

# Barriers to access: why are some visually impaired young people with albinism in Malawi not attending school? Overview and guidelines.

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Field report part 1 is available from: <https://curve.coventry.ac.uk/open/items/887e54e8-8538-4028-9d96-b2b6d3b96615/1/>

Field report part 2 is available from: <https://curve.coventry.ac.uk/open/items/0ea99e7e-e820-4933-804e-ea945e125eb0/1/>

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# Barriers to access: why are some visually impaired young people with albinism in Malawi not attending school?

## British Academy Small Research Grant (2012-2015)

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### Lay Summary

Albinism is an inherited condition where very little melanin pigment is produced, resulting in pale skin that is very sensitive to the sun and poor eyesight. In African populations, those affected look visibly different from their dark skinned peers, which can lead to ostracism, bullying and social isolation. This study explored the lives of children and young people with albinism along the lakeside and in the mountainous northern part of Malawi. It revealed how albinism affects the whole family, not only the person affected, and how they can be considered as sub-human and 'useless', although attitudes within families were generally positive and supportive. Acceptance by the father was a key factor, in terms of both financial and emotional support. The importance of parental choice in the mode of education of children with albinism was a common theme; some children were happy boarding at Resource Centres attached to mainstream schools which provide specialist care whereas others preferred to remain at home, within their own communities. The security of those with albinism was the predominant concern for families, constantly fearful of attack as they are targeted for their body parts for use in rituals and 'good luck' charms. The outcomes of the study have been used to devise a set of guidelines to recommend to government and other agencies, to improve the safety, access to health and education and social acceptance of these families. Advocacy posters have been used to raise public awareness and promote respect for those with albinism.

### Field reports

Two field reports with details of the study are available online:

[Field report Part 1](#)

[Field report Part 2](#)

## Overview

### Security for families with albinism<sup>1</sup> in Malawi

The situation for people with albinism, particularly the children, in Malawi changed dramatically over the three year period of this grant. In the first two years the focus was on investigating inclusive education as well as social practices and attitudes that influenced the attendance and participation of this group of visually impaired children at school. In the last year the worsening security situation, with reports of killings, abductions and mutilations of individuals with albinism, resulted in a national and international response to raise awareness to combat these attacks. The results of this and other studies have provided an extremely useful evidence-base to support and inform advocacy efforts at this difficult time for families with albinism.

One stakeholder interviewed described how *'having a baby with albinism shakes a family'*. Our study provided first-hand accounts of how albinism impacts on everyone in the extended family, including non affected siblings and other family members. Although attitudes within families with albinism tend to be positive, in the wider community they are often considered 'the other', as sub human, as commodities to be bought and sold rather than human beings to be respected as members who are 'different' in the colour of their skin, but have the same feelings and aspirations as their dark skinned compatriots.

The deteriorating security situation has instilled fear in these families as they wonder *who is their friend, who is the enemy?* The latter part of the project highlighted a new aspect of child protection, of how to ensure the safety of children with albinism, particularly in getting to and from school. The remit of training around issues of albinism needs to be across the sector, to be widened to include other stakeholders, especially social welfare and community rehabilitation workers, as well as the police and politicians. Training manuals should focus on knowledge/information on albinism for a broad range of stakeholders (similar to the one developed by the research team for teachers as part of another project in Malawi).

The Government of Malawi through the Ministry for Gender, Children, Disability and Social Welfare are working with agencies such as UNICEF to undertake investigative research to explore the root causes of this upsurge in violence against people with albinism in Malawi and make recommendations on what action to take to prevent these abductions, killings, mutilations and exhumations of body remains.

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<sup>1</sup> 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.

## Summary of the project

**Background:** 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. Families who have children with albinism face particular challenges in countries in sub-Saharan Africa which can lead to devastating consequences. These families feel particularly vulnerable when faced with the constant threat of their loved ones with albinism being kidnapped and killed in order to sell and use their body parts in ritual charms which, in turn, are believed to bring good luck to those who carry out the brutalities. These attacks were first [reported](#) by the BBC in 2009 and have continued, raising international condemnation. The current climate of insecurity for people with albinism in Malawi, particularly in areas that border the country (Tanzania, Mozambique and Zambia) is having a strong impact on the daily lives of people with albinism, to the extent that parents of children with albinism are afraid to send their children to school. The financial rewards and incentives of selling body parts of those with albinism are high, with even family members and friends implicated in some attacks. Concerned parents are unsure who they can trust and are resorting to extreme practices of over-protecting their children with albinism: keeping them within eye range, not letting them mix with other children and preventing them from participating in community activities for fear of being kidnapped or killed.

