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Education of children and young people with albinism in Malawi

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Commonwealth Secretariat

Ministry of Education, Science and Technology, Malawi

Sightsavers

Education of children and young people with albinism in Malawi

Final report

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Abbreviations

DEM	District Education Manager
FEDOMA	Federation of Disability Organisations in Malawi
INGO	International Non-Government Organisation
IT	Itinerant Teacher
LVDs	Low Vision Devices
MIEP	Malawi Integrated Education Programme
MoEST	Ministry of Education, Science and Technology
PEA	Primary Education Adviser
SEN	Special Educational Needs
TAAM	The Albino Association of Malawi
TA	Traditional Authorities

1.0 Executive Summary

Children and young people with albinism are doubly vulnerable: they are visually impaired and their striking difference in appearance, looking ‘white’ in a black population, makes them the target of bullying and name-calling. This report presents first-hand evidence from all stakeholders, showing how support at every level of the education system, as well as by the Traditional Authorities, parents and the community, is required to facilitate their education.

The majority (73%) of visually impaired children in central Malawi supported by specialist itinerant teachers on one programme for the visually impaired had albinism, indicating this condition is the main cause of visual impairment among children. This study revealed worrying evidence that some children with albinism in rural areas were not attending school and evidence of gender inequality, with twice as many boys as girls with albinism going to resource centres. This needs urgent further investigation if Malawi is to meet the Education for All goal of achieving gender equality by 2015.

This report collates information from teachers, parents and children with albinism to produce a list of guidelines which are inexpensive and easy to implement. Early identification and appropriate support are essential. There is a common misconception that albinism is progressive and children with this condition will eventually go blind. This is a fallacy and leads to this group being taught Braille, which is both inappropriate and a waste of resources. Pupils with albinism should be encouraged to maximise their existing functional vision as there is no evidence that albinism leads to loss of sight. On the other hand, examples of good practice and a generally supportive attitude towards the inclusion of pupils with visual impairment in mainstream schooling were identified. These need to be disseminated so they become widespread across the sub-Saharan region. Training of specialist teachers should be improved, to inform them about albinism and how to support those with albinism by working with the class teachers to encourage inclusion, rather than removing them from the classroom for special tuition.

Children with albinism on one programme had been given monocular telescopes, but this study found no evidence these were being used. Any interventions should be researched and evaluated. Provision of any low vision devices must be carefully considered and their effectiveness assessed before widespread implementation, to ensure they are suitable for use in a classroom environment or at home. Simple measures such as wearing a wide brimmed hat both indoors and outside, is an effective measure to protect the skin from damaging sun exposure and the eyes from bright light.

This report offers recommendations for improving the education of those with albinism via the provision of accurate information on albinism and clear guidance from the Ministry of Education cascading down to the level of classroom teachers. As a consequence of this study information pamphlets on albinism will be produced; one for children and young people and another for parents and teachers.

Recommendations

This section sets out specific recommendations for the Ministries of Education, Science & Technology and Health as well as key agencies responsible for the education of children with albinism and the training of teachers (more detail in Appendix 5).

Albinism is always associated with poor vision, due to nystagmus (involuntary eye movements) and photophobia as well as other eye problems such as squinting and astigmatism. Visual impairment is present from birth and is life-long, although it is not progressive and varies in severity between individuals.

Information about albinism and strategies to improve the education and well being of children and young people with albinism should be disseminated across countries in Sub-Saharan Africa as albinism occurs at a relatively high frequency throughout the region.

There is the need to promote greater awareness of albinism through national advocacy strategies and International Non-Government Organisations.

Category	Recommendation	Responsible agency/individual
Education and Visual impairment	Teachers should identify pupils with albinism ***at the start of their school career***, so that appropriate measures can be put in place ***immediately*** to alleviate their visual impairment, protect their skin and facilitate their learning.	Head teachers and class teachers, supported by the Ministry of Education (Basic Education Division and Special Needs Education Directorate).
	Braille is not recommended 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.	Ministry of Education and Ministry of Health should send circulars to schools informing staff about the condition and what they need to do to support children with albinism.
Specialist support	District Education Managers should identify and allocate responsible persons e.g. an itinerant or head teacher, to	District Education Managers should work with Primary Education Advisers to ensure all schools have a

	inform and train class teachers and liaise with parents/guardians. Itinerant teachers should visit children with albinism either once a term (for children who require frequent follow-up visits) or on an annual basis (to advise new class teachers and provide technical support to the child e.g. review equipment and low vision devices).	designated teacher who has some training and can liaise with class teachers and parents/guardians. DEMs, PEAS, Itinerant teacher, head teacher.
Low cost interventions	Children with albinism may never receive a formal assessment of their vision by a clinic. It is essential that class teachers carry out simple assessments in the classroom (e.g. observations) and identify appropriate, low cost interventions that can be put in place immediately to promote the learning of pupils with albinism.	Teacher training colleges, head teachers and class teachers, with guidance from the Ministry of Education.
Sun Protection	The most effective, cheapest and accepted form of ‘aid’ is a wide brimmed hat and dark glasses to protect children and young people from the sun and glare.	Ministry of Education, Specialist teachers, FEDOMA, TAAM.
Low vision devices	Low vision devices such as monocular telescopes and magnifiers should only be provided to children and young people with albinism with their consent. There should be frequent monitoring and evaluation of the usefulness and acceptance of these devices.	Ministry of Education, Ministry of Health, eye clinics, INGOs.

Guidelines for teachers	Clear guidelines on the education of children with albinism should be available to specialist teachers and class teachers. These will include strategies on helping children both in school and in the community.	Ministry of Education and Teacher training colleges.
Teacher training for classroom teachers	Information on albinism should be integrated into different parts of the teaching curriculum – included in definitions of disability, early childhood education and low vision (use of low vision devices, hats, reading stands), and carry out functional assessments of vision (e.g. WHO Low Vision Kit).	Montfort Special Needs Education College and lecturers teaching special needs education courses at teacher training colleges.
Teacher training for Special Educational Needs (SEN)	Teacher trainees following the two-year diploma course in SEN should be encouraged to conduct case studies on albinism as part of their course work and school placement in order to build a local base of knowledge and experiences which can be shared with colleagues.	Montfort Special Needs Education College (lecturers running the specialist modules on visual impairment, particularly low vision).
In-Service Training and refresher workshops	Workshops on albinism, low vision and inclusive education of pupils with visual impairment should be organised to 'train the trainers' for example, a key group of head teachers and itinerant teachers, who can then cascade information about albinism locally. Workshops should involve and include families affected by albinism and members of TAAM	Ministry of Education, District Education Managers, TAAM.

2.0 Introduction and Context

2.1 The study

This report presents results from a research study on the education of pupils with albinism in Malawi, co-funded by the Commonwealth Secretariat, Sightsavers, Coventry University and the University of Birmingham. The study was conducted by a researcher at the Visual Impairment Centre for Teaching and Research (VICTAR) in the School of Education, University of Birmingham, a bioscientist in the Faculty of Health and Life Sciences, Coventry University and a member of The Albino Association of Malawi (TAAM), with logistical support by a project officer from Sightsavers (details of the research team in Appendix 1 and of ethical clearance in Appendix 2). Two field visits were conducted in central and southern Malawi during 2010-11 (details in Appendix 3) with both preparatory and follow up visits by the local research assistant from TAAM.

2.2 Albinism in Africa

In Africa people with albinism are visibly different from their black peers. The lack of pigment in their hair, skin and eyes makes them highly susceptible to sun-induced skin damage. They are visually impaired but usually attend mainstream schools in Malawi. The superstitions and myths surrounding the condition often lead to rejection and ostracism by the community. The international non-government organisation - Sightsavers and an advocacy group, TAAM, offer support to this vulnerable group.

