

Barriers to access: factors limiting full participation of children with albinism at school in northern Malawi: Part 2

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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 visits to Malawi in September 2014 and March 2015

Funded by British Academy Small Research Grant (2012-2015) to Coventry University



Boniface Massah of the Association of Persons with Albinism in Malawi (APAM) with a young boy who also has albinism at an awareness day

Blantyre, Malawi, 19 March 2015

The theme of the day was *Living without Fear in Malawi; Birthright of Persons with albinism*

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*Guidelines for supporting the educational and social inclusion of children and young people with albinism in Malawi

This report documents field visits funded by a grant from the British Academy to Coventry University. These trips to Malawi were undertaken in September 2014 and March 2015; the final trip was to deliver feedback to stakeholders and develop guidelines for the education of children with albinism¹ in collaboration with members of The Association of People with Albinism in Malawi (APAM). This report addresses the escalation in attacks on people with albinism since late 2014 which has shocked the country and had such a devastating effect on all aspects of the lives of these families, including the education of children with this condition.

Context: security and safety of those with albinism in Malawi

Note that more background information on albinism in Malawi, the aims and context of this study, and the methodology adopted can be found in the accompanying field report for the earlier part of the study, in September 2012. This can be found online [here](#)²

Security issues for people with albinism in Malawi

In January 2015 The Association of People with Albinism in Malawi (APAM, formerly TAAM) reported an increase in kidnappings and killings of people with albinism in the country. The body parts of those with albinism are being used in ritual charms which are believed to bring good luck. Inevitably those targeted are the most vulnerable, including children. APAM are receiving reports of families not sending their children with albinism to school, but keeping them at home to protect them. Following these attacks members of APAM have been vocal in calling on the government to intervene and in appearing on radio and television to condemn these attacks.

Documented attacks on families with albinism

- In June 2013 a young man was lured to Mchinji on the border with Zambia with the offer of a job. He was warned that he was being targeted and managed to escape the traffickers. The local police and social welfare officers were informed.
- In March 2014 a nine year old school girl was kidnapped on her way back from school by two men. She was rescued by a passer-by who heard her cries and intervened. The case was reported to the local police station.
- In November 2014 a 25 year old woman with albinism in Mulanje district was found dead in a garden. Her body was found with all the limbs missing; the hands and feet were recovered nearby. The rest of her body and face were intact. She had last been seen drinking with her boyfriend from Mozambique. This murder happened close to the border with Mozambique and the police at the border crossing were informed, as well as the local police station.
- On 5 January 2015 an 11 year old girl was kidnapped at night by three men, one of them her uncle, but managed to escape. This area (Machinga) has many people with albinism who are reported to be living in fear.

¹ Albinism is an inherited condition resulting in a lack of pigmentation in the hair, skin and eyes. In African populations this makes a stark contrast to the usual dark pigmentation.

² Lund, P., Massah, B., Mchekeni, F. and Lynch, P. (2015) [Barriers to access: factors limiting full participation of children with albinism at school in northern Malawi](#). Coventry: Coventry University.

- On 16 January a two year old girl was kidnapped from her parents home at night and is still missing. Two days later a 68 year old woman was reported missing and found dead, with her head, legs and arms cut off.

In early March 2015 the Member of Parliament of Machinga East, Hon Esther Jolobala raised the alarm about abductions in her constituency and called for a national response. One man suspected of being involved in an abduction near the Mozambique border was apprehended but died when he jumped off a police vehicle while being transferred to the police station. On 19 March 2015 APAM organised an awareness day in Blantyre entitled 'Living without Fear; Birthright of persons with albinism' which attracted a large audience of over 200, with speakers from the political, legal and health arenas covering a broad range of issues around albinism. The key focus was on the recent abuses, with family members of those abducted talking powerfully about their experiences. This event attracted extensive local media coverage and support from the local members of parliament and a senior chief.

The government of Malawi and UNICEF are formulating a comprehensive plan to respond to these attacks at all levels.

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?

SUMMARY OF ACTIVITIES

Table 1 Visits interviews and meetings conducted in Malawi on two field visits, in September 2014 and March 2015

Location	Activity	Participants	Page number
Nkhotakota; offices of Malawi Council for the Handicapped (MACOHA)	Focus group discussion	7 adults (2 female, 3 male) with albinism; a mother of a baby with albinism; wife of one of males with albinism	11
Mzuzu town (capital of northern Malawi) and surrounds	Visits to families with Chairman of the Mzuzu branch of APAM (Association of Persons with Albinism in Malawi); interviews	3 families visited; interviews with a mother of two children with albinism & one with four children with albinism; adult with albinism	13
Chitipa in northern Malawi, on the border with Tanzania	Visits to two families in rural villages; interviews	Interview with a father of a young boy with albinism & mother of a young woman with albinism	16
Nyungwe Primary School	Meeting; discussion and introduction to albinism information materials	Headmaster & 3 teachers	19
Bandawe Girls Secondary School		Headmaster	19
Mzuzu, Education Division of the Synod of Livingstonia, Church of Central Africa, Presbyterian-CCAP	Meetings to discuss the project and collaboration	Separate meetings with Deputy Head of Education, the Secretary and 7 field officers on inclusive education programme	20
Loundo Training College, Embangweni (rural north western Malawi)	Training workshop	5 Lecturers at teacher training college	21
Karonga Teacher Training College	Meeting to discuss future training workshop	Principal and 3 SNE specialists	21
Mzuzu University	Meetings to share outputs, discuss project & future collaboration	Lecturer, Ambumulire Phiri	22
University of Livingstonia		Vice Chancellor, Professor Nyasulu	
TEMWA (NGO in remote lakeside village in northern Malawi, Usisya)	Meeting to share albinism information materials & discuss how they can support families with albinism in their catchment area	3 Members of the team	22
TDI (Tubepoka Development Initiative), Chitipa; funded by Willow Creek Community Church in the US		Executive Director & 5 field officers	22
Usisya Community Radio Station	Meeting to discuss raising awareness of albinism via radio programming	3 volunteer radio announcers	23
Dinosaur Radio Station, Karonga		Head of station	
Catholic Community Radio Station, Mzuzu		Head of station	
Blantyre, 19 March 2015: <i>Living without Fear in Malawi; Birthright of Persons with albinism</i> Albinism Awareness Day; More than 200 participants, including speakers from hospitals, parliament, a senior chief, the Malawi Law Society, Police and Ministry			

All project activities were conducted in close collaboration with Massah and other members of the Association of Persons with Albinism in Malawi (APAM).

SUMMARY OF FINDINGS

Security and safety for families with albinism in Malawi

The latter part of this study was conducted during a difficult and distressing time for families with albinism in Malawi, with an escalating deterioration of the security situation of those with albinism following reports of kidnappings and killings. Families became afraid to send their children with albinism to school in some areas.

