

Barriers to access: factors limiting full participation of children with albinism at school in northern Malawi: Part 1

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Barriers to access: factors limiting full participation of children with albinism at school in northern Malawi

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Field report on visit to Malawi in September 2012

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A man with albinism in northern Malawi sits in front of his shop in Karonga market.

Read his story on pages 20-21

Aims and context of the study

Children with the inherited condition albinism in Africa lack pigment in their hair, eyes and skin and are an especially vulnerable group: they are 'white' in a black community, visually impaired, highly susceptible to sun-induced skin damage and suffer social stigma and rejection.

The main aim of this study was to identify factors influencing access to and participation in education for young people with albinism in five rural villages in northern Malawi. An additional aim was to document local community beliefs about albinism which may impact on their educational opportunities and environment. This study, conducted in partnership with the Malawian Ministry of Education, the charities Malawi Council for the Handicapped (MACOHA) and The Albino Association of Malawi (TAAM), will have a high social impact by informing educational policy of this vulnerable group of children in Malawi.

This would generate evidence-based knowledge to inform education policy development and implementation, and support inclusive education for this vulnerable group.

This study builds on previous research (2010-2011) by the team on the education of children with albinism in the central and southern regions of Malawi (Lynch and Lund, 2011; Lynch, Lund and Massah, 2014¹). The earlier study informed the development of two information booklets, one for teachers and another for children with albinism, covering educational, health and social issues of albinism. These were distributed during the field work in an effort to help inform parents, teachers and children with albinism about this condition and improve their educational experience and level of achievement.

The Malawian context

Malawi is a landlocked country located in central southern Africa. It shares borders with Tanzania on the North, Zambia on the West and Mozambique on the East and South. The population is young, with 45.1% aged between 0 and 14 years.

The Northern region has a population of 1, 698,502 (2008) and covers an area of 26,931 km². This region has six districts (out of a total of 28 districts in Malawi), namely Chitipa, Karonga, Likoma, Mzimba, Nkhata Bay and Rumphu. The administrative city is Mzuzu where most government and NGOs are based.

¹ Lynch, P., and Lund, P. (2011) Education of children and young people with albinism in Malawi. London. Field report for Commonwealth Secretariat.

Lynch, P., Lund, P., and Massah, B. (2014) Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi. *International Journal of Educational Development* 39, 226-234

Each Education Division in Malawi includes 4-6 Education Districts which are further divided into zones, with each zone having 6 -10 primary schools. A primary school may have up to 3000 pupils and between 200- 350 teachers.

Agriculture accounts for 40% of GDP and 88% of export revenue in Malawi. The climate in the Northern Region has high rainfall and favours agriculture; a number of crops are grown including tobacco, maize rice, cassava and groundnuts. It also has large farms of coffee and rubber that are cultivated along the slopes of the mountains of Nkhata Bay district.

In the past the Northern Region has not been well connected with other parts of Malawi, which has hindered development. Since 1994, when Malawi underwent a political shift from the one-party dictatorship of the Malawi Congress party (MCP) to a multiparty system of government, there has been a political drive by the United Democratic Front (UDF) to develop the north, although it has remained less developed compared to the southern and central regions. However, economic progress has been made, with improvements in the spheres of transport, communication, infrastructure development and trade.

This region borders Tanzania where it has been widely reported through the BBC and Aljazeera that people with albinism are being killed and mutilated (Allen, 2008²). Miners are buying body parts of people with albinism for use as 'good luck' charms. Over the last five years there has been increased demand for these body parts due to these superstitious beliefs.

Special Needs Education in Malawi

"Inclusive education is concerned with removing all barriers to learning and with the participation of all pupils vulnerable to exclusion and marginalisation. It is a strategic approach designed to facilitate learning success for all children. It addresses the common goals of decreasing and overcoming all exclusion from the human right to education, at least at the elementary level, and enhancing access, participation and learning success in quality basic education for all."(UNESCO, 2000³).

Special Needs Education (SNE) is a system for providing a conducive learning environment for pupils who require extra support in order to achieve their full learning potential. Scottish and South African Evangelical Missionaries introduced SNE services in the early 1950s by supporting the education of pupils with visual impairments. A 2008 baseline study on inclusive education in one education division in central Malawi (Chavuta et al., 2008⁴) found that pupils with disabilities enjoyed learning together with those without disabilities, receiving care and attention mostly from their peers, rather than teachers. This study revealed a communication gap between pupils with disabilities and their teachers. Teachers felt they needed to be equipped with additional knowledge and skills on how to teach and manage pupils with diverse learning needs. The reasons given by teachers and community leaders for absenteeism from school included children being sent to look after domestic

² Allen, A. (2008) Living in Fear: Tanzania's albinos. *BBC News* [online] available from <<http://news.bbc.co.uk/1/hi/world/africa/7518049.stm>> [4 March 2013]

³ UNESCO (2000) Inclusive Education and Education For All: A challenge and a vision. Pp 24

⁴ Chavuta, A., Itimu-Phiri, A.N., Chiwaya, S., Sikero, N., and Alindiamao, G. (2008) Inclusive Education Project. Available from: <<http://www.eenet.org.uk/resources/docs/Malawi%20baseline%20study.pdf>> [4 March 2013]

animals, selling goods in the local market, going fishing or watching video shows on market day. There was a need for children to do these chores and engage in small business activities in order to alleviate family poverty,

The overall aim of the current Malawian national strategy regarding education is to provide an enabling environment for children with special educational needs within the regular school system with SNE seen as a key area of focus in the development of educational programmes to ensure that children with disabilities are not disadvantaged and can complete their education to reach their full potential. Inclusive approaches are carried out at all levels- primary, secondary and tertiary education- although the focus has been on primary education. Implementation of inclusive educational practices is conducted through specialised teachers in designated special schools, via support to integrated Resource Centre units in mainstream schools staffed with specialised teachers and via itinerant teachers assisting in mainstream schools. The itinerant teachers serve several schools within an education zone.

Responding to the inadequate educational provision for children with visual impairment, the Ministry of Education, with the support of international charities such as Sightsavers (<http://www.sightsavers.org>) have set up resources centres with specialist teachers to support their learning.

Schools catering for visually impaired pupils in the Northern Region include:

1. St Mary's Boys Primary School Resource Centre for the visually impaired, Karonga
2. Nyungwi Primary Resource Centre, Karonga
3. Ekwendeni Primary School Resource Centre for the visually impaired, Mzimba North
4. St Maria Goretti Primary School Resource Centre for the visually impaired, Nkhata Bay
5. Chilumba Secondary School, Karonga
6. Ekwendeni Girls Secondary School, Mzimba North
7. Mzimba Secondary School, Mzimba South
8. Robert Laws Secondary School, Mzimba South

Research questions

1. What are the educational experiences of children with albinism in the Northern Region in Malawi? Where are they educated and what support systems are in place to assist them?
2. How does economic necessity or poverty affect the health and education of children with albinism?
3. What solutions and strategies could lead to greater access for children with albinism to appropriate education at their local school?
4. What is the local communities' understanding of albinism?

Study Methodology

The researchers adopted a qualitative approach, using drawings, narratives and focus group discussion to explore the impact of albinism on the lives of those with albinism, notably their access to education. The study was conducted in a participatory manner, with participants involved from an early stage of the study design. Male participants were interviewed by a male researcher and females by a female. The interviewers spoke both local languages, Chichewa and Tumbuka, allowing participants to express themselves in their home language. Participants were informed about the study and signed consent forms before being interviewed; in the case of children consent was also obtained from a parent, guardian or teacher. Permission was obtained to take photographs to provide evidence of participant's school and home environment.

The study design included observations and face-to-face unstructured interviews, using open discussion to collect information on issues the participants considered important. Prompts were used if necessary to ensure health, education and social areas were covered. Teachers and policy-makers were interviewed in English, with open discussion to allow them to identify issues they considered important to the education of young people with albinism. This approach was used to triangulate the data and compare it with that obtained during previous field work by the research team in the south and central regions of Malawi.