2.3 Schooling in Malawi

Malawi, like many countries in sub-Saharan Africa, is struggling to meet the demands of surging numbers of school enrolment into the lower school grades (standards 1-5). The average class size in Malawi ranges from 36 to 120 pupils per teacher (UNESCO GMR, 2011[1]). Schools often have poorly equipped classrooms and pupils have no textbooks or have to share, sometimes between five or more. Many schools do not have desks or enough classrooms for children to sit in, resulting in teachers having to teach pupils outside under a tree. Given the very difficult conditions class teachers are working in, it may seem inappropriate to ask them to take on the additional responsibility of supporting children with low vision (including those with albinism) in over-crowded classrooms.

2.4 Supporting the education of visually impaired pupils: resource centres and specialist itinerant teachers (ITs)

The Dutch Reformed Church set up the first special school for learners with visual impairment in Chilanga, Kasungu District, in 1950 and other faith-based organisations built a further two special schools. In the 1960s international non-governmental organisations introduced a new model of teaching children with visual impairment – the resource centre. These are attached to mainstream primary schools but are similar to special schools in that the children board at a hostel, usually located next to the school. Children with visual impairment go to a separate

[1] UNESCO (2011) Global Monitoring Report – *The hidden crisis: Armed conflict and education*

resource room for additional tuition, usually Braille literacy and maths, given by resource teachers in the afternoons.

The Special Needs Education Directorate of the Ministry of Education, Science and Technology (MoEST) supports two approaches to educating children with visual impairment in Malawi: the resource centre and the deployment of itinerant teachers through the Malawi Integrated Education Programme (MIEP). There are currently (2011) 55 ITs working on the Malawi Integrated Education Programme across the 12 districts, but they do not cover all the zones in each district. Both resource and itinerant teachers are trained at the main special education teaching training college, Montfort Special Needs Education College.

In Malawi there are residential resource centres for learners with visual impairment attached to 14 primary schools, 15 secondary schools and 7 tertiary institutes across the country. These fulfil an important function in the education of blind pupils and those who are visually impaired, including those with albinism. Many of these centres have excessively high teacher-pupil ratios (e.g. 1:30) and are in urgent need of repair and renovation, particularly in the primary sector. There are currently 70 children and young people with albinism boarding at resource centres across the three regions. There is a much higher number of boys enrolled at the resource centres (n=48) than girls (n=22) which is disproportionate because the condition affects both girls and boys equally.

2.5 Specialist teaching provision by itinerant teachers

Itinerant teachers (ITs) are usually qualified school teachers with some formal training in the education of children with visual impairment. They travel around local mainstream schools and communities to offer advice, resources, and support to visually impaired children, their teachers and their parents.

The duties of an IT are varied, including:

- identifying, assessing and referrals;
- working with pre-school children at home;
- working with teachers and children at school;
- providing practical support and advocacy;
- ‘sensitising’ communities about the importance of sending children with visual impairment to school.

In addition some ITs also provide support to children with other disabilities but their core responsibilities are with supporting children with visual loss.

2.6 Motivation for this study

This study is based on an earlier scoping study into the education of children with visual impairment carried out by University of Birmingham for Sightsavers in 2008. Evidence from this study revealed that children with albinism were receiving different levels of education at resource centres and mainstream schools, mainly because of the insufficient training of class teachers and a lack of accurate information about the condition.

Furthermore, it was found that many children attending specialist resource centres had not been formally assessed by an eye specialist, mainly because there are very few qualified optometrists in Malawi. Children with albinism were being accepted into resource centres partly because of a commonly held, though mistaken, belief that they would go blind in later years. It was therefore considered necessary to teach these children Braille in the erroneous assumption that they would need it in the future, when they lost their vision. Albinism, however, is not a progressive condition and does not lead to blindness, making teaching Braille an inappropriate intervention and misuse of resources. There is also the danger of inappropriately committing these children and young people to a lifetime of Braille which is not widely available outside the school system.

This report explores some of the ways teachers can support these children through the use of inclusive education practices that can increase their participation in all school activities and enhance the quality of their learning experiences.

3.0 Research aims

The main research aim was to explore albinism directly by capturing the experiences of children and young people and their families, and indirectly through those involved in their education, notably the itinerant teachers who support children with visual impairment in mainstream schools.

The research team planned to collect evidence on:

- The use of different learning media by pupils with albinism (print and Braille);
- The level of their functional vision;
- The level of educational support offered by different professionals working with these children, including resource teachers, class teachers and specialist visiting teachers for children with visual impairment (itinerant teachers);
- The issues children with albinism and their parents considered of prime importance in supporting them at school;
- Local explanations about the cause of albinism in Malawi and traditional beliefs surrounding the condition.

4.0 Study Design and Methodology

The field research, conducted over two visits to Malawi in September 2010 and September 2011, was designed to capture different perspectives: from those living with albinism, their families and their teachers. Multiple participatory methodologies, including focus group discussions, drawing activities and semi-structured interviews were adopted. Visits were conducted either at schools or at home, facilitated by careful pre-planning by the local research assistant from TAAM. The local researcher assistant and the programme officer from Sightsavers played a critical role in collecting primary data, organising logistical arrangements and facilitating interviews and focus group discussions in Chichewa (the language of instruction used in Malawi).

Conscious of the need to use sensitive facilitation when asking children about their experiences at school and in discussing the myths and superstitions that surround albinism in Malawi, drawing activities (with young children) and semi-structured interviews (with older children and adults) were adopted. This was considered the most appropriate way of investigating the level of education and social support offered to children with albinism and exploring the more submerged issues surrounding this genetic condition. Drawing and collage activities helped create a more relaxing environment as well as demonstrating how children with albinism were able to use their functional vision in a classroom environment, without the use of any visual devices or spectacles.

The interview schedules collected demographic data (gender, age, number of years at school) at school (type of education: mainstream/special, specific information about what assistance they receive data school) and how albinism affected their daily lives. A total of 60 children and young people with albinism (40 boys and 20 girls), as well as members of staff and family members from mainstream schools and resource centres were interviewed (see Appendix 3 for list of schools and villages visited) in districts. Focus group discussions were held with itinerant teachers who work in two districts in central Malawi and four groups of parents of children with albinism.

Visits to schools took place at the beginning of the academic school year when new children were being enrolled and class teachers were getting to know their new classes. It was therefore important to interview teachers who had taught the children the previous year as well as the children's new class teachers when visiting schools.

The Malawian based research assistant carried out two follow-up visits to two children who had been given magnifiers, to gather feedback on their use.

Permission was obtained from the participants to take photographs of them and their drawings. Photos of children reproduced here do not reveal their faces but provide evidence of their school and home environment.

5.0 Data on the education of children with albinism in Malawi

5.1 Educational support for children with visual impairment

(a) Majority of visually impaired pupils have albinism

In 2010 Sightsavers MIEP reported a total of 96 children with low vision of which 70 children have albinism (Table 1). This means that almost three-quarters (73%) of all the children on this programme have albinism.

Sightsavers no longer supports programmes in northern Malawi but is concentrating on serving central and southern regions of the country. TAAM estimate similarly high numbers of children with albinism around Lake Malawi and in northern districts. Further research needs to be carried out to gather data on frequency rates and the educational experiences of children and young people in these regions.

Table 1: List of children with low vision and children with albinism in each education district in the MIEP

District	No of children with low vision	Number of children with albinism
Blantyre Rural	13	11
Blantyre Urban	16	13
Chikwawa	4	2
Balaka	9	6
Machinga	3	3
Mwanza	6	4
Salima	5	3
Zomba Urban	7	4
Zomba Rural	2	2
Lilongwe Rural (East)	13	11
Lilongwe Rural (West)	8	6
Lilongwe Urban	10	5
Total	**96**	**70 (73%)**

Key: Data based on the Malawi Integrated Education Programme in 2010

(b) Provision of low vision devices (LVDs)

Sighsavers provided 57 of these children with low vision (63%) with a monocular telescope to use in the classroom but no follow-up evaluation of their use has been undertaken. The team found no evidence of the prescribed LVDs being used in classrooms or at home.

