

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

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Recommendations extracted from the research : An investigation into the impact of stigma on the education and life opportunities available to children and young people with albinism in Tanzania and Uganda

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## 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 were launched at the conference 'We are Human Too!' on 24th November 2017 at the Africana Hotel, Kampala, during which stakeholders had the opportunity to reflect on their roles in implementing them. The quotes featured in this report are from the research respondents.

*Hadiija, grandmother of a young child with albinism told us: I would request to help us implement our views. I request what we have shared be worked on and implemented.*

### 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.**

*Amina (mother of child with albinism): 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.*

*Lydia (mother of child with albinism): ...the father of the child has never surfaced ever since I delivered, I look after the child myself.*

*Sharik (teenage boy 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.*

*Hasifa (woman 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.*

*Isa (father of children with albinism): On giving birth to my first born with albinism, people who came to see me scared me a lot; asking me why I gave birth to such a child...Some people encouraged me while others advised me to chase the wife but I kept on refusing since I love my wife. My wife later gave birth to the second child without albinism, so I continued being strong. After a year she gave birth to twins and both with albinism, so people again were shocked and stressed I should chase my wife.*

*Sherry (woman without 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.*

*Wilberforce (man with 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.*

*Amina (mother of child 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."*

*Elizabeth (woman with albinism, a mother of a child without albinism): Said 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.*

*Moses (father of boy with 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.*

*Peter (man with albinism): My parents were God fearing people and God helped them and they loved me as I was.*

*Julius (Equal Opportunities Commission): 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.*

## **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’.**

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

*Betty (teenage girl with albinism): 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.*

*Sharik (teenager 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?”*

*John (man 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.*

*Eunice (woman 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.*

*Fred (Religious leader, without 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.*

*Joel (father of two children with albinism): The teacher also called the boy weird names like a ghost.*

*Paul (teenage boy 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.*

*Betty (teenage girl 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".*

## **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.**

*Emma (woman with albinism) The biggest challenge we face in our lives; the sun affects us, it affects our eyes, the skin.*

*Latifu (teenage boy with albinism): With hot sunshine my skin went bad with many wounds.*

*Paul (man 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.*

*Julius (Equal Opportunities Commission, without 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.*

*Joseph (Country Director ADD International-Uganda , 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).*

*Sherry (woman 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.*

*Paul (teenage boy with albinism): 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.'*

*Ngobi Manson(Dermatology officer and medical school lecturer: 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.*

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

## **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'.**

*Jamal (father of child with albinism): On the side of witchdoctors, they surely hunt these people so we must take serious note on this.*

*Paul (local councillor): 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.*

*Fred (religious leader): 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.*

*Julius (Equal Opportunities Commission): 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.*

*Gertrude (journalist): 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.*

*Peter (man with albinism): 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.*

*Joel (father of children 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.*

*Sherry (woman without 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.*

*Gertrude (journalist): 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.*

*Fred (religious leader): 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.*

*Adam (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.*

*Sherry (woman without albinism): 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.*

## **Recommendations 5. Employment 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.**

*Gertrude (journalist without 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.*

*Elizabeth (woman with 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.*

*Peter (man 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.*

*Emma (friend of person 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."*

## RECOMMENDATIONS FROM TANZANIA

Drawn up by Standing Voice with input from the NELICO team and support in the field from Dr Patricia Lund of Coventry University. These recommendations were contributed by members of the Tanzania Albinism Society (TAS), with local government input.

Below we have compiled key recommendations presented to the research team by research participants present at the dissemination events in November 2017. These participants primarily consist of TAS members in Geita and Ukerewe, our two research locations, as well as local government.

Recommendations are categorised by recurrent theme for clarity and practical application. Namely:

- Implementing progressive policies and laws Promoting access to education
- Promoting access to health services
- Promoting financial stability and employment Promoting security
- Building awareness
- Promoting political inclusion and legal capacity Improving sustainability and future planning

In addition, as suggested by TAS members present, we have stratified the intended responders to these recommendations as follows:

- National government [TIER 1]
- Local government in coalition or collaboration with the community [TIER 2]
- People with albinism and their families [TIER 3]
- Non-Governmental Organisations (NGOs) [TIER 4]

### **THEME: Implementing progressive policies and laws:**

#### **[TIER 1] National government**

Ensure meeting the challenges faced by people with albinism is maintained as a government priority, despite inevitable competing demands on the state. Specifically: policies, laws, and services should be proportionate to the extent of the challenges encountered by citizens who have albinism.

People with albinism should by law obtain free healthcare in Tanzania, and this should translate into properly implemented free healthcare for specific health challenges related to albinism.

**THEME: Promoting access to education:**

**[TIER 1] National government**

The Ministry of Education should incorporate albinism awareness programmes into primary and secondary syllabuses.

National government should implement measures to address reported poor rates of school enrolment among children with albinism.

Ministry of Education should promote access to vocational college for people with albinism.

**THEME: Promoting access to health services:**

**[TIER 1] National government**

The national government should allocate budget for sun lotion.

Efforts should be made by national government to ensure people with albinism have equal access to mainstream health training and awareness services.

**[TIER 2] Local government in coalition or collaboration with the community**

Special units for people with albinism should be established in hospitals under the authority of local leaders.

**THEME: Promoting financial stability and employment:**

**[TIER 1] National government**

Cash support made available to poor households, such as support administered by the Tanzania Social Action Fund (TASAF), should prioritise people with albinism within these schemes. This prioritisation should not be impeded upon based on the assumption that complimentary NGO support exists for people with albinism.

Consideration at the national level should be given to financial assistance for people with albinism, which may take the form of tax credits or a disability allowance.