Local reports suggesting that partners or family members were involved in arranging these attacks made it very difficult for parents and children with albinism to know who to trust. Visits around Karonga and Chitipa in September 2014 gave first hand information on the situation of persons with albinism in these districts, which border with Tanzania where these abuses have been more common.

Key outcomes from interviews in this region highlight the need to;

- Organize awareness meetings with all stakeholders, to mobilise broad-based community support
- Provide specific support to parents in areas where they fear their children may be targeted
- Develop networks and partner with local organizations working in the community
- Generate more evidence on the threat to children with albinism and develop a community response in consultation with parents, relatives and persons with albinism.

Other findings

Albinism affects the whole family, not just those with the condition

The interviews and discussions revealed the extent to which albinism affects the whole family, not only those with the condition. One family recounted how their black father could not find another wife after the death of their mother, as he had children with albinism. A woman with albinism described the effect on her six children (all black) who face '*challenges*' as children of a mother with albinism; other children in the community fear they will transmit albinism to them, so they are isolated.

Exclusion of those with albinism as they are not 'real' people

A family outside Mzuzu said their children with albinism were included in some activities but not others; they felt that some people in the community did not believe those with albinism are real people, like them. As a community they helped each other, but some did not believe that those with albinism could do certain things and

as a result they were sometimes separated and excluded. An example they gave was that at the graveyard the community did not allow the older boy with albinism to help with digging the grave and did not allow the girls with albinism to help cook at funerals. People said '*this job is not for you to work*'. They felt this was unjustified discrimination as their children with albinism '*can do anything*'. There was no problem with participation at weddings and they joined in other activities such as football and singing in choirs and at festivals.

People with albinism are not 'suitable' marriage partners

A 35 year old woman with albinism was divorced by her husband and has not wanted to pursue another relationship due to problems she has encountered with the family of prospective partners who consider her '*unsuitable*'. The mother of a 26 year old man with albinism in Mzuzu said her son had been in a relationship with a black girl but it only lasted three days before her family came and took her away.

The importance of family support

Despite the widespread negativity surrounding albinism, many positive aspects emerged from the study. Although having children with albinism is often seen as a valid reason for a man to divorce his wife in Malawi and other sub-Saharan African countries, families in northern Malawi reported support from fathers. One mother of children with albinism received regular money from her husband who works as a domestic worker in South Africa, where it is common for men in the north of Malawi to seek employment. Two young people with albinism living in rural northern Malawi were sent to live with their uncle in Mzuzu, who helped support and educate them, with another uncle also contributing to their needs by paying their school fees.

Within families there was generally support for siblings with albinism. A woman living in the capital of the Northern Region of Malawi, Mzuzu, reported that her children, including two with albinism and four who did not have the condition, were supportive of each other although the youngest black child did not understand why those with albinism had to put on sun protective lotion. She kept asking her mother if her sister with albinism was a *mazungu* (white European). This highlights the need for providing information on albinism to the whole family, including siblings, that is appropriate for even young children to understand.

Limited financial resources make it difficult for families to support those with albinism

Even with financial support from fathers families found it difficult to pay for the additional costs of sending a child with albinism away to a Resource Centre (where they would receive help from specialists in visual impairment) to board. Although the education itself is free, the family have to find the money for transport, soap and other essentials. This meant a child with albinism was often late starting the school term.

There was a marked contrast between Mzuzu (a large urban area) and more remote rural areas in terms of opportunities to access education, notably higher education and training. All three families visited in Mzuzu in September 2014 had young adults studying at secondary school level and aspiring to enter college, or pursue further training. One mother had found the financial resources to send her younger children

to board at a school with a Resource Centre for the partially sighted where they also had access to a regular supply of sunscreen lotion and the support of specialist teachers. The mother commented that they now had more friends down there than in their own community, although they did play with the local children during their holidays.

Support from the community

The positive impact of community support was shown by the appreciation families expressed when a church group visited their children with albinism who were boarding at a Resource Centre attached to a primary school in Nkhotakota. This woman's group interacted with them as well as bringing material assistance. The mother of a five year old daughter with albinism reported her young daughter was well accepted in their lake side village community, attending a pre-school organised by Indians at their mosque.

Participants also indicated cases of support by individuals outside the family. A woman with albinism at Nkhotakota had a brother with albinism who was looked after by members of the Institute of Education who were impressed with his drawing talents. He is now an artist and makes his living selling his pictures.

Self advocacy

A man with albinism, an effective local advocate, talked eloquently during a focus group discussion about the need for those with albinism (particularly adults) to be more pro-active in joining in and participating in local activities:

'We also discriminate ourselves by choosing to sit alone, in isolation and not associating with others. We should not get discouraged. If we want to go and watch that (football) match but do not go as people will laugh at us, we should take courage and attend.' (Limhani, a young man with albinism and Chairman of the Nkhotakota branch of the albinism association APAM)

Raising awareness and providing information on albinism

The information materials (booklets, posters, radio dramas) produced by the researchers for Malawi were well received and appreciated by stakeholders. For example, a mother of four children with albinism in Mzuzu commented on the information booklets on albinism for teachers that were developed as part of an earlier project in Malawi:

'Teachers need to understand that to be albino is not the wish of the mother or father, but of God'.

A visit to the headmaster of the highly regarded Bandawe Secondary School highlighted the importance of raising awareness on albinism among his pupils, so that this group, destined to be future leaders and influential members of Malawian society, are well informed and recognise the potential worth of those with disabilities.

Visits to other stakeholders revealed the lack of awareness of albinism; one local NGO described the visit by the team as *'a wake-up call'* that had opened their eyes to issues of albinism. They planned to include support for this group now that they were informed of their needs.

Disability training to include aspects of albinism

Meetings with various stakeholders in northern Malawi highlighted the need to broaden the range of partners in the albinism project and exploit local support in introducing joint training workshops covering more than one disability, for example hearing impairment and albinism. In combined training inclusive education could be explored in a more holistic way. Chiefs, pastors, social welfare officers, community development officers, health surveillance assistants as well as teachers should be included in training workshops. The role and responsibilities of these different groups could be explored, resulting in separate action plans for supporting children with albinism. This could be incorporated into on-going inclusive education programmes such as that run by the Synod of Livingstonia of the Church of Central Africa Presbyterian (CCAP). Their officers could follow up every three months to review, give feedback, and see where they can strengthen and assist the programmes.

Support structure for families with albinism

Sources of support for families with albinism in the Northern Region include:

- Members of the extended family, for example uncles
- Teachers at all levels, from pre-school to tertiary institutions, including local universities
- Political support via Members of Parliament, Traditional Authorities, civic societies
- Faith based organisations; the Church, both Catholic and Presbyterian (CCAP), Islamic organisations and evangelical groups
- External donors supporting the health needs³ of those with albinism (eye and skin care) as well as integrated training programmes for parents and teachers through the CCAP Synod of Livingstonia's inclusive education programmes
- Individuals or groups of well wishers, including local and international NGOs
- APAM, the Association of People with Albinism in Malawi, raising funds
- Community and other local Radio Stations raising awareness through their programming.