5.2 Teacher Training on how to support children with visual impairment

(a) Training of class teachers on visual impairment

All primary class teachers receive limited education in special needs as part of their pre-service training course at one of the seven teacher training colleges, and all primary schools have guidelines in the form of a 'Disability Toolkit', giving general advice on how to accommodate and integrate children with disabilities in mainstream classes. These guidelines contain basic information about the causes of visual loss, how it can be prevented and suggest general teaching strategies for children with low vision e.g. placing a child near the front of the room or near a window. There is no evidence to testify whether this Toolkit is actually being used in schools and no evaluation of how it is being used by class teachers.

(b) Training of specialist teachers on visual impairment

The team visited Montfort Special Needs Education College, the main teacher training institute that specialises in the training of specialist teachers in visual impairment and other disabilities. The research team met three lecturers who run the new two-year diploma training course for teachers specialising in the education of visually impaired children which was set up in 2010.

(c) Training on albinism provided in the curriculum for specialist teachers

Lecturers follow a handbook provided by the Ministry of Education. Upon inspection, the research team discovered that there was very little content on albinism or on educating children with this condition. Discussions with the lecturers revealed that some had a basic knowledge of the genetic cause of albinism. As part of a module on low vision they provided limited information about the origins of albinism and how to help these children in the classroom. Lecturers also gave trainee teachers advice on how to help children to protect their eyes by giving children *'tinted glasses to prevent too much sunlight'* and '*a hat to prevent too much'bright light entering their eyes'*.

The myth that albinism leads to blindness

Lecturers at Montfort Special Needs Education College also held the incorrect belief that as children with albinism become older, they develop blindness and therefore need to learn Braille. If this myth is being taught to all newly trained visually impaired teachers this perpetuates this misconception throughout Malawi and needs to be addressed urgently.

5.3 Schools educating pupils with albinism

5.3.1 Mainstream Schools

(a) Young people with albinism not attending school

The team heard anecdotal evidence that some children with albinism were not going to school. An itinerant teacher in the west of Malawi, a specialist in visual impairment, knew of one family in his region where the children with albinism refused to go to school, they stayed at home. He said:

'Their friends laugh at them and they do not want to go to school.'

On the second visit in September 2011 this report was investigated by two members of the team.

Two siblings with albinism not attending school

A visit to the rural trading village where this family lived revealed their circumstances. The family was large, with 9 children. Although the other (black) children had all received some schooling the two children with albinism were not attending school. The 17-year old daughter had never received any schooling, despite the school being located in very close proximity to her house. The young son had not returned to school at the start of the new school year, despite the efforts of the local headmaster to encourage the family to send him. The head believed the reason was poverty; the young boy had no school uniform and did not want to appear different from his friends who wore uniforms. The young boy with albinism was extremely talented, praised for his ability in learning Arabic at the mosque school and his innovative use of local materials to set up a home-made puppet theatre to entertain his family and friends. Further details in Appendix 6.1

Further investigation of the scale of non-attendance at primary school needs to be undertaken, particularly in rural areas.

(b) Positive attitudes to inclusion in mainstream schools despite challenges

All of the primary schools visited had very high numbers of children enrolled in Standards 1-3. One rural primary school in Blantyre Rural had a total of 421 children in Standard 1 (212 boys and 209 girls). In Malawi, because of high repetition rates, it takes an average of 12 years for a child to complete the eight-year primary school cycle, and as a result as few as 10% of Malawian children in Standard 6 reach the 'desirable' level of reading literacy (UNESCO, 2008[2]). Levels of successful primary completion (i.e. to the end of Standard 8) have dropped as low as 40% with many children dropping out of school before Standard 5 (MOEST, 2000).

[2] UNESCO (2008) Global Monitoring Report

Generally, the team found school staff were positive towards including children with disabilities despite the challenges of insufficient training and large class sizes.

The interviews with class teachers revealed examples of good practice:

- Children with albinism were '*encouraged*' to sit at the front of the classroom and allowed to move close to the chalkboard if necessary;
- A small number of class teachers demonstrated good skills such as providing large print sheets for children with albinism;
- Teachers wrote in bold, clear, letters on the chalkboard and allowed pupils with albinism to wear their hats in class.

Areas of concern identified by the team include:

- All of the schools visited did not have sufficient textbooks to meet the increased enrolment of children in the lower standards (1-5); pupils were sharing one book between five or more. This has serious implications for children with albinism who have low vision and cannot see the book at a distance. They need to have their own book which they can hold close to their face to be able to see the letters;
- Class teachers did not keep any notes or record on individual children and were not sharing their experiences of teaching children with albinism with teachers at the start of a new academic year; thus any experience gained by teaching a pupil with albinism was not passed on to the next class teacher;
- Over half of ITs interviewed (total number = 20) visiting the schools were not working closely with class teachers when visiting children with albinism, but tended to remove them from the class room and interact with them on a one-to-one basis.

5.3.2 Resource Centres

(a) Problems in reading print lead to children with albinism learning Braille

Children with albinism attending the resource centres visited by the team were being taught Braille because teachers believed their eyesight would deteriorate when they got older. Class teachers appeared to base their judgment on children's difficulties in accessing print or seeing the blackboard. They reported that children said they were '*unable to read the letters in a textbook*' because they were '*too small'*. On other occasions, eye specialists said children needed to learn Braille because of their poor visual acuity.

The resource teachers felt they had insufficient knowledge on how best to support children with albinism due to a lack of appropriate training at the teacher training college. The resource teachers attempted to tailor the curriculum according to the children's needs, but due to lack of resources all the children (both blind and low vision) tended to receive the same training: learning to read and write Braille.

The research team used participatory workshops to determine the level of functional vision of these children who were being taught Braille.

(b) Children with albinism produce detailed drawings during participatory workshops

The team collected evidence of how children with albinism used their vision by providing them with different art materials (glue, coloured paper, pencils, crayons and felts) and requesting they produce line drawings or pictures that represent aspects of their lives either at home or at school. The children enjoyed cutting and gluing different materials onto card and discussing them with one of the research team.

All the children participated in these activities, producing detailed drawings of their homes, bicycles, cars, buses and other objects that had meaning to their lives. All children wore their hats indoors, to help reduce the amount of light reaching their eyes. Most children bent right over the desk, holding their heads very close to the paper to produce their drawings, as shown in the images below.

The children's families and the resource teachers were able to witness the children they teach Braille complete very detailed drawings on paper. The resource teachers were surprised by this evidence of the amount of vision these children had.

In spite of this proof that the children had useful functional vision, teachers will continue to teach children with albinism Braille in resource centres unless they are instructed not to do so by the Ministry of Education.

Children with albinism completing an art activity as part of a workshop

Examples of drawings produced by two children with albinism at Salima School for the Visually Impaired

5.4 Role of itinerant teachers

ITs are expected to visit children they support at their local mainstream school, giving them instruction on how to use a low vision device such as a monocular telescope or a magnifying glass and to help them access the curriculum.

An interview with an IT highlighted the importance of the traditional authorities (TAs), notably the chiefs, in encouraging families to send children with albinism to school and in fostering positive attitudes towards albinism within the community.

Case study of an IT in a rural area of western Malawi

At the time of interview (September 2011) he was the only IT in his district, with 13 schools in his zone. Although he specialised in visual impairment he also looked after pupils with hearing loss, learning difficulties (including two pupils with Down Syndrome) and dwarfism, as well as those with low vision. He had no transport provided for his itinerant teaching duties but used his own personal bicycle for transport.