The in-depth interviews captured critical moments in the lives of the participants, their level of acceptability in school and community, and the family's economic situation. They were conducted through home visits to the families or at their school and lasted about 40 minutes. Information recorded included family details, demographic data (name, age, gender, school, class standard, number of years at school), sun protection habits (use and availability of hats, sun lotion and other protective clothes), school environment (friends, teacher support, distance from home), specific educational support at school, the impact of albinism on their lives at school and within their community and their understanding of albinism. Participants were asked about any myths they had heard about albinism.

Participants

25 Interviewees belonging to communities along Lake Malawi included class teachers in mainstream schools, specialist teachers in visual impairment attached to Resource Centres, as well as pupils with albinism, their parents and adults in the community with albinism (see Table 1). In depth interviews were conducted with nine young people with albinism (4 male and 5 female). Five home visits in villages were made to interview family members, including two adult males with albinism. The young people with albinism and families were chosen in consultation with local community workers, who accompanied the researchers on the visits.

Ethical approval for conducting this study was obtained from Coventry University. All participants signed a consent form and agreed that their information could be shared.

Table 1: Participants interviewed in Malawi

| Name of School | Males with albinism | Females with albinism | Family members | Teachers |
|--|----------------------|------------------------------|--|----------|
| St Mary's Boys Primary School Resource Centre for the visually impaired, Karonga | 2 | | 1 Grandmother (Guardian) visited at her village | 2 |
| An adult with albinism was interviewed in Karonga at his home and workplace (shop) in the market | | | | |
| Ekwendeni Primary School Resource Centre for the visually impaired, Mzimba North | | 1 | | 2 |
| St Maria Goretti Primary School Resource Centre for the visually impaired, Nkhata Bay | 1 | 1 | 1 Father of these two children visited in his village | 2 |
| Chinteche Private School | | 1 | 2 | 1 |
| Nkhotakota Primary School Resource Centre | 1 Brown albinism* | 2 One with brown albinism | 2 Mothers of two young people with brown albinism visited in their village | 1 |
| Nkhotakota: a 38 year old man with albinism and his wife were interviewed in their village | | | | |
| Total number interviewed | 4 | 5 | 6 | 8 |

*Those with brown albinism have more pigment, with darker hair, skin and eyes than those with the classic pale appearance, but are still visually impaired
 Visits to schools took place at the beginning of the academic school year (first two weeks of September 2012) when new pupils were being enrolled.

Limitations of the study design

Children and families identified for interview in this study were selected by community workers operating at village level or by local church groups. These may not be representative and may not include the hard to reach families in remote rural areas. A new project using radio and mobile phone technology to attempt to reach this group began in September 2012.

Results

This section presents the study's findings on the educational environment and experiences of children with albinism along the shore of Lake Malawi in the north of the country. It reports on the local communities' understanding of albinism, how poverty affected the education of children with albinism and suggests possible solutions and strategies that could lead to greater access for children with albinism to quality education at their local school.

Understanding of albinism at birth

The common understanding of albinism within these rural village communities was that it was something that happens at birth, due to the will of God. One participant explained that people with albinism are people *'like us (with black skin), only that they have a white skin'*. There was a common perception that children with albinism had *'weak' skin*.

Families who knew someone with albinism, or had a family member with albinism, were more knowledgeable and usually more accepting of a new born baby with the condition. These participants explained that they knew *'the baby is normal like any other person'*. Despite prior knowledge, one parent of two children with albinism, whose mother had albinism, considered himself *'unfortunate'* as *'the only one in his village'* who had a child with albinism.

A 43 year old shop keeper, the only one in his family with albinism, reported being rejected by his father and his grandfather on his father's side, despite belonging to an ethnic group where children *'belong'* to the father who is responsible for looking after them. Relatives and friends had intervened, counselling them that *'this child is a gift from God.'*

A young man with brown albinism (the only one of six children with albinism) reported: *'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.'*

Self-awareness of sun sensitivity and visual impairment

The nine young people with albinism interviewed did not know why they were white and not black like their friends and parents. They knew they were *'different'* in that their skin was very sensitive to sun burn and they had low vision. The only explanation from their parents and relatives was that they were born like that, with white skin. They were encouraged to live normally as it is *'from God for some people to be born different'*.

They wanted to know more about why they were born with albinism. In the words of a young boy:

'I don't know why I look like this but I would like to know why I am like this.'

All young people interviewed knew they had to avoid sun exposure as much as possible, and many adapted their daily activities accordingly. One young boy only played football in the evening, when the sun was low, so he did not get sunburn.

Sometimes they were tempted to join their friends at the lake: one boy's grandmother reported that he *'occasionally goes to swim in the lake with his friends which exposes his skin to the sun and he gets very burnt, with sores all over his body, especially on his back'*.

Pupils were aware of their poor eyesight and the need to sit close to the board in class, although even then they sometimes could not see what was written there, for example two young boys with albinism knew they *'could not see far'*. A young man with brown albinism said: *'I do read well when I hold the paper close in my hand. That's better than writing from the board.'*

Sun protection

A 43 year old man with albinism who had a job as a stall holder in the local market and wore effective sun protective clothing was not sunburnt, demonstrating the advantages of having an indoor job with limited sun exposure.

None of the young people interviewed was wearing protective clothing on the day of interview; most were in short sleeved shirts (often school uniform) and shorts or skirts. One young woman with albinism, who was severely sunburnt, had a lightweight protective hat with a wide brim, but would not wear it although she walked four km to and from school twice a day. In the words of her father: *'she refuses to wear it as she wants to be the same as the others, she feels shy about wearing something different'*. She was given an umbrella in the hope this would prove more acceptable and offer protection from the sun.

Hats donated by well wishers were often baseball style, which offered no protection to the neck or side of the face.

Glasses

None of the young people interviewed had either sunglasses or prescription glasses at the time of interview; three mentioned having had glasses in the past which had got broken. Despite this, one young boy said he did well at school, being third in class at the end of term exams as his teachers were supportive, positioned him at the front in class and often gave him his own book to read. A 22 year old woman at a private school received glasses from her local hospital but only wore them for studying at home, not at school, as her fellow pupils mocked her.

Peer attitudes

All those interviewed experienced name calling and mockery about albinism, especially about their pale skin. This lessened once people got to know them. In the words of a young boy with albinism:

'In the community at first people used to laugh at me, even at school, but now they have stopped. I think they are used to me now.'

Two young women at boarding school made similar comments:

'Some fellow pupils who have just joined school mock me as they are not used to me, but with time they get used (to me) and eventually they stop.'

'People call me names like mzungu (ghost) and mzungu (white person). At first I felt sorry for myself when called these names but now most people are used to me and I know that those who are still calling me these names will get used to me too.'

One boy with albinism did not respond to 'bad words and questions', choosing to ignore and avoid them: *'I often just move out of that place and leave them alone'*.

There was also a lack of understanding of albinism among peers; a boy reported that some classmates thought he was being pompous, and exaggerating, when he was given his own book to use and wore his hat. He said he did not mind them as he knew that it was because of his skin condition. Due to the mockery of the other students he did not feel confident at school although he did have friends:

'Although some pupils think that way, I still have more friends who are so supportive and the teacher punishes everyone who mocks me.'

All nine young children interviewed had friends in class who helped them:

'My friends at school are so supportive, if I do not see properly they help me by telling me what has been written on the chalkboard so that I should not miss something that the teacher has written on the board.'

'My fellow pupils have been often helping, as most of the times it is difficult for me to see far.'

'I have a lot of friends who help in class, especially when I cannot see properly.'

A female pupil reported help from her many friends when she could not see what was written on the board, even though she sits at the front of the class. Friends also allowed her to copy their notes. Despite this peer support, she was mocked by some of her fellow pupils, which made her cross with people around her, as she felt different. In the past she had responded by beating people of her age who called her names, but her parents told her it was not right, she should just believe that she is like anyone else.

Some pupils with albinism were able to reciprocate by helping their peers: the father of a boy with albinism, said he was very proud of his son *'who operates a computer very well and teaches his friends.'* The pupils with albinism at his school used the computer in the Resource Centre in the afternoons, so had more access and practice.

