

# Living with Albinism: Stories from Malawi May 2013

Lund, P. (Editor), Simbota, I.D., Kassim, I. Mnandi, E., Machinjiri, E., Chimodzi, V., Thelele, M., Massah, F.

## AIMZ: Albinism in Malawi & Zambia

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# AIMZ: Albinism in Malawi & Zambia

## Promoting inclusive education for children with albinism

Young people with albinism, their families and their teachers talk about educating learners with albinism at school



Boniface Massah meets a young boy with albinism while on field work for AIMZ in Malawi.



Shakira Zibel, a young Malawian woman with brown albinism, uses an umbrella to protect herself from the sun.

### The AIMZ project

Using radio drama and mobile phone messaging to:

- educate communities about albinism and
- train teachers on techniques to accommodate children with albinism in mainstream schools

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## **Ian Desmond Simbota**

A talented young scriptwriter who is writing radio dramas for AIMZ in Malawi, to help train teachers around albinism issues.

This is his account of living with albinism.



Ian with his friend and co-scriptwriter on the radio dramas, Michael Nyirenda

## Thought from a confused mind: My true story

After 25 years of my life in this world I stand to tell the story of my life both negative & positive, showing how hard is it to live in Malawi with a disability, the hot & cold objects I have touched in sacrifice to see myself alive today.

Am the second born son in a four-children family, two with albinism & two without. We grew up in a single parent family with a mother who raised four children, bringing us to school, working as a cleaner. She used that little money to try reach her dream of seeing us (at school). That was after she broke up with my father who didn't like our disability & thought my Mum was the problem. He then brought a decision that we have to be killed, but my Mum went against it, up until they divorce. But the funny story about it is that when my Dad went to marry another woman the first twins they had were also with albinism. So they (my parents) divorced way back that I didn't even see his face & we just heard that the man died & nobody within my siblings saw his face.

I remember to have stopped going to school, not because of school fees because primary school in Malawi is for free, but it was the beginning of disability challenges for me at school, then it was very bad. Discrimination & teasing were started by the teacher, then to students, a situation that was very hard to handle especially at a younger age. Having abandoned school two times the third time, that's when my Mum took a step to go & talk to the head teacher. They disciplined the teacher, they started punishing the students who offend my disability & they gave me freedom to be wearing trousers instead of normal uniform which is short sleeved shirts & short trousers. I could put on a hat around campus. It took a long time to find freedom because I was the only one with a disability of albinism.

I always aim at standing as the example to my friends with albinism & I consider my Mum as my role model for the courage she took to raise four children with less resources.

## Idrissa Kassim

### A young man with albinism attending secondary school talks about his family and his education:



In our family we are six children and I am the last born, the only one with albinism.

For school it's only the first born named White, the third born Rose and I who went to school; the others, no, for my parents it was difficult. They could not support them to go to school. White reached form 4, my sister Rose dropped out in standard 4 and I am now in form two.

At primary school my friends were giving me different names and saying bad things which I did not like, but still others, like my sisters, were encouraging me despite all this, by telling me that I must still go to school. My mother worked to pay for my school fees. She used to give me at least two buckets of groundnuts, and said to me *'My son get these groundnuts for yourself to support you at school.'* I used to roast the groundnuts and sell them to get money during my holiday. I recall during that time I was not even bothering my mother- I used to buy soap, exercise books for myself. I could budget my money well. That's why I am here now.

Although I sat in front in class but still I face problems to see well. So my friends could write notes for me or read on the board for me, others borrowed me their notebooks to copy notes at home.

At Secondary School many people encourage me to do my school. The teachers help me by telling me to wear a hat and also do all the organization for my school fees; they do it so that I get education, so they ask different organizations to support me.

