for a job. I told one of trustees of the school about my friend with all qualifications needed for teaching and I was allowed to come along with him. On reaching we found her and she asked “Is this the person you have been telling us that you have? Do you want to scare our children? We won’t accept him, rather look for someone else.”

Emma (friend of person with albinism)

“Some don’t want to buy what we sell, just because an albino has touched the clothes. I cannot set up a business because I have a fear people won’t buy and if I go to search for a job, people don’t want to employ me, maybe they think I can’t perform. … we need money to sustain our lives.”

Lillian (woman with albinism)

“Now, as far as this is concerned that is fighting poverty as I may sum it, for us, our role as the media; one, we are going to say, people living with albinism have got a deal to begin sensitising other people living with disability on how they can get out of poverty. And this is going to be through continuous stories that we shall publish in the newspapers.”

Kirunda (journalist)

"At first people didn't like me, because they said "this one does not see well, he is visually impaired, how can that one support the education of our children?"…Some community members said I was a curse so I could not help their children to be blessed on the side of education but when they saw me participate in different activities at school, training the choir, teaching well, aaaah!, they started believing that I could work as the rest of the teachers."

Paul (teacher with albinism)

"When I was about 20 years old (I met) a girl with albinism; she shocked me; she was working at the petrol station; when I realised she did work just like any other person, meaning that she could do all other people can."

Charles (Councillor for people with disabilities)

"So thanks to the government of Uganda, that they brought the disability grant. Persons with albinism in Mbale have participated; they got goats. Some of them have produced, multiplied, some of them have bought cows and we believe soon they will also have their own land; that after selling their cows, they will be able to purchase land also be independent not to depend on their parents."

Sherry, Co-ordinator for an albinism foundation in Eastern Uganda

"My experiences about earning an income would have been very good if I had capital to set up a small business such as selling silver fish, tomatoes, eggplant."

Oliver, man with albinism

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