He monitored 23 children, all in mainstream schools, including 4 children with albinism and 8 with cataracts. He knew of children with albinism kept at home (including the family subsequently visited by the research team, although the mother did not recall having a visit from him). He reported that their peers laughed at them and they did not want to go to school; in one family the children with albinism refused to go to school, but stayed at home. He has noted *'problems with the environment'* for pupils with albinism, including stigmatization from other pupils. In addition, he felt some teachers '*pay little attention to them'*. He thought training of teachers (during the holidays so it did not interfere with their normal teaching duties) was important to educate people about albinism and visual impairment in general, as well as parents and chiefs. He felt the chiefs could '*help parents to bring children to school'* as well as '*assembling the community to make them aware of the right of each child to education and discourage discrimination'.*

Focus group discussion

The research team lead a focus group discussion outside Blantyre, with 16 ITs participating (10 male and 6 female; nine from Blantyre Rural and seven from Blantyre Urban). All the ITs reported having at least one child with albinism on their caseload (see table 2). The ITs in Blantyre Urban reported a total number of 45 children and young people with albinism and 30 in Blantyre Rural. Two ITs in Blantyre Rural had six children with albinism each and one IT working in Blantyre Urban had eight children with albinism.

There was considerable variation between ITs in the frequency of their visits to children with albinism (see table 2). On average the ITs said they spent between one

and two hours with the child and visited the school between once and twice a week, carrying out different activities e.g. checking academic progress, checking children had applied sun lotion, were wearing hats and providing guidance and counselling when required. More detailed tables of caseloads and visits are contained in Appendix 4. Overall, ITs felt they should not be overprotective of a child with albinism but should ensure (s)he is not excluded.

Table 2: Summary of reported number of children with albinism on ITs' caseloads and frequency of visits in Blantyre Urban and Rural

Number Of ITs	Reported number of children	Frequency of visits to schools	Number of hours spent at school	Total number of children with albinism on ITs' caseloads
7 ITs in Blantyre Urban	1-16*	Once a week – once every two weeks	1 hour – 5 hours (school day)	45
9 ITs in Blantyre Rural	1-6	Once a week – once a year	1 hour – 5 hours (school day)	30

*One of the ITs was a coordinating IT and may still be including some of the children from other ITs' caseloads.

Focus group discussion with ITs at a teacher training centre near Blantyre

The main focus of the discussion with ITs was to learn how they supported the education of children with albinism.

1. The main points raised by ITs concerning their support of pupils with albinism in mainstream schools were:

Ensuring the classroom environment was appropriate:

- Position in class was important; one IT commented that they should be '*given freedom to sit where they felt comfortable*'; others felt it should be at the front;
- Clothes worn; children with albinism should be allowed to choose their clothes, to wear protective clothing to protect their skin from the sun and be allowed to wear their hats indoors to protect their eyes;
- Use of their own book; pupils with albinism should be given their own text book, even if there is a limited supply for the group and pupils were having to share; ideally they should also be allowed to take text books home to continue studying in their own time.

Suggesting additional support by class teachers:

- Raising awareness that the usual duration of the lesson may be insufficient as those with albinism are not as fast as others and do not see the information as quickly; they need extra time;
- Ensuring large print examination scripts were available e.g. for Std 8 exams; informing teachers about who should use any large print material available;
- Informing invigilators that children with albinism should have additional time to complete assessments; ideally the low vision learner should be invigilated in key exams by a specialist teacher, well informed about their visual impairment;
- Sensitising teachers about the words they use to describe those affected by albinism; local names can be derogatory and make them the focus of bullying; if teachers make or tolerate abusive remarks about albinism the other children will copy this behaviour.

Ensuring inclusion in all school activities:

- Involving the child with albinism in all class activities, including physical; the group felt it important to actively encourage inclusion;
- Including pupils with albinism when assigning leadership roles so that they feel involved in the school activities or giving them the responsibility of aiding others, e.g. if they show a particular skill.

2. The use of low vision devices (LVDs) was discussed:

- ITs felt they required additional training/orienteering on how to use these if the learner with albinism was given one. Results from the questionnaire show that none of the ITs had received any training on how to use a LVD;
- It was important to monitor the use of LVDs and ensure they do not get stolen or taken off children.
- ***Note: Sightsavers had funded the purchase of monocular telescopes to help learners see the chalkboard, but the team did not see any being used.***

3. ITs felt they had a duty to the parents and families of the pupils with albinism they assist, as well as to the wider community, by:

    - Acting as a liaison between the home and the school, including the teachers and fellow learners;
    - Co-ordinating the interaction between the child with albinism and the parents, ensuring there was family support and understanding;
    - Informing staff and other pupils about albinism via staff meetings, parent/teacher meetings and assembly when all the learners were gathered;
    - Sensitising the community and facilitating discussion about albinism and the needs of those living with the condition with other community leaders including chiefs;
    - Informing the local community about albinism by involving the mass media e.g. inviting TV/radio presenters to their resource centres and speaking at youth clubs.

4. ITs thought they should be involved in other ways in supporting the pupils with albinism by:

    - Collecting or arranging for the collection of skin lotion and showing them how and when to apply it; TAAM (The Albino Association of Malawi) distributes donated sun protective lotions and the possibility of using ITs to distribute these was discussed e.g. TAAM could arrange a system whereby the ITs could sign for the sun lotion and hand it out;
    - Keeping themselves well informed via meeting such as Open Days organised by the umbrella disability organisation – Federation of Disability Organisations in Malawi (FEDOMA).

The main problem identified by the ITs was transport:

- Some caseloads were distributed over quite large distances and some ITs spent a lot of time travelling, often on bicycles, to visit children at different schools.

Changes to practice that were discussed included:

- The value of observing the pupils in their own classroom environment, rather than removing them from the group and interacting with them on a one-to-one basis;
- The importance of functional vision assessment to evaluate to what extent children with albinism are able to use their residual vision, even if they are not using low vision devices, so that the IT can work with the child to maximise their visual potential;
- The need to keep detailed and accurate records that can be shared with class teachers; a few ITs kept individual education plans, learners' progress records and low vision assessment forms as well as information on each visit whereas others did not have any files.

5.5 Children and young people's perspectives on their experiences at school

Workshops at Resource Centres

The voices of the children with albinism interviewed at Resource Centres during two participatory workshops are presented below, giving first hand accounts of their experiences at school.

(a) Classroom environment: position at the front and use of their own book

All the children said they have problems seeing the blackboard and books. They were aware that they needed to be placed at the front, with one pupil commenting:

'I would prefer to sit in front at the middle so that when the board is full with notes I can be able to see from one end to the other.'

The provision of books was variable between schools with pupils saying:

'I don't have or use my own personal book. We share one book for a group of 5 pupils and I don't hold the book. It is my friends who hold it, so due to my poor sight I can't see and read in the book.'

'When reading a book, I don't have a personal book so we share in a group of 6 or sometimes 7; I have no chance to hold the book so I struggle to see properly. As a result I just sit in the group. I would prefer if I was holding the book.'

Young girl with albinism sharing a textbook with two other children in a Primary School in Blantyre Rural

Other children reported:

'I read from text books and I hold the book alone for me to see properly. In our class everybody has a book, we don't share.'

'I hold the book alone for me to see properly.'

(b) Support at school from staff and peers

Generally pupils reported positive support at school, for example from the headmaster. A pupil at Salima Resource Centre commented:

'My fellow pupils don't talk bad about me because the headmaster said that no one should do that and he gives punishments.'

Others described the peer support received:

'My fellow pupils sometimes read to me when I can't see on the board or I use their school books to copy the notes.'

'*I don't see properly so sometimes my friends write notes for me and help me in reading the notes.'*

Others received less help from their peers, with one reporting that fellow pupils would not allow him to copy from their books as they thought he was '*stealing their wisdom*'.