Societal attitudes

A young man described the name-calling and negativity that surround him whenever he goes out. With reports of the killings and mutilations of people with albinism in Tanzania and other neighbouring countries, this has now taken on a more threatening and sinister aspect:

'...still I face challenges whenever I am going out of my house as people may see me & start to laugh or call me names like napweri ziyele or they start telling one another in my presence that 'look at that, that's business in Tanzania, let's get him'.'

A 17 year old woman with albinism reported that after her father's death her mother decided not to return to her home village, as she thought it would be difficult for the

community to accept her three children with albinism. The family received financial support from her mother's brother. People mocked her mother as the children with albinism do not do some of the household chores like farming and fetching firewood as her mother does not want them to be exposed to the sun. Therefore people think they are 'useless'.

Another young woman with albinism said many people in her community did not want to associate with her, which made her uncomfortable so she did not '*feel free to move easily in the village*'.

A 43 year old shop keeper had been happily married twice, to women who did not have albinism, and had children from each union. Both relationships had broken up, one due to '*pressure from the wife's community as she had married a man with albinism*'. Of his second marriage, he said they lived happily until his mother-in-law came and took her daughter away, as she was not happy that she had married a man with albinism. He was supported by his sister who employed him to look after her shop, paying him a monthly salary.

This contrasted with another couple interviewed, where a man with albinism had married his cousin after her first husband left her as she had epilepsy. Her family had accepted her husband with albinism as he was a relative, so '*they were already used to him*'. They had two black children, although the community thought her husband '*could only give birth to albinos*'.

Myths and beliefs

Myths and beliefs about albinism mentioned by young participants included:

- '*Magicians use albino's body parts as a concoction for people to become rich*'
- '*Albinos are sold and people get rich*'
- '*When albinos sit in the sun they melt*'
- '*People say that whenever an albino sits in the sun they develop cancer*'
- '*They do not live long; they live less than 30 years and then die*'
- '*Albinos do not die a normal death, they just vanish*'

After reporting these stories those interviewed often mentioned that they did not believe them, although they found them hurtful.

Family resources and support

The findings revealed differences in terms of resources and levels of poverty that had a direct impact on the education of children with albinism. In the villages visited the main economic activities were fishing and subsistence farming. Although most families were able to produce sufficient food for their families, they struggled to provide for the additional needs of the child with albinism in terms of buying protective clothing, sun glasses, sun protective lotion and providing transport money to send their child to a Resource Centre. Income from the sale of fish and produce was barely sufficient to support the basic needs of the family as a whole, making it difficult to give priority to the needs of the child with albinism. Even a father who worked as a school teacher found it difficult to support his family of seven children, two with albinism, despite help from the older children who worked in South Africa

and sent clothes and money. One grandmother, guardian of two grandchildren with albinism, received little assistance from her family, could not make ends meet by selling bananas and was dependent on charitable handouts of food and clothes. The children were abandoned by their father after the death of their mother. Although a fisherman, he did not support his two boys at all and had no contact with them.

Interviews with the parents and guardians revealed that, due to limited financial resources, some children with albinism had no choice but to assist the families in farming and fishing. Although the parents noticed that their child's skin went red after being in the sun, their help in the field was needed. One young man with brown albinism helped on the family's rice plot, saving his share of the crop to sell to buy books and clothes for school. The need to contribute economically to the family resources meant that most children with albinism interviewed in rural villages were obliged to work out of doors. Some did this early in the morning, for example a young girl walked down to the beach early to sell doughnuts to the fishermen.

One mother visited in her village was extremely protective of her 20-year old daughter with albinism; she let her sit indoors most of her time when at home. The mother did all the household activities like cooking and washing of dishes alone, thinking that if she allowed her daughter to do any job she would be abusing her, due to her 'weak' skin. The daughter did not contribute to any of the household chores and had not acquired the household or farming skills necessary for her to run her own home in the future.

Strong parental support was demonstrated by the firm line taken by a father who would not tolerate name calling and mocking of his children with albinism by anyone in the community. Another family in Nkhotakota were very supportive of their two children with albinism. Both wore long-sleeved clothes but did not have hats. The father worked as a tailor and the mother had a rice plot in a nearby rice scheme; a relative working in South Africa also helped support the family.

Education of children with albinism

Support for inclusive education of young people with albinism in northern Malawi focused on mobilising community resources, raising awareness on disability issues and encouraging parents/guardians to send their children with special educational needs to a Resource Centre. One resource school, Ekwendeni School for the Blind, had conducted a major awareness-raising meeting in their education zone just before the start of the first school term in September, to ensure that the community was well informed on disability and education. A specialist teacher at the school reported that the immediate impact of this awareness meeting was demonstrated by the large number of pupils with disabilities, including those with albinism, enrolled at this school. At the time of the study visit, two weeks after the school re-opened, they already had 25 children with albinism and were expecting more. Another Resource Centre attached to a mainstream school, St Maria Goretti Primary School, showed the same practice as at Ekwendeni, as expressed below by one of the specialist teachers:

'We try to get those children with albinism to this school, right now there is a young boy in the nearby village, we are trying to tell the parents to send him here but they don't want to. We need to tell them why he should be at this school.'

A visit to this young boy's home revealed that the parents wanted to keep their son at home until he was older, before sending him away to boarding school:

'I think he is young to go there at that school, we need to look after him until he is a bit old. The teacher told us that they need him to do his school there because it is special for them but we have not yet sent him.'

The father said they had heard of the killings of people with albinism in neighbouring Tanzania, although they had not heard of any cases in Malawi^{*5}. He was concerned to ensure his children were safe both at home and in the community. Their village is located along the main boat route on Lake Malawi used by fishermen and other traders from Tanzania coming to Malawi to buy and sell goods. The family feared for their children with albinism and were on the alert if any stranger came to the village. The father reported an experience he had with his daughter who has albinism:

'I went to collect my daughter from a boarding school at Nkhata Bay district and we used the boat on our way back to the village. So some men on the boat started saying bad things to my daughter, that she is money in Tanzania, but I gain courage and asked the men to stop saying bad things and mind their own business. I even told them that my daughter is more educated than them who just drink and do fishing. I challenged them that she will do well and everyone will know about her education successes in the village.'

An articulate young man with albinism contrasted his early schooling at his local village school with his present position boarding at a school with a Resource Centre and specialist teachers (although very limited facilities):

'In the village my school was very difficult, I could not see well and the teachers were writing very fast. The time I was 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 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.'

His mother added: *'It is difficult to support them at the local school, as they called them bad names like mzungwa (ghost).'*

A 15 year old girl boarding at a Resource Centre also felt the benefits of having a supportive specialist teacher available to help the visually impaired pupils revise what they had not followed in class. She felt supported by peers who helped her in class and by teachers who allowed her to sit in the front row. This made her feel more comfortable at the Resource Centre School, unlike back home where many people in the community did not accept her as much as her fellow pupils at the school do.

*Since late 2014 there have been reports of abductions, mutilations and killings of people with albinism in Malawi

In a contrasting case, a 20 year old woman was so homesick boarding away from home at a Resource Centre that she ran away, determined to return to her mother. This event was described by the mother:

'When she was sent to boarding school at the Resource Centre she was well accepted and started doing well in class. But it come a time when she started to be quiet and cry, to say that she wants to go home. When the teachers tried to find out from her what had happened she never explained, to the extent that the school had to invite a relative to talk to her. The more they tried the more she remained isolated and cried more. After all these efforts failed the school decided just to keep her at the boarding school, just to force her, assuming that with time she will accept the situation and stay at the school. But to the surprise of all, the young girl ran away from school and reported to police that the authorities at the school are forcing her to be at the school.'

She returned to her village where she reported having lots of friends who often come to chat to her. She joined the local school to continue her education and participated in village activities.