## **Idrissa has the following message to teachers on how to support learners with albinism at school:**

- Support us at school by writing big things on the board and also borrow (lend) us notes to copy at home during our own time
- Advise us to wear hats so that we do not get sun burns because it's hot here
- See us as people; do not stigmatize us or call us bad names
- Take part in raising awareness on albinism



## **Edith Mnandi**

### **One of Idrissa's teachers, describes her role:**

I need to:

- encourage him to work hard and not to leave school
- encourage the parents so they can also take part in encouraging him to education
- encourage fellow students to help him when they see he has problems.

Eliza is an advocate for people with albinism and works for Malawi Council for the Handicapped (MACOHA)



Extract from Eliza's poem **The Voice from an 'Albino'**

Society, please don't burst with questions. People with albinism are just the same as you are. We can do what you can do and we eat what you eat. If you understand this you will never be led astray. Yes, you will never be wrong in the presence of God.

The Voice of 'Albino', yes, it's our voice.

## Elizabeth Machinjiri

### A woman living with albinism tells how support from her parents and teachers encouraged her at school:

I once left school because of short sight- I was failing to see the chalkboard, failing to read the text book due to the small print and failing to participate because of mocking by my fellow students and some teachers.

At first albinism was strange to the country, seeing someone with albinism caused them to be laughed at. My mother was being mocked by her friends: *'This child, you are wasting your time sending her to school. You will never benefit from her. This is a child without hope'*. My mother was frustrated and drawn down and had no interest. She said to me: *'Stay inside the house, I will give you everything you need. Don't worry, it is God's will.'* Inside the house I was thinking, why me?

My father said: *'Let us go to discuss with the headmaster and find a way, how you will be learning there.'*

'My father loved me; both (my parents) were happy with me. He went to discuss with the head and find a way. They agreed that my niece (in the same class as me), will be assisting me, sharing the notes. By the end of that year I got number one in class.

While I was in form 4 I had two friends who were teachers; they were happy to teach me, after classes they came to my home and teach me voluntary, saying: *'There in class you are failing to see everything so we are helping you to achieve'*, so that I should be able to sit for the examination (in form 4).

I am saying to all those who have children with albinism that this child is a child like anyone else. Send them to school, do everything which is good for them, so they might enjoy their rights as a human beings. For this, they might contribute to the nation.



## Virginia Chimodzi

### A young teacher living with albinism recalls her educational journey:

I started standard 1 and then I was not realizing that I have low vision. I realized when I was in standard 4. In the first three years I thought that everyone has the same vision as I have. I was unable to see on the chalkboard and then after I realized that I have low vision, then I started following the teacher, saying *'Can you borrow me some books?'* I told him that I have a problem to see on the chalkboard and then he was giving me the book.

I was then getting position one from standard 5 up to standard 7. I was selected to Lilongwe Girls secondary school and there I had problems in maths. I was trying with other teachers but it was failing. Then came another teacher when I was in form 3 and said *'I will be teaching form 3 because I want to assist Virginia'*. He was teaching me mathematics in class and thereafter we were sitting under a tree and he was helping me after class. In 2009 I was selected to go to Kasungu Teachers Training Centre.



Virginia at her home village (above) and at the school where she is a teacher (left)

# Mussa Thelele

## Talks about his family and experiences in education:

My Dad and Mom are alive and we are six children in the family. I am the fourth born and only one with albinism. I have been raised up by my Mom. There was some conflict in the family after my birth, so my Dad left my Mom. My Mom remarried and now I stay with my step Dad. My Mom is a farmer; she grows rice and cassava. I do help her in the farm often in the morning at 5 am.

I am in standard six and I have been at this school since 2007. I did my class 1-5 at home in the village. In the village my school was very difficult, I could not see well and the teachers were writing very fast. The time I finish writing they were rubbing the board to write more notes. It was hard because I was slow in copying the notes due to my poor sight.

The teacher could not wait for me to copy the notes. They were not even able to give me notes to copy at home. It is when I was told by the teacher that I need to go to a special school, not at this school, because I have my own place in a special school. At this school (Resource Centre attached to a mainstream school) my friends do help me in class, so it's easy for me to do well. My friends also read out notes for me from the chalkboard if I can't see them well.