(c) Ways in which pupils felt their teacher could assist them

Responses to the question '*How can your teacher help you?*' revealed common issues, outlined below:

- ✓ Let me sit in the middle, at the front, near the blackboard ('*I love to sit in the middle but sometimes the seats are filled with other pupils'* (so he sits near the window))
- ✓ Give me my own book, even if there is a shortage
- ✓ Allow me to copy from the book, not the chalkboard
- ✓ Allow me to wear hat/glasses indoors
- ✓ Ask teacher to write in big, bold, clear letters
- ✓ Ask for more time to complete tasks
- ✓ Ask them to write notes for me.

(d) Community attitudes towards children with albinism: name calling and myths

Children with albinism were asked about how they were treated in their communities and what could be done to improve their lives. Representative quotes capture their responses:

‘*I need reading glasses to help me read and I would like others to stop calling me names like napwere!*

‘*The community should stop bullying and calling me bad names for me to be happy and play comfortably with friends at home.’*

‘Most people here are cruel towards me. I don’t quarrel with them but they fight me and they beat me up, even my friends…but what I want is us to be good friends. I want to live and chat with different people without problems.’

The pupils were aware of myths and beliefs about albinism:

‘*People say albinos that do not die but just disappear, so you cannot trace their bodies as we do with other people.’*

(d) Information on albinism

When asked if they wanted to know more about albinism, many responded by saying they wished to find out more about their condition:

‘I would be happy for someone to tell me more about being an albino.’

‘I want to know why a child can be albino yet his parents, grandparents are black…it becomes very strange.’

Interviews in rural areas

Two contrasting case studies are presented below to illustrate the educational experiences of young people living with albinism in rural Malawi.

The first is a young woman with albinism who has recently completed her education at a teacher’s training college in Malawi. She was proactive in seeking help at school and, with the strong support of her family, had a successful school career, reaching her full potential.

Virginia’s story: Case study of a young woman living in a rural village

At her birth Virginia’s mother was told by people in her village that she ‘*will not grow and die young*’. She challenged local beliefs and ensured her child received a good education, despite being denied a place when she first took her to the local primary school, with the headmistress saying she should attend a special school for the blind. With the support of another teacher (a friend in their village) Virginia was subsequently enrolled. Her mother proudly told us that there was now a photograph of Virginia at this school, as an example of an ‘*exemplary pupil’*.

At the start of her school career Virginia did not realise she had low vision:

‘In the first 3 years I thought that everyone has the same vision as I have.’

Once she realised she was the only pupil in the class who could not see the

chalkboard, she requested and received additional help from her class teachers, who gave her additional lessons after school, and peers who allowed her to copy their notes. She described how some fellow pupils thought she had an unfair advantage when teachers gave her examination scripts on paper (rather than reading from the board as everyone else did):

'When they give her the examinations, they give her with answers.'

The teacher then gave the same paper to a selection of other pupils as well, so they could all see they contained only the questions.

With this help she was always top of her class and went on to train as a teacher.

(Transcript of this interview in Appendix 6.2)

The second concerns Limbani, a 14 year old who felt he did not receive support at school and was not motivated to continue. The team gave him a hand-held magnifier and evaluated its use at a follow-up visit. This case study highlights the problems of introducing low vision devices for children with albinism in a mainstream classroom setting.

Limbani's story: Case study of a boy living in a rural village

Limbani was supported by his aunt after the death of his parents. He had been at school for 12 years, the only pupil with albinism. He said his fellow pupils '*disturb him'* and would like to attend a resource centre rather than a mainstream school as he did not feel his teachers made any arrangements to assist him. The school had no text books; only the teacher had one and transmitted information to the pupils by writing on the board. Limbani was not supported by an itinerant teacher. In the words of his aunt:

'the teacher's attitude hinders the child to learn properly. Teachers should understand how to help a child with albinism."

Limbani had received help from friends who explained what was written on the chalkboard. He shared a desk with a friend; they move their desk close to the board if it gets too sunny and he cannot make out what is written there. He participated in team sports, playing soccer with the village team in the late afternoons. The team donated a magnifier, showed Limbani how to use it to magnify text and contacted him a few months later to get feedback on how he was using it. Although this magnifier could be kept in a pocket and used discreetly Limbani reported that other pupils at the school '*disturbed him as they also want to use it just for* fun' and he was not using it at school, but used it for his homework. The research assistant from The Albino Association of Malawi (TAAM) supported Limbani by visiting the headmaster and requesting that the itinerant teacher assist him and monitor the use of the magnifier. Limbani was not motivated to attend school; according to the headmaster his guardians did not see the value of sending a child with albinism to school.

5.6 Parental perspective: views of parents of children and young people with albinism

Focus groups with parents

Focus group discussions with parents at four centres; one attached to a demonstration school at Montfort (see Appendix 3), lead to the compilation of a list of ways in which they felt teachers should support their children with albinism at school.

The main themes that arose from the discussions are summarised below:

- **Beliefs about the cause of albinism:** A common belief was that '*God has wanted it to be'*. One mother said that she has heard people say that there was '*mwanaphepo*' (that the mother had some infection in the womb when she was pregnant and this caused the child to be white) indicating a belief that albinism is a disease. One parent had been told that she had neglected her child. She also said that her husband asked her why she had given birth to '*an albino'*. Her response was that '*it is a gift from God'*.

  Some parents recognised the hereditary nature of albinism, with a mother saying '*when you are the first one in your family the other children to be born in the coming generations might also have people with albinism after you*'.

  The father of a child with albinism commented:
  'We have five children with the second born albino. After the birth of this albino child my wife asked me why this child was white. This I had to explain from the background in our family. My grandmother was an albino and also my sister has four albino children so it means this child is not a mystery in our family.'

- **Cultural beliefs:** Myths that are common in many parts of Africa were reported, including the 'death myth', that people with albinism do not die a natural death, the dead body just disappears into thin air. Another cultural belief is that albinism is contagious, that if a pregnant woman comes close to or looks at a person with albinism they could give birth to a baby with albinism: *'In my village when a woman is pregnant they say that my child (*with albinism*) should not come close to her or the woman should not look at her or carry her, because she will give birth to an albino, This I have experience so, so long and it is very common in our village, especially to elderly women when talking and giving advice to pregnant women.'* Some people say to those with albinism '*do not come close to me because you will infect me with your white skin*'.

- **Medical examination:** Only one parent reported their child had been examined by a skin specialist. Few children with albinism had received full clinical eye checks at hospitals.

- **Skin protection:** Parents were aware of the need to protect their children's skin from the sun. A mother commented: '*Before using sunscreen, once my*

son walked in the sun it was like he had been poured with hot water or fire burns but now he can play in the sun and the skin does not get burnt'.

Two parents used sun lotion which they purchased from different suppliers including a local organisation in Salima that looks after vulnerable groups. They had been given instructions on how to apply the lotion to their children after bathing them.

One mother ensured her daughter wore long sleeve clothing to school. She also encouraged her to wear her hat during hours of daylight. Another made sure her son wore a hat from around nine in the morning until sun set.

- **Educational inclusion in mainstream school versus resource centre**: Parents expressed a strong preference that their children should be educated in '*mixed schools'* (mainstream schools) and that their participation in these schools should help educate other children about albinism.

Conversely, parents who sent their children to Montfort Demonstration School (with a residential unit for children with visual impairment) were generally against their children attending their local mainstream school because of name calling (*Napweri, Mzungu wadala* – pretending to be a white man but you are not) and lack of support from class teachers and head teachers.

One guardian suggested that pupils with albinism were put up into the next class to get rid of them; his nephew had attended a government primary school but failed the examinations sat at his mainstream school, so he was put back and has since progressed successfully: *'....so you can see that the other teachers at a government school just don't care for these pupils and let them go to the next class even if they have failed, just to get rid of the pupils, but this is very bad.'* He took care of his nephew as the parents '*don't see any value in an albino because if they are educated they don't get good jobs. My plea would go to government to consider people with albinism when it comes to employment'*.