Resources for SNE in schools

Stark differences in the level of available resources to support visually impaired pupils were observed in the schools visited. Resource schools in Karonga, Mzimba, and Nkhata Bay, supported by missionaries, foreign donors and government, were equipped with assistive devices including computers and magnifiers, and had access (although erratic) to donated sun lotion and caps. In Nkhotakota the Resource Centre received only government funding and the resource room had few learning materials for children with albinism. Although the teachers were very supportive and pro-active they felt isolated and excluded from donor support. This resulted in less support available to children with albinism at this school and compromised the role of specialist teachers. The head teacher of a private school appreciated the information booklets of albinism: *'as a private school we are not often reached so this will help us to understand albinism and also the teachers will know how to support the girl with albinism.'*

One of the key challenges identified in this study, faced by both specialist and mainstream teachers, was the lack of specific information on management of the health, social and educational needs of pupils with albinism. These included issues of sun protection, self esteem, use of protective clothes at school and appropriate assistive devices for low vision. Although some schools had assistive devices such as magnifiers, these were often stored in a box and were not being used, or were available only in the Resource Centre and not in the mainstream classroom. Other factors included the limited number of specialist teachers, resulting in children having to travel long distances from their villages to attend a school with a Resource Centre, and the limited materials available to support the child in mainstream class rooms.

Teacher and peer attitudes

Most of the schoolchildren interviewed who attended schools with Resource Centres attached reported positive attitudes, encouragement and support from their teachers, who understood their visual impairment, tried to accommodate them in the classroom and allowed them to wear protective clothes such as hats. One mentioned

support from the teachers in trying to prevent mockery and name-calling by the other pupils.

Some of the support was intermittent: '*Sometimes the teacher gives me my own book but it is not often.*'

Barriers to access

Access to education for children with albinism in rural areas remained a challenge due to multiple barriers including:

- poverty or limited family resources
- long distances to travel to schools with Resource Centres
- limited educational material and information on albinism
- limited use of assistive devices such as magnifiers
- insufficient information on low cost interventions to manage albinism by classroom teachers
- variability in resources at different schools e.g. access to computers by donors
- a lack of understanding of the sun sensitivity and visual impairment of young people with albinism among their peers
- discrimination and name-calling by some peers

There was pressure on families to send their children with albinism to board at Resource Centres. Distances and the cost of travel from rural villages to these boarding schools were barriers; at one Resource Centre pupils with albinism started the new school year late due to these difficulties. Some children did not wish to be so far from home as demonstrated by a young woman who went to the police to ensure she could leave the Resource Centre and return to her mother. In another family the father sent his older children with albinism to board at a Resource Centre but kept his youngest at home where they could be protected, especially as the family were concerned about the risk of kidnapping by traders from Tanzania who used the local fishing port. They had heard the stories of abductions and killings in neighbouring countries and wanted to ensure the safety of their young children with albinism. They also did not want their young child exposed to negative comments by strangers and felt they could best protect them within their own community.

There was a lack of understanding among peers of the visual impairment associated with albinism and the need for affected pupils to wear a hat and have their own book, for example one boy's classmates just thought he was being '*pompous*' when he was given his own book in class, although his teachers supported him and positioned him at the front. Some pupils reported difficulty seeing the board, even if they sat at the front of the classroom. None of the pupils visited were wearing glasses; some mentioned having had a pair once, but they got broken. Poor vision prevented full participation in activities e.g. one young boy stopped playing soccer with his friends as he could not see the ball or the ground and hurt himself when playing. He sometimes joined his friends swimming in the lake, but suffered sunburn, blisters and sun lesions.

Mockery (usually related to the skin colour) and name-calling were rife. This led to lack of confidence at school although some tried to ignore the taunting and found better acceptance as their peers got used to them.

The myths reported included the belief in the magical powers of the body parts of people with albinism, used as get-rich charms. Other beliefs were that those with albinism are fragile, that they melt when they sit in the sun. These indicate a need for accurate information about albinism to be available to the community.

Discussion

Inclusive education is not just about schools, but includes wider community initiatives (Stubbs, 2008⁶) Misconceptions and prejudice around albinism are often the root cause of exclusion. The understanding of albinism within the communities visited is that it is a condition that comes '*from God*'. There was little understanding that albinism is an inherited condition. The fear of attack and abduction, fuelled by media reports of the brutality in Tanzania against people with albinism, had spread to neighbouring Malawi. Villagers along the lake, which is used as a trade route to Tanzania, feared this could happen to members with albinism in their communities.

Young people with albinism reported that they received love and support from their relatives and close community, although they look visibly so different from them due to their white skin colour. The strong family bonds that exist in the north of Malawi may have helped reduce or at least alleviate the stigma and discrimination faced by young children with albinism. The cultural system in the north results in the community living as one family, hence involvement and inclusion of everybody is one of the norms. This has helped to encourage some young people with albinism to go to school in the community.

Although aware of the need to protect their skin from the sun, young boys found it difficult to resist the temptation to join their friends in playing football and swimming in the lake. A young boy's grandmother reported that he went swimming with his friends in the lake and got very sunburnt, with blisters on his body. Some tried to minimise their sun exposure; one young boy said he only played outside when the sun was low so he did not get burnt by the sun. In rural Malawi it is rare to see anyone wearing a hat and both boys and girls in this study showed resistance to wearing floppy, wide brimmed hats which they considered unfashionable and resulted in ridicule and mockery from peers. Even when protective clothing and low vision devices such as magnifiers were available, they were not always used, or only used in a limited way. As an example, a young girl said she wore her glasses at home but not at school as she feared ridicule. Young people with albinism reported a lack of understanding from their peers about their condition and why they needed assistance in class. A young boy said that sometimes it was difficult for him to have his own book as other pupils feel he was '*just being pompous*'. It is imperative to raise awareness of these issues in the community, and especially among teachers and peers at school, to enhance understanding of albinism and increase tolerance.

⁶ Stubbs, S. (2008) Inclusive Education where there are few resources. Available from <<http://www.eenet.org.uk/resources/docs/IE%20few%20resources%202008.pdf>> [4 March 2013] pg 11

Family poverty and the variation in resources at different schools were factors affecting access to quality education for young people with albinism. Additionally, it also affected their general living conditions, limiting their access to basic services like health and their quality of education at school. Families with support from both parents and the extended family contrasted starkly with single parent families striving to support children with albinism on very limited means.

This study provided evidence that educational inclusion for children with albinism was actively promoted in the Northern Region of Malawi, with pupils making use of donated computers with software to support visually impaired pupils in schools with Resource Centres attached. On the other hand, it also suggested a fragmentation and inconsistency of educational efforts and resources which were impeding progress in implementing policies to address the specific interests of children with albinism. For example, the researchers found that although most schools visited had magnifiers, these devices were not being used, or were used only in a limited way. It is important to understand why pupils were not using magnifiers in class, in order to provide appropriate devices that are acceptable to the children and they would feel comfortable using in a classroom environment. The study also discussed other teacher interventions such as explaining to the other pupils why the child with albinism was wearing a hat and sitting in front of the class, and encouraging peer support, such as asking a boy's friends to join him at the front of the class rather than all sitting at the back. These class room interventions are key to making pupils with albinism feel more comfortable at school and thus promoting access to quality education for them. Interventions that focussed on the individual, removing them from their peers to receive separate attention, for example in a separate Resource Room, can cause disaffection among the other pupils (see Stubbs, 2008⁷). Adaptations that involve and include other pupils, ideally the whole class, and are based on an understanding of the issues pupils with albinism face, are more likely to lead to greater acceptance.

In one village a mother reported a critical moment in the life of her daughter with albinism, when she ran away from her boarding school at a Resource Centre to report to the police that she was being held against her will, and that she wanted to return to her mother in her home village. This was a brave decision for a young woman to make, exerting her right to get an education in her local school and live in her own village, with her mother. This is a powerful demonstration of courage and the ability of a young girl with albinism to demand her rights. She realised that she could be helped if she presented her case and that her views would be respected.

Summary

This study showed that given the appropriate support pupils with albinism could access quality education within their local communities. There was a continuing need to improve their health care, and enhance their social integration by sensitisation and awareness campaigns highlighting the challenges faced by people with albinism.