**[TIER 2] Local government in coalition or collaboration with the community**

Local councils should promote access to council loans for people with albinism.

**[TIER 3] People with albinism and their families**

Communities should assist people with albinism to be visible and active members of their society.

People with albinism should actively seek employment and related ways to achieve and maintain financial stability. It is recommended that people with albinism keep pursuing opportunities even if people attempt to isolate them. Testimony reveals the result is commonly that the individual becomes valued and community acceptance follows.

### **[ALL TIERS]**

People with albinism's access to start-up funds should be promoted, along-side training in financial management.

### **THEME: Promoting security:**

#### **[TIER 2] Local government in coalition or collaboration with the community**

Local Government Authorities should promote effective security measures which do not infringe upon the health or wellbeing of people with albinism in their area. Local government initiatives must be developed that enable people with albinism to continue interacting with their community while remaining safe; secure but free and non-restricted.

Local Government Authority security measures should be based upon consultation with people with albinism.

#### **[TIER 3] People with albinism and their families**

Community should promote effective security measures which do not infringe upon the health or wellbeing of people with albinism in their area. Community initiatives must be developed that enable people with albinism to continue interacting with their community while remaining safe; secure but free and non-restricted.

### **THEME: Building awareness:**

#### **[TIER 2] Local government in coalition or collaboration with the community**

Local government should contribute to awareness-raising ensuring the younger generation are better informed, and that this momentum is built upon over time.

#### **[TIER 3] People with albinism and their families**

People with albinism and their families should seek to understand and accept albinism, as a catalyst for shifts in wider community perspectives.

Family members of people with albinism should be educated about albinism when a child with the condition is born, to enhance their own ability to pass this knowledge on to their children and wider community.

It has been effective in some cases for people with albinism to join community groups, which provide entrance points for inclusion in the community.

### **[ALL TIERS]**

All stakeholders should tackle misconceptions, such as that people with albinism have weak skin and therefore cannot do manual tasks.

**THEME: Promoting political inclusion and legal capacity: [TIER 2] Local government in coalition or collaboration with the community**

**Ward Councils and Village**

Councils should ensure there is a committee place reserved for a disabled person, to ensure adequate representation of persons with disabilities in decision-making.

**[TIER 3] People with albinism and their families**

By people with albinism seeking to be part of regular committee groups, they can be contributing to any issues that are relevant to their lives and therefore achieving social inclusion.

**THEME: Improving sustainability and future planning:**

**[TIER 1] National government**

The government should avoid dependence on NGOs whose future presence cannot be guaranteed.

National government should work progressively with NGOs. The government should develop its data collection on the population distribution of people with albinism.

**[TIER 2] Local government in coalition or collaboration with the community**

An accurate record of people with albinism (stratified by gender and location) should be recorded at District and Town levels, with district and town councils responsible for collecting this data on an annual basis. This compliments less regular census data collection.

**[TIER 4] Non-Governmental Organisations (NGOs)**

Programmes that NGOs implement should be incorporated into national-level government systems.

NGOs should focus their efforts on linking people with albinism to the government, providing people with albinism with direct channels and platforms to address the government.

NGOs should give project feedback to the government, so the government can benefit from findings.

**Recommendations on data collection and education**

On a visit to a secondary school on Ukerewe Island with the Standing Voice team, with prior approval from the local educational authorities, Lund spoke with the Biology teacher and viewed the Biology syllabus for secondary school (Forms I to IV) of 2005 produced by the Ministry of Education and Culture, The United Republic of Tanzania as well as that for Advanced Secondary Education (Form V-VI) dated 2010. Among the teaching/learning

Strategies were a plenary discussion on the various types of genetic disorders which lead to a specific objective that students should be able to explain their causes and effects. An assessment criterion for this objective was How accurately can the student explain the causes and effects of genetic disorders?

The worked examples in the supporting handbook included albinism as an example of an inherited, recessive condition, with worked examples showing the possible genotypes of progeny from parents with or without albinism. While largely accurate, these would benefit from revision to present genetic information a more easily accessible fashion and to update the information. For example, this document states '1/20 000 can be an albino' which is not true for Tanzania where the census in 2012 data indicate the frequency is about ten fold higher than this.

The explanation about albinism is clear and concise, with minor inaccuracies as shown from the quote below. It is good to indicate this is a condition that occurs in all animals the phenotype presented with light skin, hair and pink eyes is the appearance of someone with another type of albinism and is not the classic phenotype common in east African populations which is usually characterised by some residual pigment, with hazel or blue (not pink) eyes : Albinism is the absence of pigmentation in animals and plants. In (sic) human albinos are characterised by lack of melanin which is responsible for the dark colour of the skin, hair and iris of the eye. As a result the person (albino) has light skin, white hair and pink eyes. Albinism is an inherited disorder and is caused by a recessive gene.....

The Tanzanian Ministry of Education and Culture is to be applauded for including albinism as a study topic at secondary school. There is evidence from our study that education and awareness about albinism has improved in recent years; this training at secondary school is one of the educational initiatives supporting this change.

**The following recommendations are made to support the learning of albinism in Tanzania:**

To include a simplified version of albinism for younger children so they are introduced to the idea of albinism as an inherited condition early in life

To introduce suitable teaching aids to support the Children's booklet which has been translated into Swahili and other materials developed as part of this project would provide suitable teaching aid

To revise the section on albinism on the next revision of these booklets To continue to include data gathering on the frequency and distribution of albinism to update the 2012 census data; there is evidence that this is being done at local district and town level in Geita

The project team did not investigate the teaching in schools in Uganda; ideally this topic, of such importance to the region, should be integrated into the biology syllabus of all countries in east Africa.