Extending the albinism project

The project team recognise the need to expand the education project to include secondary and tertiary institutions. On an inclusive education project in central and southern Malawi, funded by Sightsavers, Teacher Training colleges were key collaborators, with Machinga Teacher Training College producing a training manual around albinism and embedding issues of albinism in various parts of their core curriculum to ensure that all teachers receive basic training and awareness.

Freely available online information materials on albinism

The team have developed country-specific, accurate and objective information materials on albinism. When the recent abuses of people with albinism led to an

³ Those with albinism lack melanin in their skin, making them extremely vulnerable to sun induced skin damage; the condition also results in visual impairment.

immediate and outraged response from many agencies, both national and international, many said they were ill informed about albinism and requested more information on albinism in Malawi. The team were able to share the open access materials available freely through Coventry University's online repository.

These materials are all open access and are used for training around issues of albinism in Africa (click on the links to access them):

- two booklets on Albinism in Malawi; [Information for children](#) (also available in [Chichewa](#)) and [information for teachers and parents](#)
- a booklet for [children with albinism in Zambia](#) and another [general one for Africa](#) covers issues of inheritance. [Posters](#) and a [radio drama](#) called LOVE BUILDS have also been developed to support advocacy efforts and educate communities about albinism.

The team are committed to developing further materials. Two more episodes of the radio drama LOVE BUILDS are currently (June 2015) in production in Malawi and Lund is developing a booklet for young children, with maximum use of images and limited text, to explain key aspects of albinism to young children. She can be contacted at

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Report of field activities

Focus group discussion in Nkhotakota (a town on Lake Malawi)

Focus group discussion with seven adults: 2 females and 3 males with albinism, one black mother of a baby with albinism and the black wife of one of the males with albinism; this couple have two young children with albinism. All were active members of the local chapter of the albinism association, APAM. The meeting was held at the offices of the Malawi Council for the Handicapped (**MACOHA**) with their director observing and participating.

The main discussion point was to obtain feedback on the broadcast of the first episode of a radio drama (LOVE BUILDS), produced on a related inclusive education project funded by Sightsavers, which had been broadcast in Chichewa and English through the local community radio station. The storyline of the drama follows a young girl with albinism at school, highlight the health, educational and social issues she encounters and demonstrating how parental, teacher and community support can help her overcome the challenges she faces. The focus group were asked what other issues, based on their experiences, they would like to see included in future episodes.

Discussion points:

Limbani Malunga, an effective and enterprising Chairman of the local association, reported that their district association includes about 100 people with albinism. They were well satisfied with the awareness that was raised by broadcasting the radio drama LOVE BUILDS: it had caused much discussion within their communities. One young mother of a baby with albinism gave a very detailed and eloquent account of the storyline and the impact it had made on her.

Limbani made the point that those with albinism should make more effort to integrate themselves:

'We also discriminate ourselves by choosing to sit alone, in isolation and not associating with others. We should not get discouraged. If we want to go and watch that match but do not go as people will laugh at us, we should take courage and attend.'

The group described community attitudes to albinism:

- If the mother and father are both black and they have a baby with albinism the mother is usually rejected
- There are difficulties with a spouse or prospective spouse's family when marrying
- When their children with albinism go out to play they come back crying; in the villages they say they are ghosts and do not want to play with them.

Access to sunscreen, to help protect them from the sun, was an issue of concern. They used to have access to 'lotions' via the Social Affairs department, MACOHA or the district hospital but supplies were not regular and they would prefer to have one central delivery point.

Individuals described aspects of their lives, mentioning challenges they had faced and individuals who had helped them or their children at school and in the community:

A 27 year old man with albinism, the youngest in his family and the only one with the condition in a family of five, was educated up to Form 2 at a local private school. He was self employed and had a black girl friend still at school. He went to South Africa and worked with a company fixing roads for two months but came back to Malawi as he was not well accepted there.

A 35 year old woman with albinism from a family of seven, four with albinism, was educated to Form 2 at a community secondary school. She was married, but had divorced. The father of her black baby boy re-married. She lives alone and would like to re-marry. However there were always problems with the family of prospective partners: they say she is not '*suitable*'. So if anyone showed an interest in her and wanted to marry her she '*refuses*' and says '*No*', as she did not want to get involved with any man's family again. She had a small scale business, 'buy and sell', buying groundnuts, frying them and selling. She thought this was '*good*' but she had little capital.

A 33 year old woman with albinism has six children, none with albinism. When her mother died her father had problems finding another wife as three of his four children had albinism, herself and two brothers. She had dropped out of school in Form 2. When she was in Standard 6 at primary school her father died; they were taken in by their brother (who does not have albinism) but their sister in law did not accept them. She was made to cook food but was not allowed to share it out amongst the family members. The sister in law did this and disguised the fact that she was giving a very small portion to those with albinism. Their brother thought they were getting enough food but they were not. As staying with this brother was not working, they decided to say good bye and leave. They then stayed with an aunt and uncle on her mother's side, on a farm, but they were mistreated; these relatives refused to let them go to school as they had albinism and she relied on piece work to find food.

Her six children are all black, none has albinism, but they still face challenges as children of a mother with albinism. Others fear they will transmit albinism to them, so they are isolated.

When her brother with albinism was in Form 4 he was taken to Zomba by well wishers, inspectors from the Institute of Education, who looked after him. He is an artist who draws pictures which he sells in offices. She recounted his story: one of their brothers (who does not have albinism) is a teacher; the brother with albinism wrote a poem and drew a large picture for him to use in his class as a teaching aid. His talent was recognised by teaching inspectors from the Institute of Education, who took him under their wing and arranged for his education.

A black woman whose husband has albinism, as do the youngest two of their six children, both girls: one aged eight who is in Standard 1 at a local boarding school that has a specialist Resource Centre attached and the other aged five who attends a pre-school in their village organised by Indians at their mosque, where she is the only one with albinism. She has a small scale 'buy and sell' business, selling tomatoes at home.

Both girls with albinism are well accepted and have friends.

She recounted an occasion when a mother's group from the local Anglican church went to the Resource Centre where the children with albinism reside, to interact with them and show they are accepted. They sang for them and brought gifts of food, soap, clothes and lotions for their skin.

Her husband who has albinism is a fisherman; he reported he '*did not have much schooling*', leaving at Standard 3. He does not fish alone but goes out with four friends, both at night and during the day. He wanted his children to be educated so they can have a '*better life*'.

Family visits in and around Mzuzu (the main town in the Northern Region of Malawi)

Massah, in his role as director of APAM, the Association of Persons with Albinism in Malawi, commented on the impact of these visits:

'In Mzuzu three families were visited to explore education issues of persons with albinism. These visits aimed to encourage families in supporting the education needs of their children with albinism, as well as raising awareness of the project materials like the posters and albinism booklets.'