⁷ Stubbs, S. (2008) Inclusive Education where there are few resources. Available from <<http://www.eenet.org.uk/resources/docs/IE%20few%20resources%202008.pdf>> [4 March 2013] pg 43

Evidence from this study has supported local advocacy programmes and provided an evidence-base to enable both governmental agencies and charities to enhance their educational services for pupils with albinism, enabling them to target their support more effectively and efficiently. It has also informed teacher training programmes at local Teacher Training Colleges, which form part of a separate but synergistic research study in central Malawi⁸.

The study highlighted some of the solutions and strategies that could lead to greater access to appropriate education for children with albinism at their local school.

Recommendations

- Ensure dissemination of information booklets on albinism (written by the research team and available in English and Chichewa) through the education system, including to private schools, and to community groups
- In consultation with the pupil and family, task teachers to identify appropriate interventions (and assistive devices if available) for individual pupils with albinism; ensure peers understand the purpose of these
- Train teachers and healthcare professionals in the particular needs of those with albinism
- Facilitate peer support by fellow pupils in class

Note: there is a second field report on visits in 2014 and 2015, as well as a general overview document on this study, with detailed guidelines.

⁸ 2012-2014, Integrating community and media networks to promote educational inclusion of children and young people with albinism in Malawi and Zambia. More information available from [Sightsavers Innovation Fund](#), £72,464

Appendix

Details of visits to schools, villages and education offices, with Narrative Case Studies

This section presents summaries of the interviews with 9 pupils with albinism at schools with Resource Centres, 6 guardians/parents, 8 teachers, 2 adults with albinism and the wife of one of them. Visits were made to families in 5 rural villages.

Visits in and around Karonga

1. Visit to District Education Manager's (DEM) office:

The DEM was not available to meet the researchers, who instead briefed Mr J. J. Nyondo, Desk Officer for Primary Education about the study and introduced the information booklets on albinism and advocacy posters.

Contact: demkaronga@g.mail.com

2. Two pupils at **St. Mary's Boys Primary School** interviewed & one female guardian (grandmother) at her home in a near-by village

St. Mary's is a boys-only school with a Resource Centre for visually impaired pupils attached, with two specialist teachers. They have boarding facilities, with hostels about 500 m from the school, and are supported by the Catholic Church, who run an orphanage in the area.

The school has a dedicated Resource room with air conditioning and computers, available for use by the visually impaired pupils in the afternoon, after their regular lessons. Donors have provided stand-magnifiers to position over text, but these were in storage and not being used at the time of the visit.

The school was educating four pupils with albinism. A specialist teacher, Mr Manda, reported that one other pupil had recently been selected to go to Chitipa Secondary School.

Two of the pupils were interviewed; both interviews were conducted, transcribed and translated by the local male researcher (Massah).

Pupil 1: Male in Standard 7; 9 children in the family; 3 with albinism

This young man comes from a village in Karonga District. His father is a tax collector in the market and his mother a house wife. He has been at St. Mary's Primary School since standard two and is currently (2012) in Standard 7. He is the sixth born in a family of nine children; three have albinism. One of his young brothers who also has albinism, is in Standard 5 at the same school.

He does not know anyone in their family background who had albinism other than his two brothers. His mother and father both have black skin. He had chapped lips on the day of the visit, but did not show any other signs of sun-induced skin damage. He said he does not play much in the sun, only playing football when the sun is low, usually around five in the evening, so that he is not burnt by the sun.

He is doing well at school; he is usually third in class at the end of term exams. He sits in front of the class so that he is able to see the black board as he cannot see far. The teacher gives him his own book to read. Sometimes it is more difficult for him to have his own book as other pupils feel he is just being pompous. He has only one cap, given by a friend who knew that he needs to wear a hat. He has had the cap for almost a year and wears it every day, from 6 am to 6 pm, as it is always hot in Karonga. Sometimes, he gets some lotion (sunscreen) from Lusibilo Orphan Care; otherwise he uses Vaseline, which contains no sunscreen. He had glasses when he was in Standard 2 but they got broken, so now he does not use glasses.

Challenges that he faces at school and in the community due to albinism include:

- Fellow pupils mock him because of how he looks (his skin)
- Other pupils do not understand why he puts on a hat at school, they always think he is exaggerating, but he says he does not mind them as he knows that he is doing it because of his skin condition
- Due to the mockery of the other students he does not feel confident when doing things at school.

‘Although some pupils think that way, I still have more friends who are so supportive and the teacher (especially Mr Manda) punishes everyone who mocks me.’

He mentioned beliefs concerning people with albinism he had heard:

- *‘Magicians use albino’s body parts as a concoction for people to become rich’*
- *‘When albinos sit in the sun they melt’.*

He said that he does not believe what people say about albinism as he knows that he is *‘like anyone else’*.

Pupil 2: Male aged 14 years; 2 children with albinism in the family

This young man lives with his grandmother at a village in Karonga. There are two children with albinism in the family, him and his brother. His mother died when he was young and his father disappeared to another area to run away from the responsibility of taking care of the children.

At the time of the interview he was wearing a cap given by a friend with albinism at the school. He boards at the hostel.

At school, he has friends who support him and he sits in the front line in class as he cannot see well, but even in front he sees with difficulty. He is given additional time to complete examinations and notes from the teacher to copy in class.

‘Some boys do say bad words and questions- I don’t answer them- like why are you born white? ...I often just move out of that place and leave them alone.’

After school, I like to play soccer with friends but I stopped now because I used to hurt myself. I cannot see the ball very well or the ground. I could bump into the ground sometimes when I miss the ball.

In terms of why I look white I don’t know, even my grandmother (does not know), I think it’s from God. In the community at first people used to laugh at me, even at school, but now they have stopped. I think they are used to me now.’

Guardian: Interview with this young man's guardian, his grandmother

She was interviewed at her home in her village; the interview was conducted, transcribed and translated by the local female researcher (Mchekeni), in the presence of the UK based female researcher (Lund).

Pupil 2 lives with his grandmother and young brother who also has albinism. Their grandmother was born in 1944 and her husband died a long time ago. Their mother was the eighth born in the family, the last born. When she gave birth to babies with albinism, they faced a lot of challenges, as people called them names like *mzungu dondo* (fake white man). The grandmother accepted her grand children with albinism without complaining, as she knew these children are a gift from God. The family do not know about or have any previous background of albinism in their family.

The boy's mother died in 1996; the father is still alive. He is a fisherman, but has not helped the children since their mother's death. Both boys were abandoned by their father and the grandmother does not know where he lives now.

Their grandmother earns her living by farming and selling bananas. In addition she gets some help from one of her sons who has a job with the traditional court in Karonga. Although she has other children (uncles and aunts to the boys with albinism), the rest do not help her as they drink too much. If worse comes to worse she goes to Lusibilo Orphan Care run by the Catholic sisters to seek help with food, and for clothes for her two grandsons.

Sometimes one of her young grandsons with albinism goes to the lake with his friends to swim, which exposes his skin to the sun and he gets very burnt, resulting in blisters which leave him with sores all over his body, especially on his back.

3. Interview with an adult male with albinism aged 43 years

He was interviewed at his home in Karonga and visited the next day at his place of work in the market (at his invitation), by the local male researcher (Massah) and the UK based female researcher (Lund); the interview was conducted in English.

He was born in 1969 and is from a village in Karonga. When interviewed he was wearing protective clothing with long trousers and a long sleeved shirt buttoned high at the neck. Although he had elastosis of the neck (thickening of the skin due to sun exposure), he was not sunburnt.

His parents have four children, three females with black skin, and him. He is the only male and the only child with albinism. After their father died their mother remarried and had a boy with black skin.

He belongs to the Nyakyusa ethnic group. He stressed that in this group the children 'belong' to the father's side and it is the responsibility of the father to look after the children. Despite this, when he was born he was rejected by his father and his grandfather on his father's side, until relatives and friends counselled them that this child is a gift from God.

He married a woman without albinism and they had one child, a girl who is now 14 years old and takes care of the house for her father (she was present in the house at the time of the interview). The couple lived happily for over four years but then

separated because of pressure from the wife's community, unhappy that she had married a man with albinism. After this separation he re-married and had two boys, aged 10 and 6 years. They were happily married until his mother-in-law came and took her daughter away, as she was not happy that her daughter had married a man with albinism.