Mussa has a variant form of albinism called **brown oculocutaneous albinism**.

Although those with this type of albinism have some pigment, they still suffer from low vision and sun-induced skin damage.

Dr Patricia Lund, Coventry University



During examinations they are giving us print but it is in small font. I do read well when I hold the paper close in my hand. That's better than writing from the board.

## Mrs Felista Massah

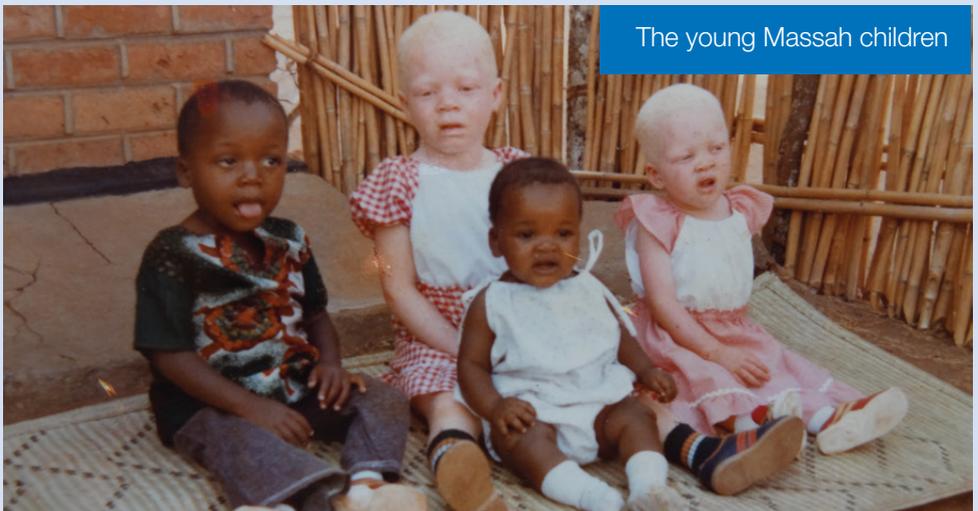
### A mother of three children with albinism talks about her experience in educating them:

I realize that they (children with albinism) are going to a blind school when I go to study for ophthalmology in 1994 so I said: *'Why are these children coming to a School for the Blind? My children (with albinism) are not at a blind school, but they are doing fine. They are in the normal primary school.'*

Then we were trying to counsel them at the School for the Blind: *'See, they can read at a near distance (if they hold material very close to their eyes). I have got these children (with albinism), but I have never thought to take them to the Blind school and learn Braille.'*



Mrs Massah and one of her sons, Bonface; she counsels mothers in how to take care of their children with albinism



The young Massah children

Children with albinism can see to draw if they are allowed to bend close to the paper



Previously, some children with albinism were educated in Schools for the Blind in Malawi and taught Braille as there was a mistaken belief that they go blind.

Dr Patricia Lund, Coventry University

Most children with albinism in Africa are born to parents who are both black; they are each carriers of the 'albinism' gene and have a one in four chance of having a baby with albinism.

Dr Patricia Lund, Coventry University



A child with albinism holds an object close to her eyes to examine it

Albinism is associated with low vision, not blindness

## Working with The Albino Association of Malawi (TAAM)

**Boniface Massah** (Project officer and the Chair of TAAM) with **Dr Patricia Lund** of Coventry University, UK (Project Manager of the AIMZ project)

We are working with schools, teacher training colleges, educational officials and other partners in Malawi on the AIMZ project, including:

- Ministry of Education, Science & Technology
- FEDOMA: Federation of Disability Organisations in Malawi
- MACOHA: Malawi Council for the Handicapped
- Chancellor College, Zomba
- Catholic Relief Services
- Radio Maria
- ZODIAK Radio
- Nkhotakota Community Radio Station
- The Story Workshop



### Contact us!

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