The chairman of the association's Mzuzu committee, Christopher Chilimira, facilitated the visits and took advantage of the trip to mobilize families of persons with albinism. This was advantageous to the association as members often do not attend meetings due to a lack of visibility of the association in the city. So only a few members meet as a group and share ideas. We hope that this will help the families visited open up for meetings and also invite others, to strengthen the committee. The visits motivated the leaders of the association to work as a team to reach out to more persons with albinism in the region.'

Christopher Chilimira, Chairman of the Mzuzu branch of APAM, introduced the families and accompanied the researcher (Lund) on visits to three families around Mzuzu.

Christopher is 34, married and from Karonga, the only one in his family with albinism. He has an older sister who is black and married. He got married in 2011 but does not have any children. A UK based small charity supported his wife to start a business. He tried to get his licence to be a driver but failed as he could not see number plates. He now has an indoor job at a local supermarket.

When young he lived near the lake and his skin had '*wounds*'; his friends would chase him as they said that he '*dirtied the water so he should not swim together with them*'. He stayed with an uncle (his father's brother) who was a teacher. When he came to Mzuzu a 'big manager' from his area in Karonga invited him to a meal, eating together; this had clearly made a big impression on him.

He stayed with his mother for some time, but not for long as she remarried and went to Ekwendeni (a specialist school with a Resource Centre for visually impaired). Now his mother is sick and has come to stay with him, although *she* had not invited *him* to visit her when she married again.

Christopher said they call those with albinism *chimlandi kundi* in Tumbuka: someone who is dormant and cannot do anything.

Family 1 (Mzuzu town)

The first visit was to the mother of two children with albinism; she is Tumbuka and has six children. All the siblings share clothes and food; she says they all '*have each other*' and are mutually supportive. Those who are black treat the siblings with albinism like the mother does although the young (black) one asks why her sister is putting on the lotion (for sun protection). Is she *mazungu* (a white European person)? The mother explained, No, she is not *mazungu*.

Her oldest son has albinism; born in 1988 he is 26 and a photographer, freelancing taking photos of weddings etc. He helps his mother a little but does not live in Mzuzu. There was a relationship with a black girl but it only lasted three days and then her family came and took her away. Her daughter with albinism is working to improve her grades for MSCE (Malawi School Certificate of Examination) so she can enter university. She is in Form 4 at a community secondary school, going to school from 2.30 to 4.30 pm.

Her husband left them in 2009; she described him as '*a drunkard*'. She felt that the man '*responsible for the family*' (the father) had abandoned them and she has had no support from him since then.

The family is supported by the mother who does 'buy and sell'; there were bags of charcoal in her house on the day of our visit. They receive help from MACOHA (Malawian Council of the Handicapped) to pay school fees and belong to a Pentecostal Church. The church does not assist them but they are well accepted there. There are no problems in the community as regards their albinism.

She was '*happy and grateful*' to see the '*pictures*' (information posters on albinism produced as a result of this and other projects in Malawi).

Family 2 (outside Mzuzu)

The mother of four children with albinism lives in a rural area some distance from Mzuzu town. They attend the monthly meetings of the albinism association (APAM) in town, but they are always late as they have to walk from home. The father works in South Africa as a domestic cleaner. He has been there for five years and sends money back to support the family. One of the older sons (aged 25) is also in South Africa and works in a house in Johannesburg.

Four of the seven children have albinism; at the birth of her children with albinism the mother thought '*this is what God has given me as a gift*'. The oldest child with albinism, Martha (age 21) is in Standard 8, Takondwa (always happy) is 18, Chikumbusi is 11 and Cynthia 8 years old. Takondwa went to residential Mzimba Secondary School and has just completed his MSCE. The results were due to be released soon after our visit. He wants to go to university to study English law at Chancellor College. Chikumbusi has been at Ekwendeni School for the Blind for four years and is in Standard 3. Eight-year old Cynthia is in Standard 1 at Ekwendeni. The school is free but they have to pay for transport (2000 MK X3 terms) and soap etc. When the children travel to Ekwendeni they walk to town to get the bus;

sometimes they are late going back to the residential school at the start of term as they have to *'wait for preparations to be completed'* e.g. buying soap.

When asked why she sent her children to Ekwendeni she said she had a friend with a blind son who goes to Ekwendeni and told her about this school. The children now have more friends at Ekwendeni than they have at home as they spend more time there, although they do have friends in the community and play *jingo* (skipping) and football.

The family are Seventh Day Adventists and walk to church on Saturday. She has recently got sunscreen for the children and they are well protected with SPF 30/40; they had six bottles on the day of the interview.

The mother said *'they' (people) 'do not believe those with albinism are a person like them'*. As a community they help each other, but don't believe that those with albinism are able to do certain things and they are sometimes separated in activities; for example at the graveyard they don't allow the older boy to help with digging the grave. They do not allow the girls with albinism to help cook at funerals. They say *'this job is not for you to work'*. They felt this was discrimination as they *'can do anything'*. There was no problem at weddings and they join in other activities such as football and singing in choirs and at festivals. They are included in some activities but not others.

The information materials on albinism were well received by the family. In the words of the mother *'they give a lesson to encourage the children to go to school. Teachers need to understand that to be albino is not the wish of the mother or father but of God'*.

Researcher's observations: This family seemed relatively well off with several brick houses and a large sound system in their main room; Takondwa had a bicycle.

Family 3 (Mzuzu town)

The third visit was to 18 year old Vitumbiko who has albinism; he lives in the outskirts of Mzuzu town. His family are farmers from Chitipa (on the northern border of Malawi, close to the Tanzanian border) but he stays in Mzuzu with his uncle. Two of the seven siblings have albinism; his sister (aged 16) who has albinism is also in town. She is in Form 4 and is also awaiting MSCE results. The uncle (their father's brother) called them to stay with him so they could be close to a school. He is married and works as a carpenter; he provides them with accommodation and food. Another uncle gives them clothing and school fees. This uncle works in Tanzania as an accountant, close to the border.

Vitumbiko did his MSCE in 2012 and got a score of 42 (university entrance required points of between 6 and 20); his dream is to do a course in business management at a private college. He started a four year business studies course at Mzuzu Technical College which has fees of 70 K MK per semester, but did not write his examination as he could not pay the exam fees. The problem is that the college is a long distance for him to walk to in the sun. He had friends at college but no girl friend. He felt well accepted by the community and joined in funeral and other activities.

Family visits in Chitipa, a town in the Northern Region of Malawi close to the border with Tanzania

Thomas Nkhonjera, a field officer for the Education Department of CCAP (Church of Central Africa Presbyterian) accompanied Lund on a field trip to Karonga and Chitipa in September 2014. This is his home area where he grew up and worked. He thus has extensive local knowledge, speaks the local dialects and was an invaluable member of the field team.

A key visit to a family with a young boy with albinism living outside Chitipa was reported by both Nkhonjera and Lund.

Family 1 (rural Chitipa)

The report by Thomas Nkhonjera gives the geographical and cultural context of the area and shares his opinion, based on his experience as a field officer, on the local attitude to those with disabilities.