At the time of interview he was working as a shop assistant in his sister's shop; she pays him a monthly salary. When the researchers visited him there he was sitting outside his shop in the crowded market, interacting and chatting with the neighbouring shopkeepers.

Visit in Mzimba

Ekwendeni Primary School at Mzimba

1. Meeting with head, deputy head, class teacher and specialist teachers (n=7; 4 male and 3 female); interview with 2 specialist teachers

The meeting was conducted in English with both local researchers (Massah and Mchekeni) and one UK based researcher (Lund) present.

Ekwendeni School for the Blind has a Resource Centre with specialist teachers for the visually impaired. They had five computers used every afternoon to assist pupils with low vision in Standard 4 and above. The specialist teachers undertook eye testing of the visually impaired pupils; they did not teach Braille to any of the pupils with albinism.

Ekwendeni Primary School has strong political support due to its link to the CCPA church which is highly influential in the Northern Region, both locally and at policy level. The school is also supported by volunteers from abroad who come to work at the near-by mission hospital, which benefits from overseas donations and visits from specialist medical personnel. The teachers acknowledged the support received from well wishers who visit the hospital and work on projects run by the church.

The school has an intake of between 29 and 34 pupils with low vision or blind; some had not yet returned for the new term on the day of the visit by the research team. The local District Education Manager (DEM) had issued instructions that any child with albinism in the locality should come straight to this school. The teaching staff indicated their commitment to support people with albinism in the area.

2. Interview with one female with albinism at Ekwendeni Primary School

Pupil 3: Female aged 17 years; 3 children in the family, all with albinism

The meeting was conducted, transcribed and translated by the female researcher (Mchekeni).

This young woman comes from a village in Mzimba District and is in Standard 8 at Ekwendeni Primary School, where she boards. She is the last born in a family of

three children. They were all born with albinism; both parents have black skin. After her father died in 1996 her mother decided not to return to her home village in Rumphu as she thinks it would be difficult for the community to accept her children. The interviewee and her sister visit there once in a while, at her uncle's place (her mother's brother), who supports them financially. He has been of help as her mother relies solely on subsistence farming.

At the time of interview she was wearing a dark wig which she sometimes wears to '*look different*'. At the time of interview her skin was clear, with no evidence of sun burn. She reported using sunscreen since 2004 and showed the researchers her sunscreen- a waterproof SPF 30 sunscreen with both UVA and UVB Protection. The teacher for special needs collects lotions for all those with albinism which are donated to Ekwendeni Hospital.

She has never visited a clinic about her skin as she always wears a hat. The one she was wearing at interview had been donated by the late president on a visit to the school. These donations were baseball style caps, not round hats with a wide brim, and offered inadequate protection to the neck and side of the face. She usually plays in the shade because she does not want her skin to be burnt by the sun, and was able to explain why her skin is different from others, that she has less pigment.

She sits in the first row in class as she cannot see properly when she is sitting at the back. '*They also give us our own books to read.*' The teachers have been supportive of her education and she goes to the Resource Centre in the afternoon for lessons. She has many friends both in class and in the dormitories at the boarding school. '*My fellow pupils have been often helping as most of the times it is difficult for me to see far.*'

She does not have glasses but sometimes borrows from friends. She uses magnifiers sometimes, which they get from the Resource Centre and return afterwards.

She reported challenges in life because of her skin colour:

- '*Some fellow pupils who have just joined school mock me as they are not used to me but with time they get used (to me) and eventually they stop*'
- People at home mock her mother as the children with albinism do not do some of the household chores, like farming and fetching firewood, because her mother does not want them to be exposed to the sun. Therefore people think they are useless
- Others call them different names like Yellow man, *mzungu*, *napweri*

The myths about people with albinism that she has heard are that:

- '*They do not live long; they live less than 30 years and then die*'
- '*They are used for magic.*'

She does not take any notice of what other people say or listen to their beliefs on albinism, but lives a very positive life as she knows that she is like anyone else.

Visit in Mzuzu

Meeting with Acting EDM (Education District Manager), Mzuzu

The Acting EDM was briefed about the albinism project and our visit to the north. He was very supportive of using the information booklets and promised to ensure their distribution to schools that have pupils with albinism.

Visits in Nkhata Bay District

1. Interviews with two pupils with albinism at **Saint Maria Goretti Primary School at Nkhata Bay**; this is a government-run boarding school with a Resource Centre situated about 700 m from the school, with two specialist teachers supporting the pupils at the Centre and in the mainstream classroom.

The school has two pupils with albinism, in the same class. Both were interviewed by the local researchers.

Pupil 4: Female in Standard 8; 4 children in the family, she is the only one with albinism

She comes from a village in Nkhata Bay and is in Standard 8 at Saint Maria Goretti Primary; she has been at this school since Standard 4. She is the only one with albinism in the family of four children, two boys and two girls. Her father passed away when she was less than one year old. Her mother remarried and had three children, none with albinism.

She does not use any sunscreen and on the day of interview her skin showed sun induced damage to her face, neck and arms. She once visited the skin clinic when she developed sores on her body due to sun burn.

She commented:

'I sit in the front row to enable me to see properly on the board as I do not see far. The teacher encourages us to be sitting on the front rows. Sometimes the teacher gives me my own book but it is not often. Usually I read with other pupils and I sit in the middle of the classroom. My friends at school are so supportive, if I do not see properly they help me by telling me what has been written on the chalkboard so that I should not miss something that the teacher has written on the board.'

After normal school hours, in the afternoon, she goes to Resource Centre for extra classes with the specialist teacher.

She does not have a hat for sun protection. The specialist teacher gave her sun glasses but they were broken a year ago. She wore them whenever there was 'too much sun'.

Some of the challenges that she experience included:

- *'Nkhata Bay is very hot which makes my skin to be burnt a lot'*
- She does not have glasses which makes it difficult for her to see on the board
- Many people in the community do not want to associate with her, which makes her uncomfortable; she does not feel free to move easily in the village.

Pupil 5: Male in Standard 8; 7 children in the family, 2 with albinism (his sister was also interviewed- pupil 6); their grandmother also had albinism

This young man is in Standard 8, boarding at Saint Maria Goretti Primary in Nkhata Bay district where there are two pupils with albinism at the school, the other is a young woman in the same class (Pupil 4).

At home he lives with his father as his mother passed away. His father is a primary school teacher at Kande Primary School in Nkhata Bay south. There are seven children in the family; two have albinism. His elder sister with albinism is at Ekwendeni Secondary School in Form 3. Two of his elder brothers and a sister moved to South Africa to work in 2010. They currently support their father with money and send clothes for the family.

'At school I have friends, I get notes from the chalkboard and sometimes my friends also help me.'

UK researcher's (Lund's) observation: On the day of interview this young man was in class sitting in the front row, three desks from the door. He was the only boy at the front, sharing a desk with two girls; all the other boys were sitting at the back of the class. He had no hat and was wearing short sleeve school uniform. Despite this, he was not sunburnt.

'Our home is near the lake but I don't go fishing. I like playing football with my friends in the village. I don't know why I look like this but I would like to know why I am like this.'

2. Meeting with two specialist teachers, **Nkhata Bay School**

The teachers discussed their role in supporting pupils with albinism, working hand-in-hand with the mainstream school attached to their government supported Resource Centre. In addition, well wishers provide them with sun lotion; sometimes they also get supplies from Ekwendeni. Although they had no assistive devices, they did their best to assist pupils in the mainstream classroom situation.

3. Interview with one young woman with albinism at **Chinteche Private School** and the head teacher

Male head teacher: The key issue mentioned by the head teacher was the teacher's lack of knowledge on how to support the girl with albinism at this private school. He personally became interested in the girl's education because he has a friend with albinism who is now working as a nurse.

In terms of peer support, he indicated that some pupils do not understand her condition, although the teachers allow her to sit in front and use long sleeves. She seems not comfortable when she is among her friends.

The school had just enrolled a young man using a wheelchair who is well accepted and supported by other learners. He hopes to encourage them to support the girl with albinism in the same as they do the boy, so that she feels comfortable at school and feels free to wear protective clothes.