**Methods and Findings:** This qualitative study in northern and central Malawi included interviews with families affected by albinism and focus group discussions and meetings with other stakeholders, including educational professionals (specialist teachers, mainstream teachers, teacher trainers, university lecturers etc), members of local NGOs, media and representatives from the Association of Persons with Albinism in Malawi (APAM). The interviews captured critical moments in the lives of participants, their level of acceptability in school and community and the family's economic situation. Participants were also asked about any myths they had heard about albinism and any reports about albinism they had heard or seen in the media, local radio or by word of mouth.

The study found that families in rural villages experienced different levels of stigma and prejudice in their community ranging from being called names in public and being excluded from community activities such as preparing food for ceremonies, and digging graves to being completely rejected by members of the family, often the father. Those living by the lake were highly susceptible to sun burn causing extreme sores and permanent damage. Some mothers have become extremely protective of their children because of the different threats arising from the hot weather and the constant threat of kidnapping and verbal abuse. Families where a male figure stands up against discrimination and actively supports a member with albinism tend to feel more secure and more positive about the future. Some participants, particularly those living in towns but also including families living in rural lakeside villages, felt more positive about their level of acceptance within society and had high aspirations for their future.

Families find it extremely difficult to raise enough money from the main economic activities of fishing and farming to meet the additional needs of a child with albinism

in terms of buying protective clothing, sun glasses, protective skin lotion against the sun and providing transport money to send their child to board at a education resource centre and pay for their basic requirements while they are there (e.g. soap). Mothers of large families who do not have support from the father of the children are more likely to experience socio-economic difficulties and often rely on their extended family to help support the children.

The study produced evidence that families of children with albinism experience constant discrimination, especially in rural areas and from those outside their immediate surroundings. Having a child with albinism shakes the whole family to the core – there is no escape, they do not know what will happen to them, especially when these children are considered as ‘a business commodity’ by those who do not value them as human beings. Those living in towns such as Mzuzu, a large town in the north of Malawi, were more confident, had high aspirations for their future and felt better accepted within the community.

In a small number of cases children and young people with albinism were supported by external benefactors who sponsored a child because of a ‘special’ talent (e.g. ability to paint). Overall this group of children were not receiving support by local organisations or adequate representation by advocates for the rights of people with disabilities due to a lack of understanding of their condition. More collaboration is needed in driving campaigns or education projects, such as inclusive education projects, to ensure they benefit those with albinism.

**Conclusions:** The increase in the number of violent episodes in both Malawi and neighbouring Tanzania is placing extreme amounts of pressure on entire families who have children with albinism. Not knowing who your enemy is can force parents to hide their children from society thus preventing them from attending school and being able to participate fully in their community.

More dissemination of information about albinism is urgently needed, with more awareness among all stakeholders, particularly those working in social protection, inclusive education and human rights, as well as community leaders such as chiefs. Parents, particularly mothers, need to know where they can find the much needed support to help them to protect their children and other vulnerable members of their family. There is a growing awareness and political willingness to address these issues following the adoption of the UN CRPD as a human rights and development instrument.

*‘Recalling that some marginalized groups of persons with disabilities such as persons with albinism, persons with psychosocial disabilities, person with intellectual disabilities, and persons with epilepsy, face life threatening violence and deprivation of liberty due to persistent beliefs and harmful cultural practices’(Nairobi Declaration, 2014)*

Further research is needed to collect more evidence from parents, relatives and persons with albinism in those areas that are experiencing the most fear from kidnapping and violence. The Government of Malawi has developed a response plan that covers areas of education, awareness and training and, in collaboration with UNICEF, advertised in May 2015 for a consultant to conduct investigative research

on the abuses of those with albinism, to attempt to identify the root cause and make recommendations on what actions should be taken.

## **Guidelines for the education of children and young people with albinism**

### **Guidelines for education and social welfare workers to use when supporting children with albinism into educational establishments (pre-school and primary school)**

Educational guidelines were developed in collaboration with members of the local albinism association APAM to embed issues of albinism in teacher training, to foster and support the integration and acceptance of children with albinism at their schools and in society. APAM are keen that these cover education at all levels, from pre-school to tertiary and that it is embedded in the training of multiple professionals, from education through health to social welfare.

These guidelines are presented in the Appendix.

## **Peer reviewed journal publication of this project**

Findings from the early field work were included in a peer-reviewed journal article:

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.

## **Conference presentation**

Presentation by Bonface Massah at the Education Conference in Malawi, held on 20-22 August 2014; organised by the Faculty of Education at the University of Malawi, with sponsorship from the Canon Collins Trust and UKAID.