STIGMA AND DISCRIMINATION AROUND PERSONS WITH ALBINISM IN CHITIPA

Chitipa district is located in the Northeast of the Northern Region of Malawi. It is bordered by two international boundaries, Tanzania to the North and Zambia to the East. Chitipa district also shares boundaries with two other Northern Region districts of Karonga and Rumphi to the North East and South respectively. The district is approximately 400 kilometres from Mzuzu, the Northern Region's city and 700 kilometres from Lilongwe, the Capital City of Malawi.

Chitipa district, the northern most in Malawi, was identified by the Vulnerability and Mapping Report in 2013 to be the most marginalized based on levels of poverty and lack of access to services and information. The district with a total population of 209,072 people (according to 2013 Malawi Population and Housing Census) has a total land area of 4,288 square kilometres making up 3.62% of the total land area of Malawi (118,484 square kilometres): its people live in 507 villages that are scattered throughout the mountainous terrain of Chitipa.

Due to cultural beliefs, practices on albinism in the bordering countries like Tanzania as well as lack of access to information, many people in Chitipa do not know who people living with albinism and other disabilities really are. They believe all kinds of things about them which are not true, such as that the mother had sexual intercourse with a European, she ate the wrong foods when she was pregnant, she ridiculed or was cruel to people with albinism, to mention a few. As a result, persons with albinism face different sorts of stigma and discrimination such as being kept indoors, denied services including health and education and risk being killed and their body parts used for business purposes. Some people in Chitipa, as in neighbouring Tanzania, believe that those with albinism have special powers and their body parts can be used in good luck charms to enhance success for any business. These beliefs and practices make those with albinism and their family members live in fear. It has become a life threatening condition in Chitipa to the extent that some families have sent their children with albinism away from Chitipa while adults are kept indoors without going to any public audience such as market places, in order to keep them safe and alive.

The threats as well as stigma and discrimination do not impact only on individuals with albinism but affect the entire family. This was evidenced in an interaction with the family of Mr. Kenwel Sikwese in Chitipa district. Mr. Kenwel Sikwese is married to Nelius Namwila and they have five children, two girls and three boys. Of the five children, the third born son Chaupe “Gift” is the only child in the family who has albinism. Chaupe is nine years old and goes to School, doing Standard 3 at a primary school which is located one kilometre away from their village. He is well supported by his brothers and sisters when going to school and after school. His fellow children in the family associate very well with him in everything that happens in the family. His grandmother is very supportive of Chaupe at home.

When asked how the condition of their son Chaupe affects their day to day living in the community, this is what the family had to share:

“Chaupe is our son. We have accepted his condition from birth and we gave him this name of Chaupe meaning “Gift” to send a message to the entire community that we love him and he is like anyone else. However, his condition is a life threatening situation here in the village and Chitipa in general. Nowhere is safe. We are close to Tanzania where there is a lot of killing of people with albinism, with a belief that albinism has special powers for any business and once one has the body parts, one gets riches. We have had some strangers moving round this village believed to be looking for our child to be killed for business. We have heard rumours from fellow community members that one day our child will be killed. As of the moment we trust no one in this village as far as the condition of Chaupe is concerned. We live in fear each and every day. We just do not know what will happen to Chaupe. I and my wife, make sure Chaupe goes to school with his friends so that he is protected. When he plays with friends, we make sure he is within our watch. This causes distress to us as well as being a burden to our child. He is not free to associate with friends freely anywhere apart from at school where the teachers provide help and make sure he is with friends at all times as a security measure. He cannot walk alone which we know creates a dependency syndrome in his life. This is not our wish. We do not get any social, spiritual and economic support from the community members apart from our church. This is a tough life in this village but we hope for the bright future for our child one day”.

Mr. Kenwel further explained that their fellow community members do not come openly to discuss the life threatening situation of Chaupe. Sometimes, the family hears their fellow community members giving directions to the house to strangers, saying they are a family having a child with albinism. According to Mr. Kenwel, this situation makes them lose attention to other aspects of parental care of the children, as their focus is on how to safeguard Chaupe from any hurt. He also said that Chaupe goes about one kilometre to school; they are worried that one day Chaupe may get harassed on his way home because he is in Standard 3 and the knock off time is different from that of his brothers and sisters whom they trust to provide security, rather than just relying on schoolmates from the same village.

It is my evaluation and opinion, as a writer and Field Officer from my work experience and interaction with community members, that in most of the villages in

Malawi I have gone to, people with any kind of disability face a number of challenges. Challenges of stigma and discrimination, given different mockery names, being harassed, denied access to services and information, to mention a few. Any project dealing with the mindset of people about one particular disability, needs to consider how to incorporate other disabilities in community awareness meetings. People with disabilities face similar challenges and community members need to be oriented in all aspects of disabilities rather than one single disability. In doing so, people with disabilities will be protected in areas like Chitipa, they will have access to services and information, stigma and discrimination will be avoided, they will have freedom of association without fear, their lives will be spared, they will progress like everyone else in the community, they will be self-reliant and participate in personal and national development.

Report by Lund on the same family visit, based on observation and translation by the field officer:

Thomas Nkhonjera interviewed Kenwell Sikwese in a rural setting outside Chitipa town. Kenwell gave informed consent for his name to be used. His son with albinism, Chaupe (a gift) was aged nine and in Standard 3 at school at the time of the visit; he is the only one with albinism in a family of five siblings. Others in the community knew that '*something is wrong here*' (in this house) although no-one came and talked directly to them. After his birth, at first there was panic from other members of the community; they viewed the family with suspicion as there had been no previous cases of albinism in the village, although the family accepted it as there had been a case in their family before- the mother's uncle had a child with albinism.

When Chaupe was born at the hospital the doctor said '*this is a gift; it happens; use an umbrella when carrying the baby*' and they bought one. They reported that Chaupe had '*eye problems when the sun is up*'; he sits under the shade. He wears a hat but takes it off and leaves it somewhere, coming home without it, and has long trousers which he wears to school.

The family felt that Chaupe was accepted in the immediate community. They belong to AIC (African International Church) which provides soap and oil.

At school his female teacher is comfortable with Chaupe and handles him well; she was helping to sensitise the community. Although the teacher helped a lot his friends put him at the back of the room, so his father went to ask the teacher to orient them and explain his needs. After that he sat in front. Other learners have now accepted his condition although at first they ran away from him, thinking he was '*not like us*'. His father felt Chaupe '*tries and does well*'. He plays football, walking to the pitch.

The family are farmers, growing maize, cassava, tobacco and soya. Chaupe is too young to help at present and the father said he would leave Chaupe himself to decide if he wants to help when he is old enough to do so.

Later in the interview the father expressed his concern about attitudes within the wider community: '*the community at large feel we are different.*' Recently the father had become concerned about the attitude of people, fearing that they would target his son for rituals. They heard rumours of what happens to those with albinism in Tanzania.