He welcomed the information booklets provided, saying that as a private school they are not often reached, so it will help them to understand albinism and also other teachers would know how to support the girl with albinism.

Pupil 6: Female, aged 22 years; sister of pupil 5; 7 children in the family, 2 with albinism; grandmother had albinism

Interview conducted by the local female researcher (Mchekeni) at the family home in their village.

This young woman was born in 1990 and lives with her father and step mother. Her mother passed away when she was young and she was raised by her step mother. At the time of interview she was waiting for her Junior Certificate Examination result (Form 2 in the Malawian Secondary Education System). She walks 4 km from her village to attend Chinteche Private School. At school she sits in the front row of classroom but does not see the board properly. She has many friends who help her when she is not able to see what is written on the board. She copies notes from her friends. She has reading glasses given to her at Nkhata Bay Hospital but usually only wears them at home when studying, rather than at school, as her fellow students mock her a lot. She has a wide brimmed hat which she was given at Central Hospital but she does not wear it.

There are many names that people call her at school and within her community including *mzungu* (white man), albino and *mkaladi* (Coloured). She does not feel 'well' whenever she is called these names and this makes her cross with people around her, as she feels different. In the past she used to beat people of her age who called her those names. Her parents told her that it is not right to do that; instead she should just believe that she is like anyone else.

Stories she has heard about albinism:

- *'People say that whenever an albino sits in the sun they develop cancer'*
- *'Albinos do not live long; they die early.'*

4. Interview with father of two children with albinism (pupils 5 and 6) at his village

Parent: father of two children with albinism

He was interviewed, in English, at his home by the UK based researcher (Lund).

He had been a head teacher for 27 years but retired from that position and now teaches a Standard 1 class at a private school.

His mother had albinism and his father was black. He has eight children (one died) from his first wife (now deceased) including two with albinism. When his daughter was born he thought *'God has given us this one'*. He considered himself *'unfortunate'* as he is the only one in his village who has a child with albinism.

'Some people call her bad names such as mazungu and napwere; she has a lightweight, wide brimmed protective hat which was donated to her but she refuses to wear it as she wants to be the same as the others, she feels shy about wearing something different.'

[The study team bought her an umbrella at the local trading store in the hope she would find this more acceptable to use for sun protection.] She comes home from the private secondary school she attends school at 1 pm and then walks back to school to study in the afternoon. She shares a friend's notes but is not given extra time for assessments.

The father reported that his son with albinism is always indoors. He is very proud of his son who operates a computer very well and teaches his friends.

He married a second time '*to have a woman to help take care of the children*'; he has three children with her, none with albinism.

After our visit to the father in his village he telephoned the head the following day to arrange a meeting at the school to discuss his daughter's education.

5. Home visit to family living in Tonga fishing village on the lake south of Nkhata Bay

Parents: father and mother of three children with albinism

This family was visited at his home by both local researchers and one UK based researcher (Lund). The information below was provided mainly by the father.

There are three children with albinism: one girl, his first born, is at Ekwandeni Secondary School, he has a young girl aged 4 who is still at home and a young boy. These were from his second wife, who is a cousin. He has three children with his first wife; none with albinism. His sister, who is also married to a cousin, has two children (one boy, one girl) with albinism in a family of seven children.

When at home from boarding school, his first born daughter helps the family by going down to the beach to sell doughnuts to the fishermen. She walks down the steep path to the lake shore early to sell, then returns so she is not out in the sun in the middle of the day.

He felt that his young son with albinism was too young to go away to boarding school; he wanted him to go to the village school where he was near his family and they could watch over him. This school was within sight of their house.

The father said he made sure that everyone in the community respected his children with albinism. One day they were catching a boat back from Nkhata Bay and a few men were bad-mouthing his daughter. He stood up for her and said she was attending secondary school and would end up with a much better education than either of them, who were fishermen and spent their money on drink.

This family (and the extended family, including the father's first wife) were very supportive of the two children with albinism who were at home on the day of the visit.

Visits in Nkhotakota District

1. Interview with field officer of Malawi Council for the Handicapped (**MACOHA**)

The information booklets were presented and the discussion focussed on how best to utilize the booklets in community activities. It was agreed that the information will be passed on to community workers and then to volunteers at village level. The

officer appreciated the information, commenting that it will assist them very much *'in addressing specific issues on albinism in our community'*.

2. Visit to **Nkhotakota LEA School with Resource Centre for the Visually Impaired** and interview with one male pupil with brown albinism

This school was educating about 2000 pupils with 26 teachers. The head seemed very supportive of the children with albinism and the other visually impaired pupils who boarded at the school. The Resource Centre attached to the school was supported by the Ministry of Education with specialist staff trained in visual impairment at Montfort College, but had very few resources, with no computers. They did not receive as many donations or support from church and other organisations as other centres supporting children with visual impairment.

Pupil 7: a male with brown albinism in Standard 6; 6 children in the family, he is the only one with albinism

This young man was clearly well respected both at school (by teachers and fellow pupils) and at home in his community. He was very articulate when interviewed by the local male researcher (Massah):

'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 and then do most of the household's work.

I am in Standard 6 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.

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.'

Pupil 8: Female with albinism aged 15 years; 6 children in the family; only one with albinism

This young woman was born in 1997 and is in Standard 4 at Nkhotakota LEA Primary school. She stays with her elder sister since her mother passed away in 2002. Her father is still alive. She is the fifth born in the family of six children and the only one in the family with albinism.

On the day of interview she was badly sunburnt; she reported that she had no hat and no sunscreen. She once used sunscreen given by the National Initiative for Civic Education (NICE). She has never visited the clinic about her skin.

She sits in the front row in class and has a lot of friends who help her in class, especially when she cannot see properly. She is usually given her own text book. In the afternoon she goes to the Resource Centre for revision of what they have learnt in class. The specialist teacher helps them a lot, explaining what they have not understood. She did not have reading or sun glasses at the time of interview; she used to have them but they were broken. She has not used reading glasses since July 2012 (2 months before the interview).

She said she feels more comfortable at the Resource Centre School, unlike back home, as many people in the community do not accept her as much as her fellow pupils at the school do. People call her names like *mzukwa* (ghost) and *mzungu* (white man).

At first she used to feel sorry for herself when called these names but now most people are used to her and she knows that those who are still calling her these names will get used to her too. She does not care what people say. She has no idea why her skin is different from others; all she knows is *'it is God's will.'*

In terms of myths she has commonly heard that *'albinos do not die a normal death, they just vanish and that albinos are sold and people get rich.'*

3. Home visit to two families in one **village in Nkhotakota north**; both have children with brown albinism

The parents were interviewed by the local researchers (Massah and Mchekeni); the UK based researcher (Lund) walked through the village, accompanied by pupil 7, and was able to observe the responses and interactions between him and his fellow villagers. Although young, he seemed to be respected and well liked.

Parent: Interview with pupil 7's mother at her home village

His mother noticed his skin got sun burnt, that his skin turns red and wounds once he stays in the sun for a long time. She thought that his skin was weak:

'I think their body is weak, you cannot even whip them, its soft.....'

Although they were going to a local school, they were not able to see well. It was difficult to support them at this village school, as they called them bad names like *mzukwa* (ghost) whereas others called them albino. At this school, due to the large number of pupils, when they sat at the back they could not see the chalkboard.

Pupil 9: Female with brown albinism, aged 20 years; 6 children in the family, 3 have albinism

This interview was conducted by the female local researcher (Mchekeni) with the UK based researcher (Lund) observing and contributing.

This young woman lives and goes to school in her village in Nkhotakota north. She was born with brown albinism in a family of six children; an elder brother and a sister also have albinism. As the last born in the family she grew very close to her mother and spent most of her time at home. Like the other children in the village she started her primary school in the nearby school, located about 4 km from her home.

She was then sent to board at the Resource Centre, but ran away and told police she was being forced to stay there and wanted to return home. This incidence is recounted by her mother who was interviewed separately (interview below). The young woman with albinism revealed that she made that decision because she wanted to be with her mother at home as she felt that her mother would be lonely and need her at home. For this reason she tried all means to get back home to stay with her mother. Her father lives in another location doing business but does support the family. The girl is happy back in the village and has joined the local school to proceed with her education.