The group at Montfort Demonstration School felt their children received a better education at the resource room and listed the reasons for preferring the centre to mainstream schools:

- No stigma
- Teachers have a better understanding of a child with albinism
- *'..also much love given to the pupils by the teacher....*'
- Staff were able to assess them and devote more time to help them with learning
- Much more specialist help could be provided than could be given in public schools
- They could learn Braille (although this was because they were told their child would go blind)

One father said he would like to see an increase in the number of schools like Montfort Demonstration School because government schools do not understand the problems faced by children with albinism.

- **Learning more about albinism:** Parents were divided about whether they would like more information about the causes of albinism and how it is inherited.

  Comments from mothers who did not feel they needed this information included:

  '*I know that any woman can give birth to a child with albinism based on the will of God.'*

  'I would not say I would need someone to tell me because, for someone to come and educate me on my child does not make sense to me. I feel it's not so important.'

  Parents keen to become better informed said:

  'I would want to know why I have a child with albinism and not my parents nor my grandparents, because it becomes really strange to understand what happened.'

  '*You see that from the same mother and father you have different children; some are albinos, others black. This brings confusion as to why and how did it happen.'*

  'My first born is an albino but the other two are not, so I want to understand what happened.'

- **Provision of information** One parent group agreed the best way would be to have somebody who is trained and knowledgeable about albinism to talk to them at a workshop: *'The problem is that if you use books most people will not use it but just ignore it, so if we discuss these issues people will listen and take home what they have learnt and be able to ask some questions for clarification.'*

- **Advocacy:** One parent expressed an interest in setting up local support groups for parents. This could be facilitated by the national group, The Albino Association of Malawi (TAAM).

Interview with a rural family

One family where four children had albinism could not attend the focus group discussion at Mchinji and was visited by two members of the team on the following day (additional details in Appendix 6.3).

The father and eldest daughter with albinism spoke of their experiences. Although well accepted within the local community and at primary school, where the teachers lived in the community and knew them, they encountered problems with acceptance at secondary school where the teachers did not know how to support them and there was a lot of bullying and name-calling. The eldest daughter had been helped by one teacher but not by others. She had received large print examination scripts for some of her subjects (which she passed) but not others (which she failed). She was therefore repeating her final year at school.

This family study highlighted two main issues:

- ✓ The impact of the attitude of individual teachers on the acceptance of children in the classroom and the effect if such support is lacking;
- ✓ The importance of receiving the required support from central agencies e.g. the Ministry of Education in providing large print examination papers.

5.7 Ways in which teachers can support learners with albinism

Issues raised during the focus group discussions with parents are listed below, in order of priority, with those the parents considered most important presented first:

- Every teacher should know about albinism and how to take care of someone with albinism; this must be included in their training;
- Teacher should protect the child with albinism from other pupils in the school;
- Teacher must know that the child must be seated in the front of the classroom;
- The teacher must give notes to the child to copy (and not rely on them seeing the chalkboard); the teachers should make sure the other pupils understand why this is done (because of their visual impairment), so that it does not look as though they are being unfairly favoured;
- They must give them the examinations with the questions written on paper (not on the board);
- They should choose a friend in the classroom with good hand writing to help them, so that the child with albinism can borrow their book, and teach the other pupils how to support this child e.g. if they cannot see a word on the board;
- They should try to offer additional classes;
- Teachers must give the children with albinism chores/punishments like any other child, but they must be indoors e.g. cleaning the classroom rather than

working in the school's garden or must be early/late, not in the middle of the day;

- Every teacher must know the protective clothes required for pupils with albinism;
- Schools must create games which pupils with albinism can participate in e.g. in the shade; this is easier to achieve for the girls as the boys always want to play football out of doors;
- Teachers should be sympathetic to the views of the child, e.g. if they say they cannot see, and not react harshly.

Parents gave the following advice, based on their experience of raising a child with albinism:

- Love the child with albinism like any other one in the family
- Encourage the child to go to school;
- Keep in touch with the teachers on the issues surrounding the child
- At home, assist with the problems they have at school;
- Share their experience of having a child with albinism to help new parents of children with albinism to cope;
- Encourage the child to interact with others, to play with others, not be secluded, but should not be overprotective of the child.

The group of parents at Chilanga focused on the need to be protective of the child with albinism; the child should be protected by the parents at home, by the teachers at school. In the community it is the role of everyone.

Families of children with albinism participating in a focus group with assistant researcher leading a final discussion

6.0 Conclusion

This report captures the main findings from two field studies visiting children with albinism attending both mainstream schools and those attending resource centres once they have spent the school day with their sighted peers at the attached mainstream school, their parents and both specialist and class room teachers involved in their education. The advantages of the special care, attention and resources available at specialist centres for children with visual impairment are contrasted with the benefits to the child of being included in their local community schools. Barriers to inclusion into mainstream schools included large class numbers, books in short supply and insufficient staff time to devote extra time to children with albinism as well as poor knowledge about the needs of pupils with albinism. The children spoke eloquently of the impact of individual teacher's attitude and approach to their experience at school.

The children with albinism made up almost 75% of the case load of itinerant teachers supporting the education of the visually impaired in the central and southern regions of Malawi. There is a paramount need for immediate recognition and intervention to assist this group at the start of their school careers. Interventions should be guided by investigation into the needs of this group and follow-up evaluations undertaken to assess the use and effectiveness of any provision of low vision devices and other assistance. Evidence from this research showed that the children visited at the resource centres were able to use print and did not need to learn Braille. There is a misconception that the visual impairment associated with albinism is progressive and that affected children will go blind. Guidelines should be issued by the Ministry of Education to ensure that Braille is not taught when it is not necessary as this is a wasteful and inappropriate use of scarce resources.

This study identified the need for specialist training on albinism, on how best to intervene to facilitate the education of a child with this condition, both at the resource centres and within mainstream schools. Workshops and training should involve and include children and families living with albinism, recognising their knowledge of the condition. Experience and expertise should be shared, among ITs, between ITs and class/head teachers and with all other stakeholders including families.

Members of the executive committee of The Albino Association of Malawi (TAAM) have expressed a strong interest in the results and recommendations from this pilot study in order to inform their policy and provide evidence for their advocacy campaigns.

The findings of this report will inform the content of two information pamphlets that are to be designed, one for children and young people with albinism and another for parents and teachers.

Appendices

1. The research team

The Partnership consisted of the following people and institutions:

- 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 five years. Paul was involved in designing of the research tools, planning and logistical arrangements of the ten-day visit to Malawi in September 2010. He worked closely with Pat and Boniface in organising the workshops and focus groups as well as interviewing the pupils, teachers and parents. He co-authored the report and is co-developing information pamphlets for children and young people with albinism and one for parents and teachers with Dr. Lund.

- Dr. Patricia Lund is a Senior Lecturer in genetics at Coventry University. She has directed multifaceted research involving individuals and families living with albinism in Southern Africa over the past 19 years. Pat was involved in designing of the research tools, planning and logistical arrangements of the ten-day visit to Malawi in September 2010 and organised the 7 day visit (with Boniface Massah) in September 2011. She worked closely with Paul and Boniface in organising the workshops and focus groups as well as interviewing the pupils, teachers and parents. Pat is developing a 'storybook on self-representation' for children with albinism and co-authored the report.

- Boniface Massah is an executive member of the Albino Association of Malawi, an NGO founded in 2005 to sensitise Malawian society on issues around albinism and to advocate for the human rights of people with albinism. Boniface has been involved in organising the field work, conducting interviews and focus group discussions with children and their parents. He was responsible for visiting families and schools in advance of the study visits, to inform participants about the research study and seek their approval. He has also carried out transcribing and translation of interview audio files from Chichewa to English.

- Hilda Lupiya is a Programme Officer at Sightsavers in Malawi and has been managing the Malawi Integrated Education Programme (MIEP) with the Ministry of Education. Hilda was responsible for organising transportation through the Sightsavers Country Office, contacting teachers at resource centres, arranging interviews with administration staff at District Education Offices and lecturers at the main teacher training college.