Researcher's observations: the family all appeared very protective towards Chaupe; the father in particular held him within the circle of his arms or kept a hand on his shoulder during the meeting.

Family 2 (rural Chitipa)

The second family visit was to the mother of a 16 year old girl with albinism who boards further south at Ekwendeni Special School. The father is a teacher at the local community school and their house looks out onto the first town in Tanzania. The mother was told by a neighbour that '*they (people with albinism) are sold in Tanzania*'. When her daughter visited them during the holidays, she had concerns for her safety. While walking with her daughter in the market she heard people say: '*That one is money in Tanzania*'. Then a neighbour came to her and suggested they get together and sell her daughter and share the money. She feared for her daughter's safety in Chitipa and sent her back further south for her protection.

Researcher's observations: the discussion on this visit was dominated by concern for the security of her young daughter with albinism, who was not present at the interview.

Visit to a Primary school in the Northern Region of Malawi

The headmaster of **Nyungwe School**, MacHudson Ng'oma was interviewed; their school is a church school, part of CCAP (Church of Central Africa, Presbyterian), with 1205 learners, 21 teachers and a Teacher Development Centre. The school had previously been generously supported by the Australian owners of the uranium mine near Chitipa, but this had closed, they had left and could now offer only limited support. The school has 17 blind/low vision learners, including three boys with albinism: one 6 year old in Standard 1, a 10 year old in Standard 4 and an 8 year old, also in Standard 4. They board at the school where there is a Resource room to support those with visual impairment. They get sunscreen from the hospital, with the children, escorted by a teacher, going to collect the supplies.

The head gave his impression of the impact of albinism in families: '*A baby born with albinism shakes a family*'.

The discussion focussed around possible training on albinism for teachers, using the Teacher Development Centre as a venue for a workshop. The information booklets and posters were much appreciated as the teachers felt there was a great need to raise awareness around the issue.

Visit to a Secondary school in Bandawe (rural lakeside setting)

Massah reported on a visit to the headmaster of **Bandawe Girls Secondary** to introduce the albinism project. It was noted that the school has very strong management and offers good support to the girls attending this prestigious school in the Northern Region. The head teacher recognised the need to have disability talks to make sure that the girls have a real life experience of issues of disability. He indicated that it is through that process that the girls will be able to recognise the potential of persons with disabilities and also change their mindset to attain an inclusive society.

This visit highlighted the need to target secondary as well as primary schools for inclusion in training around disability issues; these pupils come from around Malawi and are likely to be influential members of society in the future.

Meetings with other stakeholders in northern Malawi

Meetings at the Education Division of the Synod of Livingstonia

Massah (researcher on this project) leads the inclusive education programme of the Special Educational Needs section of the Education Division of CCAP (Church of Central Africa, Presbyterian) and is keen to integrate training on albinism within their existing and future programmes focussing on other disabilities, such as hearing impairment.

Lund and Massah met the Deputy Head of Education at CCAP to discuss the church's educational support for those with special needs and their training programmes. CCAP have a committee who monitor their schools after the first term and analyse those who need assistance. The Deputy Head explained that the families of girls selected to go to prestigious schools such as Bandawe Girls Secondary School will do whatever they can to send their daughter to school, for example selling a goat to obtain the required funds, but then the family resources dry up and there is no money for the second term and they have to be sent back home. Their sources of funding within CCAP are not steady, but they do have a pool from Ireland and the US for scholarships to support pupils at their schools.

The Deputy Head reported on ways in which they had investigated extending their training programmes to include a focus on more than one disability: they had piloted a one-day combination workshop for teachers in Mzimba South, including training on both hearing impairment and albinism. At Parent Awareness sessions for one of their externally funded programmes on hearing impairment they included families of children with albinism. Issues of albinism were also included in another programme- INSET- a one week training course on inclusive education for teachers, where participants selected included the head and two other teachers from each school. She stressed that the Synod's programmes and schools reach into very rural areas.

In a separate meeting of project officers on the inclusive education programme, they reported strong support for this approach, with a lot of interest in this integrated training programme from both parents and teachers. In the pilot joint workshop, the teachers participating created songs/poems/drama activities incorporating both hearing impairment and albinism. Teachers said they had no prior knowledge of how to care for children with albinism. The pilot identified gaps in their knowledge which the project officers felt were addressed by these integrated training sessions. The field officers also mentioned the importance of speaking to children separately from their parents, which is what they do on their two day training for parents and children with hearing impairment. The children report if they are fed before going to school, if teachers repeat if they cannot hear and how they feel their parents and teachers are treating them. This leads to very open discussions, with parents often admitting they are failing to support their children adequately and apologising to them. The team have found that it is key to train the mother of the child needing support. If they train only the father, who then goes out fishing and is away for most of the time, it is difficult to ensure support for the child, as he does not share the training he has received with the mother, who is with the child on a regular basis.

A further meeting with the Secretary of the Synod of Livingstonia indicated strong support for broadening training around disability issues and including albinism in this remit. The Secretary felt there had been too little emphasis on albinism in the SNE department, that they were *'lacking something; the emphasis was not enough'*. Now that Massah had joined the team this had been *'a sensitisation to the department'*. The Secretary was keen to integrate training on hearing and albinism. He stressed the need to collect data on frequencies of those with albinism, especially at CCAP schools. The discussion revolved around possible ways to sensitise and mobilize people to work together.

Training workshop for lecturers at Loundo Teacher Training College in Embangweni, (rural north western Malawi)

Lund, Massah and education officers from CCAP joined forces to conduct a one day training workshop around hearing impairment and albinism with five lecturers at **Loundo Teacher Training College** in Embangweni, a rural area near the western border with Zambia. It was noted that the lecturers lacked basic skills on special needs education, making it difficult for them to support the students with special needs at their college and to supervise them when they are out on practical teaching experience.

A key question the participants asked was why people with albinism call themselves disabled, why they form their own association. The participants felt this was *'self discrimination'*.

Massah explained the need for those with albinism to be in a group to make visible the challenges faced by people with albinism, and to promote their rights as a minority group in a back society. He stressed *'our skin and eye problems are permanent impairments that cannot be changed, hence the disability aspect'*.

Supporting training of those at the teacher training college forms part of the education project at the Synod of Livingstonia and they plan to follow up after the training workshop, to monitor and evaluate the following:

- How lecturers include issues of disabilities in their teaching
- How lecturers monitor students on issues of disabilities
- How student teachers are examined or assessed on special needs to make sure that they take this aspect seriously
- How lecturers could encourage student teachers to produce case studies of their experience and management of special needs learners during their one year practical period. This would form part of their final assessment.

This strategy will ensure that disability and inclusive education issues are addressed during the training of all teachers graduating from this institution.

As a follow up of this training workshop for teacher trainers, a short visit was made to **Karonga Teacher Training College** where the Principal and three Special Educational Needs specialists were very interested in the albinism project and its outputs, asking a lot of questions and being very supportive of the idea of combined training workshops around hearing and albinism.