Parent: Interview with pupil 9's mother at her home village

Learning from the other children with albinism in the family, the mother makes sure her daughter gets all the support and love *'due to her weak skin'*. She lets her sit indoors most of her time when at home. The mother does all the household activities like cooking and washing of dishes alone. She thought that if she allowed her daughter to do any job she would be abusing her, due to her condition.

She thought her daughter was well accepted in the village, with a lot of friends who often come home to chat with her. Sometimes she joins a group of her friends in the village to go to the market or attend village activities.

Her mother described an incident when she attended the Resource Centre:

'When she was sent to boarding school at the Resource Centre she was well accepted and started doing well in class. But it come a time when she started to be quiet and cry, to say that she wants to go home. When the teachers tried to find out from her what had happened she never explained to the extent that the school had to invite a relative to talk to her. The more they tried the more she remained isolated and cried more. After all these efforts failed the school decided just to keep her at the boarding school, just to force her, assuming that with time she will accept the situation and stay at the school. But to the surprise of all, the young girl ran away from school and reported to police that the authorities at the school are forcing her to be at the school.'

4. Home visit to a couple where the man has albinism in a village in Nkhotakota

The couple were interviewed separately by the local researchers (Massah and Mchekeni).

Male adult with albinism, aged 38 years; 7 siblings (2 deceased); 2 with albinism (one of these deceased)

This man was born in 1974 at a village in Nkhotakota. There were seven in his family, but now only five remain. Two males had albinism, him and a younger brother

who died due to a wound that was said to be cancer. His mother passed away when he was young but his father is still alive.

'I did my school up to Standard 5- it's when I drop out due to school fees. That time during my school we were paying, so my Dad could not afford the school fees. Currently, I do a small business of selling fish, I don't go fishing but I buy them from the fishermen and sell locally in the village market. Apart from this, I do farming in rice and maize, my garden is just few meters from my home. But due to lack of fertilizer I don't harvest that much to support my family.

I have been married for three years now (wife reported six), this is my first wife and we have two children, one male and a female. Both of my children are black but I have a sister who is also married and has a child with albinism. My other brothers are fishermen and do their business in Salima'.

He is a member of the local branch of the albinism association in Nkhotakota and had been visiting the hospital for counselling on skin protection and for a small operation on his skin. His skin looked very dry and was badly sun burnt, with numerous skin lesions.

Note by the local researcher: although he had agreed to the interview and signed a consent form to participate the local researcher thought that he was defensive and not open about discussing some issues of albinism in detail. He was not pressed for information but his wife said he had a big wound on his side and had been at the hospital for some days. He had been coughing for a long time, which was also observable during the interview. He had been taking care of his young brother with albinism who had TB and cancer, and had passed away.

Wife of man with albinism interviewed above, aged 30 years

She was interviewed by the local female researcher (Mchekeni) with the UK based female researcher (Lund) observing and contributing.

She was born in 1982 and dropped out of school when she was in Standard 4; she cannot read or write. She was not sure of her husband's education but knew he dropped out of school at primary level. Her family depends on farming as a source of income; they grow rice but on a small scale. She has been married for six years now (husband reported three). She was married before but her husband left her because she is epileptic, and married another wife. She was left with one child from this marriage, who is now 11 years old. She then married her cousin, the man with albinism. His father and mother both have normal skin. There are two with albinism in her husband's family: her husband and his young brother who passed away two months ago due to TB and cancer.

She has two children (aged 3 and 1) with him; both have normal (black) skin. She said that her husband has been coughing for some time now but he refuses to go to the hospital for treatment. He has got a very big wound next to his stomach which oozes blood a lot. This makes him unable to sleep most of the time, as he is always in pain.

When they got married people from her side accepted him as he is a cousin so they were already used to him. However she says she does not get along with one of her brother-in-laws. At one time the brother-in-law beat her because of a dispute about

fertilizer that his wife had stolen from their house. Her husband never said anything as he does not talk much.

Regarding myths she explained that people within the community were saying that 'he is only going to give birth to albinos'. When they go outside their community people call her husband different names like *mzukwa* (ghost) and *mzungu* (white man).

THOUGHT FROM A CONFUSED MIND: MY TRUE STORY

BY IAN DESMOND SIMBOTA



As part of this project, a young male scriptwriter, based in Blantyre (central Malawi) wrote an account of his life. He requested that his name be used with his 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, that's why I also consider myself as one of the hard workers for my life. Am the second born son in a four children family, two with albinism & two without. We grew up in a single parent family & happens to be a mother who raised four children, bringing us to school, then she was working as a cleaner at College of Medicine library & she used that little money to try reach her dream of seeing us schooling to a little higher, 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 divorced, 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 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.

Its through her (his mother's) effort that has made four children growing with ups & downs, 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 because we hardly have disability organizations who would have fought for us, so discrimination & teasing have been started by the teacher, then to students, a situation that was very hard to handle especially at a younger age & I remember I reached an extent of walking with a stick & I was using that to whip anybody who was offending my disability, it became worse because I remember I even lost friends because people were afraid of me, that I will beat them. Having abandoned school for two times the third time that's when my Mum took a step to go & talk to the head teacher after threatening them- of bringing them to book- they then took a step, 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.

In my secondary (school) life & the little college life I had, was at least easy because I presume the people were civilized but still I face challenges whenever am going out of my house as people may see me & start to laugh or call me names like napwero ziyele or they start telling one another in my presence that 'look at that, that's business in Tanzania, lets get him' & this affect me very much & always when I think of discrimination issues, with what I have gone through I seriously regret to have been born a Malawian. Currently am working in the albino clinic at Queen Elizabeth central hospital in Blantyre & I am one of the aspiring radio DJs with Malawi Broadcasting Corporation at their nursery department club called 'funline mix club' & I do produce, present programs & currently we just started a radio play called 'stories in action' where I am also part of it. I am an actor & a story writer & people are commending my writing job as very good so am looking forward to tell people how bad or painful it feels when you are being discriminated through my writing career in my upcoming scripts I always aim at standing as the example to my friends with albinism on the best that I can give the world & I consider my mum as my role model for the courage she took to raise four children with less resources.'

Details of the research team

1. Research Team

The Partnership consisted of the following people and institutions:

- a. Dr. Patricia Lund is a Principal Lecturer in genetics at Coventry University in the UK. She has directed multifaceted research involving individuals and families living with albinism in Southern Africa over the past 22 years. Pat was involved in designing the research tools, planning and logistical arrangements of the 10 day field visit (with Boniface Massah and Fatsani Mchekeni) in September 2012. She worked closely with Paul in writing the project proposal and planning, and with Boniface in organizing the field work. She worked with Paul and Boniface to develop information booklets for children with albinism and their teachers.
- b. Boniface Massah is chairperson of the Albino Association of Malawi (TAAM, now APAM), an NGO founded in 2005 to sensitize Malawian society on issues around albinism and to advocate for the human rights of people with

albinism. Boniface was involved in organizing the field work and conducting interviews with children and their parents. He was responsible for making contacts with families, local NGO and schools in advance of the study visits, to inform participants about the research study and seek their approval. He also carried out translating and transcribing interviews from Chichewa to English and wrote an initial draft of this report.

- c. Dr. Paul Lynch is a Research Fellow, at the Visual Impairment Centre for Teaching and Research (VICTAR), School of Education, University of Birmingham. He has been engaged in a range of international research studies into the education of children with visual impairment in Eastern, Central and Southern Africa over the past seven years. Paul was involved in designing the research tools and worked closely with Pat and Boniface on the report and development of information pamphlets.
- d. Fatsani Mchekeni has experience in data collection and has worked as a research assistant for the past seven years with various organizations. Fatsani was responsible for organising transportation and finances during the field visits. She interviewed female participants in the study and co-authored the initial draft of the field report with Bonface.

Coventry University supported this project through a grant from the British Academy and supporting Dr Lund's time on field work and writing reports.