The research was given considerable logistical and human support from Sightsavers Malawi Country Office in the form of a dedicated driver and a vehicle. Both the University of Birmingham and Coventry University supported the two researchers in the UK in terms of time to plan and undertake the field visits as well as writing this report.

2. Ethical Clearance to conduct the study

Permission to undertake the research was agreed at two levels: through the Arts and Social Sciences Ethical Review Committee at the University of Birmingham in the UK and through the Special Needs Education Directorate at the Ministry of Education in Malawi. A set of invitation letters, consent forms for teachers, parents and children were developed and sent to the reviewers as part of the application for ethics approval. Final letters of approval from the two organisations were sent to the Commonwealth Secretariat before the final contract was approved. Permission was sought to use photos to produce information pamphlets/leaflets for the children and educational professionals.

3. List of schools and education offices visited

a) First visit in September 2010

Individual(s)/Activity	Where
Interviewed family with albinism	Lilongwe Rural
Interviewed families with albinism	Lilongwe Urban
Interviewed special needs desk officer	District Education Office, Dedza
Interviewed two resource teachers running a resource room and carrying out assessments	St Joseph's Resource Centre, Dedza
Interviewed blind teacher and young man with albinism	Mtakataka, CCAP Dedza
Interviewed resource class teacher and IT	Centre for Visually impaired Salima
Drawing workshop and focus group discussion with children and young people with albinism and their guardians	Salima Centre for Visually Impaired
Interviewed child with albinism and class teachers	Katete Primary School, BlantyreRural
Interviewed child with albinism and class teachers	Maoni Primary School Blantyre Rural
Interviewed child with albinism and class teachers	Lirangwe Primary School Blantyre Rural
Interviewed child with albinism and class teachers	Chilaweni Primary School Blantyre Rural
Interviewed Special Needs Desk Officer	District Education Manager's office Blantyre Urban
Interviewed District Education Manager	DEM Office, Blantyre Rural

Visit to main teacher training institution specialising in the education of children with visual impairment. Focus group with lecturing staff who teach the visual impairment course	Montfort Special Needs Education College Blantyre Rural
Drawing workshop with children residing at Montfort Demonstration School and a focus group discussion with their guardians	Montfort Demonstration School Blantyre Rural
Interviewed teacher with albinism	Makalanga Primary School Blantyre Rural
Focus group discussion with ITs working in Blantyre Urban and Blantyre Rural	Teacher Training Centre, Blantyre Urban
Debriefing meeting with Director of Special Needs Section and Chief Officer and Sightsavers Country Office team	Sightsavers, Lilongwe

b) Second visit in September 2011

Individual(s)/Activity	Where
Drawing activities with 7 boys; focus group discussion with families (3 women with albinism; one mother of a baby with albinism; three parents of school going children); interview with itinerant teacher	Mchinji District
Drawing activities with 9 children (n=3 male and 6 female); focus group discussion with 5 parents (4 fathers and one mother)	Chalanga School for the Blind
Family visit to family of a young woman with albinism at Tembwe village (interview with mother and Virgina; met the village headman	Mchinji District
Family visit to family where 4 children have albinism at Gandali; interview with father and eldest daughter	Mchinji District
Family visit to Gumba for family visit where two children had albinism and were not attending school	Mchinji District
Interview with mother (nurse) of three children with albinism	Mchinji District

Visit with representative of TAAM and Sightsavers to the Ministry of Special Education in Lilongwe, to report on the visit	Lilongwe Urban

4. IT visits to children with albinism

Table 3: A breakdown of ITs' caseloads in Blantyre Urban

IT	Number of reported children with albinism	Frequency of visits	Number of hours spent at schools
1	6	Twice a week	2 hours
2	5	Once a week	5 hours
3	16	Once a week	1 hour
4	4	Twice a week	1 hour
5	1	Twice a week	5 hours
6	8	Once a week	5 hours
7	5	Once every two weeks	1 hour
Total	**45**		

*One of the ITs was a coordinating IT and may still be including some of the children in other ITs' caseloads.

Table 4: A breakdown of ITs' caseloads in Blantyre Rural

IT	Number of reported children with albinism	Frequency of visits	Number of hours spent at schools
1	2	Twice a month	2 hours
2	1	Once a year	1 hour
3	1	Once every two weeks	3 hours
4	5	Once a week	5 hours
5	3	Once a week	5 hours
6	4	Twice a month	2 hours
7	6	Once a week	5 hours
8	2	Twice a week	2 hours
9	6	Once a month	3 hours
Total	**30**		

5.0 Recommendations

Recommendations to facilitate inclusive education of children with albinism in Malawi

Influencing policy and resource allocation

This project on the education of pupils with albinism in Malawi involves the Commonwealth Secretariat, TAAM, Sightsavers as well as external researchers. Findings to be collated and reported to FEDOMA and the Ministry of Education, Science and Technology, Special Needs Education Directorate to ensure the evidence is available to the governmental agencies to inform policy and disseminate best practice advice to all schools.

Recommendation:

- Collate research and other findings about the education of children with albinism to be made available to policy makers and others to ensure widespread dissemination as well as neighbouring countries such as Zambia, Mozambique and Tanzania.

Information provision

The provision of information on albinism is key, to inform community attitudes to people with albinism and ensure their visual impairment is recognised, in addition to the more obvious sensitivity of their skin to the sun. Focus group discussions in Malawi favoured workshops for face to face discussion and education on all aspects of albinism. Some parents said they wished to know why albinism 'skipped' family generations.

Recommendation:

- Co-ordinate information provision on albinism to ensure it is available through as many outlets as possible, including via governmental bodies, NGOs, TAAM. Give examples of how families can have one or more children with albinism and then no children in the next generation.
- Produce an illustrated information booklet for children and young people with albinism translated into Chichewa. This booklet will need to be piloted on a sample group of children with albinism. Some possible themes include: What is albinism? (e.g. not contagious or infectious), What do I need to do to protect myself outside school e.g. playing out in the sun(wear a hat, clothing, sunglasses, sun lotion)
- Produce a set of guidelines on the education of children with albinism for ITs and class teachers. These will contain some strategies on helping children in school and the community.

School-based solutions

- **Recognition of visual impairment of children with albinism**

  Albinism is always associated with some degree of visual impairment, due to nystagmus (involuntary eye movements) and photophobia as well as other eye problems such as squinting and astigmatism, which vary between individuals.

  The vast majority of visually impaired pupils in Malawi have albinism (73% of the case load for Sightsavers). As they have a very visible difference in appearance this group are easily identified due to the lack of black pigment in their hair, skin and eyes. Although their vulnerability to sun induced skin damage is usually well recognised, their visual impairment is less obvious and may go undetected when they start school.

  Recommendation: Teachers should identify pupils with albinism at the start of their school career, so that appropriate measures can be put in place to alleviate their visual impairment, protect their skin and facilitate their learning.

- **Assessment of the degree of impairment**

  Although visually impaired, children with albinism have sufficient residual vision to enable them to use print rather than Braille. Observations carried as part of this project showed that they could do detailed drawings by holding their faces very close to the paper, even without the use of spectacles or other low vision devices.

  Recommendation:

  - Specialist teachers should carry out functional vision assessments of children with albinism to determine children's needs and find out how their vision affects their functioning in daily life and design appropriate interventions.
  - Braille is not recommended as vision will not deteriorate with age due to albinism, as this is ***not*** a progressive condition***.*** The visual impairment is present at birth and is life-long; it varies in severity between individuals.

- **Immediate and appropriate intervention**

  At the start of their school career, children with albinism must be assisted and the teachers informed of the techniques they can use to facilitate the pupil's learning. Where itinerant teachers are available, they are in a position to take responsibility for assessing and educating class and head teachers about the educational needs of pupils with albinism. It should be stressed that these interventions are not time consuming or expensive e.g. allowing a child with albinism to sit in the middle of the room, at the front and use their own book so they can hold it very close to their eyes.