Meetings at the two universities in northern Malawi

Massah and Lund had a meeting at **Mzuzu University** with Ambumulire Nellie Phiri, a lecturer who has recently returned from studying at Missouri University in USA and is planning to set up a Centre for Inclusive Education which will connect directly with the community via outreach programmes. This will provide a platform to mentor/support teachers in field. She also has future plans to develop a Masters in Inclusive Education and was appreciative of the materials and evidence around albinism collected in the albinism research studies.

Lund and Massah also had the opportunity to meet the newly appointed Vice Chancellor of the **University of Livingstonia**, Professor M Z Nyasulu who expressed a strong interest in the albinism project and involving members of his university staff in research and training around issues of albinism.

Meetings with other NGOs in northern Malawi

The team visited an NGO based at a remote lakeside village in northern Malawi, Usisya. **TEMWA** have a range of community projects including agricultural support, health training, youth clubs, training in business management and microfinance loans. They provide books and support young people at secondary schools and in tertiary education such as teacher training. They have an impressive library and adult literacy programme, a demonstration garden showing new methods of farming and a meeting hall where a group of local artists have painted pictures on the walls around the theme of gender equality. Information materials on albinism were left for their library.

At the time of this visit there were no families with albinism in the area but there had been one, the daughter of a policeman who had applied for a transfer to a more urban area as the sun exposure at the lakeside was a problem for her sensitive skin.

Thomas Nkhonjera, a field officer who accompanied Lund on a visit to the northern border region of Malawi, knew of a local NGO, **TDI (Tubepoka Development Initiative)** which was supporting a girl with albinism, and arranged a meeting with them. TDI, funded by a church in the United States, Willow Creek Community Church, work with 438 local churches around Chitipa. They have an extensive network of volunteers, passing on health and other messages. Paul Ngambi their Executive Director said:

'It shakes a family when a baby with albinism is born, people think of them as business material and do not regard them; they don't pay attention to them'.

Paul commented that this visit was *'a wake-up call'* that had opened their eyes to issues of albinism. They would include support for this group now that they were informed of their needs. Their genuine interest was evidenced by the follow-up the group conducted after this visit, gathering information on members with albinism in their area and sending this information to Lund in February 2015. This included details of 10 people with albinism, aged between one and 35 years old, one at nursery school, five at primary and one at secondary school (in Form 3).

Massah, in addition to being a researcher on this project, is also the executive director of the local albinism support group, **Association of Person with Albinism in Malawi, APAM**. They are actively fund raising to support the education of

children with albinism in Malawi, especially at secondary school. As an example a talented young man in Mchinji (western Malawi) has gone to a private Catholic secondary school in the capital Lilongwe. He is funded by his mother with APAM supporting him with materials, books and long sleeve uniforms. A group of Czech optometrists/eye specialists who visit Malawi each year are supporting eight children (one at primary school) in this area. APAM have obtained funding for printing information booklets on albinism for children from the Dutch Albinism Society and others.

In the final visit on this project in March 2015 Lund met with members of APAM to draft a set of guidelines on the education of those with albinism (see Appendix).

Meetings at radio stations in northern Malawi

Visits were also made to **local radio stations** (Usisya Community Radio Station, Voice of Livingstonia in Mzuzu, Dinosaur Community Radio Station in Karonga, Catholic Community Radio in Mzuzu) to discuss ways of raising community awareness around issues of albinism, in particular by airing episodes of a radio drama called LOVE BUILDS. This is an evidence-based series written as a drama, following a young girl and a boy with albinism, highlighting their struggles and successes at school and showing how parents, teachers and members of the community can help them achieve their full potential by having an awareness of their sun sensitivity, their visual impairment and also by promoting their social inclusion.

A visit to **Dinosaur Radio Station** revealed the potential offered by community radio stations in supporting advocacy efforts, both in gathering and in disseminating information on albinism. This radio station reaches a 100 km radius, going up to the border regions with Tanzania and reaching remote rural communities along the lake shore. They have a weekly social awareness drama and daily education programme where issues of albinism could be aired, as well as listening groups of community members who give feedback on their programmes (one was in action outside under a tree on the day of our visit). They '*get to hear what is happening*' as people come in to visit them and report. This would be a means of finding out about attitudes to albinism in more remote, rural communities and a means of evaluating the community response to interventions such as broadcasts of the radio drama LOVE BUILDS, and assessing its impact in shaping and changing attitudes.

Appendix 1

Details of the Research team

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 (Staff profile [here](#)). She has directed multifaceted research involving individuals and families living with albinism in Africa over the past 22 years. Pat was involved in designing the research tools, planning and logistical arrangements of the meetings and field visits (with Boniface Massah). 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. He was responsible for making contacts with families, local NGOs and schools in advance of the study visits, to inform participants about the research study and seek their approval.
- 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.

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

Appendix 2

Guidelines for supporting the educational and social inclusion of children and young people with albinism in Malawi

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Dr Paul Lynch (University of Birmingham)

Bonface Massah (The Association of People with Albinism in Malawi)

Study funded by Small Research grant from the British Academy (2012-2015)

Introduction

In Malawi government education systems exist at national level through basic education directorates, including the special needs education and at district level through the District Education Manager (DEM), at zone level through the Primary Education Advisor (PEA) to the school and at the community level through the primary school head teacher.

These guidelines are chiefly aimed at education officials but are appropriate for use by other governmental and non-governmental agencies in Malawi, as well as by advocacy groups at a national, regional and international level.

These guidelines were developed in close collaboration with members of the local albinism association *The Association of People with Albinism in Malawi* (APAM). They aim to foster and support the integration and acceptance of children with albinism in their communities, within the education system and the wider Malawian society. In order to provide supportive care and education for children and young people with albinism, cost-effective and efficacious programmes need to be established and integrated with existing community, education and health services at district level. APAM recognises the importance of multi-sectoral approaches and promotes the training of education, health and social welfare professionals at national, district and zonal level.

In the research studies that informed the development of these guidelines there was a strong emphasis on encouraging participants to express their opinions and experiences using their own language and interpretation, and to focus on identifying solutions they believe will work in their context. In this and related projects both family members and professionals reflect on their experiences of young children with visual impairments and contribute to the development of tools for improving their communication, play and social development skills.



The following sections provide professionals and officials with useful and practical tips on how to accommodate the specific educational, health and social welfare needs of children and young people with albinism in Malawi. These link to Article 24 in the UN Convention on the Rights of Persons with Disabilities, that *persons with disabilities can access an inclusive, quality and free education on an equal basis with others in the community in which they live* (Clause 2 b).

Facilitating strong community support for children going to school

Parents of children who have albinism may not think of sending their child to a pre-school or primary school because of concerns that their child will be teased or not treated well by the other children or by caregivers or teachers. Walking long distances to get to school is problematic to those with albinism as they lack protective melanin in their pale skin and are extremely sensitive to the sun; this adds to the parents' difficulties and anxieties.