Title of Conference: **'Education and Access – Opening spaces for the marginalised'**

Subsection 8: SUPPORT FOR, AND MANAGEMENT OF, SPECIAL NEEDS LEARNERS AND EDUCATION

8.1: Community Based Rehabilitation and Utilization of Research Evidence: a Trigger for Supporting Special Needs Learners with albinism in Malawi

*Bonface Massah, Patricia Lund, Paul Lynch*

**Abstract:**

**Community Based Rehabilitation and Utilization of Research Evidence: a Trigger for Supporting Special Needs Learners with albinism in Malawi**

Evidence from Malawi indicates that a proportion of children with disabilities remain excluded from accessing full formal education, exacerbated by stereotypical attitudes of society towards disability. The greatest challenges arise from the cost of transport, and the lack of assistive devices, rehabilitation support and specialized learning material. This paper utilises the researchers' experiences in Community Based Rehabilitation and research evidence on albinism as a case to discuss support for, and management of, special needs learners in the Malawi context. In Africa, learners with albinism are a vulnerable group: they are 'white' in a black community making them strikingly different from their black peers, visually impaired, and at risk of suffering skin damage and social stigma. Often the eye problems go unrecognized, yet they cause difficulties in the classroom situation with regard to: mobility, seeing the chalkboard, reading and writing and restricted participation in outdoor activities. Qualitative participatory approaches, drawings, narratives, focus group discussion and document reviews were used to explore the social impact of albinism on the lives of learners with albinism. In particular the views of children, parents, teachers and other stakeholders on access to education and educational policy were explored. The paper highlights some of the key determinants preventing learners with albinism accessing education in Malawi including the failure of teachers to adopt strategies to assist these pupils, and their rejection in school and wider society due to myths and ignorance about albinism. It also identified good practices for adapting Community based rehabilitation (CBR) programme for empowering persons with disabilities in Malawi to include the needs of persons with albinism. There is a need to coordinate and share information of albinism through CBR structures at local level to influence parents of children with albinism to form advocacy groups in consultation with Association of Persons with albinism of Malawi and also need to gather research and dissemination of findings about the education of children with albinism to be made available to policy makers to Influence education or health policies and resource allocation for special educational needs of the group like large print books, accessible school blocks.

## **Advocacy posters to raise awareness of albinism in Malawi**

Advocacy Posters available online at

<https://curve.coventry.ac.uk/open/items/31439895-6896-4ec2-902d-dbc3ced56409/1/>

## Appendix

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

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### 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.

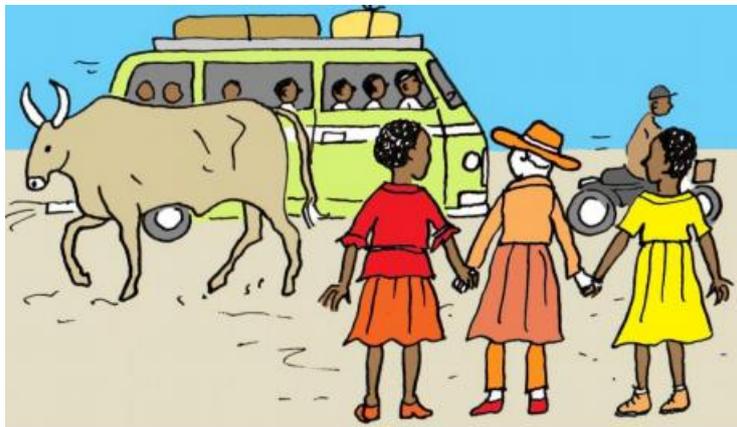
In the research studies that informed the development of these guidelines there was a strong emphasis on encouraging participants to express their opinions and experiences using their own language and interpretation, and to focus on identifying solutions they believe will work in their context. In this 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

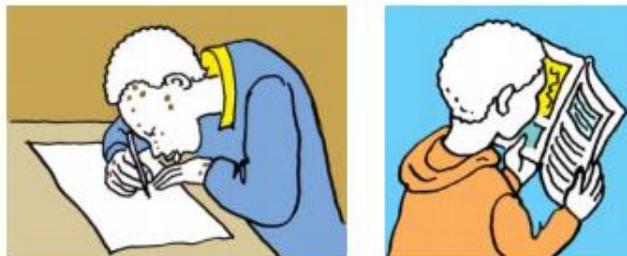
Child protection committee's training to include a component on how to offer protection to those with albinism as part of their **training programme**  
When a child with albinism enters their school, **head teachers** to immediately contact their **District Education Managers** to obtain information 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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