Key recommendations:

- Identify appropriate, low cost interventions that can be put in place immediately to promote the learning of pupils with albinism.
- Identify and allocate responsible persons e.g. an itinerant or head teacher, to inform and train class teachers and liaise with parents/guardians.
- ITs must provide class teachers with guidelines on how best to support children with albinism in class and give children some guidance on how to protect themselves against the sun and protect their eyes.
- ITs should visit children with albinism either once a term (for children who require frequent follow-up visits) or on an annual basis (to advise new class teachers and provide technical support to the child e.g. renew spectacles, review equipment and low vision devices).

Teacher training courses

The two year diploma, launched in 2010, does not contain any module or part module on assessing and educating children with albinism. Specialist teachers will have to support children with albinism at school and will require training on how interventions to increase their educational inclusion. Trained teachers are leaving college with inaccurate information about assessing the vision of children with albinism. Many ITs say they have received no training on how to use low vision devices and would like to know more about how to help children use them in class.

Recommendation:

- Course lecturers should integrate albinism into different parts of the teaching curriculum – definitions of disability, early childhood education and low vision (use of low vision devices, hats, reading stands), and functional assessments of vision.
- Students should be encouraged to conduct case studies on albinism as part of their course work or school placement in order to build a local base of knowledge and share their experiences.

In-Service Training and refresher workshops

Focus group discussions with itinerant teachers based around Blantyre identified training needs for itinerant teachers and others via workshops and other means, to meet the educational needs of affected pupils in schools and so that information about albinism will filter throughout communities, especially in rural areas.

Recommendation:

- Organise workshops to ‘train the trainers’ for example a key group of head and itinerant teachers, who can then cascade information about albinism locally.
- Workshops should involve and include families affected by albinism.
- Invite members of TAAM to participate in workshops on low vision and inclusive education.

Provision of low vision devices

Magnifiers and monocular telescopes are useful to help pupils, but may result in them being mocked by peers, leading to low compliance. All interventions including the provision of magnifiers, monocular telescopes, dark glasses or spectacles must be evaluated for effectiveness and compliance. An evaluation of the use of a donated hand held magnifier showed that a young boy would not use even this unobtrusive aid in a classroom setting as his class mates disturbed him and wanted to use it for fun. He preferred to use it for homework.

The most effective, cheapest and most accepted form of ‘aid’ is a wide brimmed hat and dark glasses. If children with albinism are allowed to wear a hat both inside and outside the classroom, this will help protect their very sensitive eyes from bright light and improve their vision. Hand held magnifiers are also useful, but compliance may be low. Prescription spectacles will correct some visual problems such as astigmatism, which will improve visual performance, but these are relatively expensive, may get broken and require regular check-ups at optometrists.

Recommendation:

- Introduce frequent monitoring and evaluation of how low vision devices are being used by children with albinism to measure their usefulness and general acceptance in classrooms.
- In consultation with the Special Needs Education Directorate, FEDOMA, TAAM and NGOs such as Sightsavers, provide appropriate low vision devices to children with albinism and monitor their effectiveness.

6. Case studies of albinism in Malawi

These case studies have been chosen to illustrate some of the complexities of living with albinism in Malawian society.

6.1 A family in rural western Malawi where children with albinism were not attending school

This family was visited by two members of the team in September 2011 after an IT reported their children with albinism were not attending school.

The parents were cousins and had nine children, two with albinism. The felt these children were well accepted by both extended families and by the community; there was '*no negativity'*.

Six of their black children had stopped school at standard 5 or 6, to get married; one was still at school but the two siblings with albinism were not attending. In fact the 17-year old young woman had never been to school. The family reported that she refused to go; she was '*shy*'. Her young brother had started standard 2 but had dropped out, although he was considered bright and talented, with an extremely good memory. If he heard a song once he could recite it and was '*number one'* at the mosque school where he was studying the Quran in Arabic. He was also creative; he had rigged up a home-made shadow puppet theatre made out of pieces of plastic and a cardboard box, where he entertained his friends and family with plays.

The local primary school was located across the road from this family's enclosure. The headmaster reported that this was the first case of albinism at the school. He had recently spoken to the family about sending their son with albinism to school. The family had promised to do so but he had not yet (about three weeks into the term) appeared. The head suggested the reason for this reluctance to come to school was that he did not have a school uniform due to limited family resources. He saw that all his friends were wearing uniforms and did not want to appear different, so stayed at home.

The teachers knew he had poor vision and should be placed near the chalkboard. The head teacher felt his class mates supported him; when he spoke they listened carefully. The young boy also received encouragement from this mother; his father attended school meetings but was very quiet and did not contribute, just listened.

6.2 A case study of a young woman in rural Malawi

A transcript of the interview with Virginia is presented below:

> I started standard 1 and then I was not realizing that I have low vision. I realized when I was in standard 4. In the first 3 years I thought that everyone has the same vision as I have. I was unable to see on the chalkboard and then after I realized that I have low vision then I started following the teacher, saying 'Can you borrow me some books?' I told him that I have a problem to see on the chalkboard and then he was giving me the book. Then, when I got into standard 5 and its when in Malawian school we start copying some notes (from std 1 to 5 is just oral teaching with a bit of maths, then 5 to 8 pupils take notes, copied from the chalkboard); then I had a problem to copy the notes from the chalkboard. So I decided to copy from my friend as he is copying, I was seeing on his book. And then I said 'No, this will not help'. And then she let the friend copy the notes in the classroom so she could copy them at home and when I'm home I could not play, but copied notes. And my sisters were assisting me in copying the notes. Sometimes they could just go straight to the teacher and take (copy) the notes from her. But I said 'No, this will not work, as somebody would not know what you are copying', so I said I will copy myself. During examinations he was giving papers to me and some others said, 'No she was giving exams'. When they give her the examinations, they give her with answers. So, the teacher changed. And then she give me the papers and some other few girls in the class, so they see it was the same and I was then getting position one from std 5 up to std 7. At Tenbwe primary school and then I went to Gillime primary school in std 8 and from there I was selected to Lilongwe Girls secondary school and there I had problems in maths. I was trying with other teachers but it was failing and then come another teacher when I was in form 3 and said 'I will be teaching form 3 because I want to assist Virginia'. He was teaching me mathematics in class and thereafter we were sitting under a tree and teaching me after 3.30 (after class). Through the paper and then we wrote our MSE (Malawian school certificate of examination) and in 2009 I was selected to go to Kasungu Teachers Training Centre. And there I was very lucky because there are a lot of notes to copy for 10 subjects. I thought 'No, how am I going to manage?'

6.3 A case study of a rural family where four children have albinism: barriers to success

The father talked about the difficulties in supporting his four children with albinism as it was expensive to buy hats, long clothes and '*the lotion'* for their skin. He was aware of their low vision and knew they must sit in front in class so they could see what was written on the board. The primary school his children attended is close to their house, the teachers live within the community, know and accept them. There were, however, problems with acceptance at the secondary school his eldest daughter attended, although he had not visited the school to speak with the teachers.

In the words of the eldest daughter she had '*a lot of problems'* in her first year at school as that teacher did not support her (he could not understand her), but the following year she got the necessary support from another teacher. There was a lack of knowledge about albinism among the teachers when she moved to secondary school; they did not know how to support her and there was a lot of bullying. Her fellow pupils could not understand why she could not see very far and looked white, so they called her names that she did not like (*mzungu, napwere*). She felt she could talk to her teachers about her eyesight problems and she borrowed notes from a friend who had good hand writing.

She is currently (2011) repeating her final year at school as she failed some of her government exams. She received large print scripts for a few subjects (which she passed) but not others (which she failed).