APAM sees a strong need for village communities and leaders to work closely with local councillors, community assistants and child protection officers to identify ways to protect the rights of families who have children with albinism and ensure that children with albinism are safe to travel to and from school.

The research team suggest the following activities to strengthen support for children going to school:

Child protection officers to work with the parents/guardians of a child with albinism, so that they can help prepare the child for school. The parent may need to stay at the child-based community centres (CBCC) to support the child to begin with, helping the caregivers and teachers to understand how to support their child

The community policing committee (Malawi police service) to be given specific training on ways to protect the lives of children with albinism and encourage them to provide the necessary protection to all vulnerable children who go to CBCCs, primary and secondary schools. **Child protection officers** should liaise closely with families of children with albinism and the staff running educational establishments to ensure the children are protected at school and are not vulnerable to bullying

Child protection committee's training to include a component on how to offer protection to those with albinism as part of their **training programme**. When a child with albinism enters their school, **head teachers** to immediately contact their **District Education Managers** to obtain information booklets on albinism from the Ministry of Education and contact local advocacy groups such as APAM and other organisations that represent the rights and interests of people with albinism; they should also investigate support from teachers trained in Special Needs Education (SNE). Community based committees to include a representative of a family with albinism to ensure **self- representation**.

Helping CBCCs and schools prepare for the needs of children with albinism

Caregivers (pre-school teachers in CBCCs) and school teachers (primary and secondary level) with no prior experience of looking after or teaching children with albinism may be unsure how to support them. Parents and other members of the family usually know how best to help their children both inside and outside the home. A workable strategy would be for the **child protection officer** or a **community assistant** to set up a meeting between the teacher and parent *before* the child starts school so that she/he can be more prepared to support those with albinism at school.

Information booklets on albinism have been developed as part of this and other projects on albinism in Africa. An extract from the booklet for children is shown in the image below:

Will I go blind because I have albinism?



No, your eyesight will change as you get older, but you will not lose your sight.

Braille is not recommended for those with albinism as vision will not deteriorate with age due to albinism, as this is not a progressive condition. Although visually impaired, children with albinism have sufficient residual vision to enable them to use print rather than Braille. Forcing those with albinism to learn Braille is an unnecessary additional burden and will limit the educational potential of children with albinism.

[Information booklets](#) have also been developed specifically to give hints and tips to teachers on how to assist a child with albinism to reach their full potential.

Below is a list of suggested ways in which parents can inform teachers about the needs of their child with albinism:

- Tell the teacher about your child's skills and abilities as well as their limitations due to their visual impairment
- Tell the teacher about your child's visual problems – explain what he/she can see and how he/she uses their sight e.g. they are able to read letters off a board if seated at the front of the class and if letters are written in thick chalk on a clean black board
- Explain that the child may have problems moving around outside and may need some orientation when he/she starts school
- Discuss any challenges your child may have e.g. playing sports such as football or doing chores out of doors in the middle of the day
- Discuss ways of adapting the classroom environment to accommodate your child, rather than removing children with albinism from the classroom for special tuition
- Encourage the teacher to include your child in all group activities, not to exclude them
- Ensure that the child does not travel to and from school on their own but is accompanied by a sibling, friend or a trusted member of the community.



Virginia has albinism. When she started school she did not realize her friends could all see the board while she could not. She asked for help from her teachers and now she is a teacher herself.

Educational professionals, such as specialist teachers (or itinerant teachers) should be invited to **teacher in-service workshops** to discuss albinism and explore ways to support these children at school. It is important that all staff at schools educating children with albinism attend these workshops so that they are well informed and can intervene immediately to support a child with albinism in their class.

Community support for children with albinism

As well as supporting teachers, there are many other ways for different stakeholders to help ensure children and young people with albinism are safe from potential threats that may be harmful to them outside school in the community. It is therefore important for families to work closely with educational establishments and staff so that their children remain safe at all times, for example when they travel to and from school, as well as at school.

Pre-school support: CBCC management committees are key agents in making the necessary arrangements to accommodate a child with albinism; they should be informed of all children with albinism in the villages. Caregivers will need to receive guidance on how to look after, stimulate play (e.g. using bright, colourful toys) and make sure this group of vulnerable children are safe at all times.

At primary school: Parent-teacher associations (including local village leaders and parents), mother groups and school management committees should all receive training and information on albinism. Ideally these committees should include a parent representative of children with albinism, to ensure self-representation at school level. In the Malawian context these committees 'own' the school and are responsible for the operation and management of student welfare and special education support so they are key agents in the support structure.

Primary Education Advisers (PEAs) and **Special Needs Desk Officers** should assist in the monitoring and sensitization plans for the inclusion of children with albinism in each district. This could be done through zonal head teacher meetings and school based staff teacher meetings. These could also be planned by head teachers or form part of in-service training for teachers at zonal rural teaching centres.

Co-ordinated support: Each child with albinism should have a class or specialist teacher (or itinerant teacher) with overall responsibility for supporting their education, for training other teachers, liaising with parents and ensuring they access all available support, including large print examination scripts and protection from bullying and name-calling.

Lobbying for enhanced government commitment

Given the recent increase in the number of people with albinism being abducted and killed in Malawi, there is a strong need for **the Ministry of Gender, Children, Disability and Social Welfare (MoGCDSW)** and its partner ministries to take a strong lead on protecting the needs of people with albinism and put in place

protocols that eliminate any type of discrimination and maltreatment of people with albinism. To this end the Government of Malawi has devised a broad-based response plan covering education, awareness, internal security, human rights monitoring, legislation, administration of justice and victim support, as well as promoting the empowerment of persons with albinism.

The **Ministry of Education of Education, Science and Technology (MoEST)** should conduct an annual audit of all school data held at district education offices to confirm the numbers of children with low vision (including those with albinism) who use large print and may require additional optical magnification through the use of low vision devices (e.g. small hand-held magnifiers).

The **Special Education Directorate** of MoEST and the **National Examinations Council** should provide specific instructions to all schools in order to reduce potential barriers to accessing appropriate assistance with examinations and assessment. Schools need to ensure students with albinism have access to test or exam papers in large print versions and are allocated additional time for the test or exam to be completed and allowing breaks (if necessary). Ideally tests should be timetabled in the morning when children are less likely to have tired eyes.

MoEST should revise its dress code on school uniform to accommodate the health and well-being of students with albinism. Children with albinism should be allowed to wear protective clothing, such as hats, long sleeved shirts and long trousers/skirts.

MoEST should ensure teacher training colleges and the civil service college (Magamero College) work collaboratively to ensure all training programmes to support people with disabilities include a component that deals with albinism.

Malawi Human Rights Commission (MHRC) could produce a short information video (approximately 15 minutes) highlighting some of the ways different agencies (social welfare office, human rights organizations, the police, the media) can support and promote positive attitudes towards people with albinism.



Final message! There needs to be a strong push for these guidelines to be sent to all DEM offices and schools across Malawi, including those in remote, rural settings.

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