

Promoting the educational inclusion of children with albinism in sub-Saharan Africa

Evidence from Malawi

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Children with the inherited condition albinism look very different from their dark-skinned peers in Africa. They lack pigment in their hair, skin and eyes, making them 'white' in a black community. In addition to their extreme sensitivity to the sun, they are visually impaired and often suffer rejection, ostracism and poor social integration. Deeply rooted myths surround albinism, including the belief in some parts of Africa that their body parts have an occult power. In Tanzania, the lives of those with albinism are threatened by killers targeting them for use as 'good luck' charms¹. This practice has spread to other countries in the region and has become a serious human rights issue².

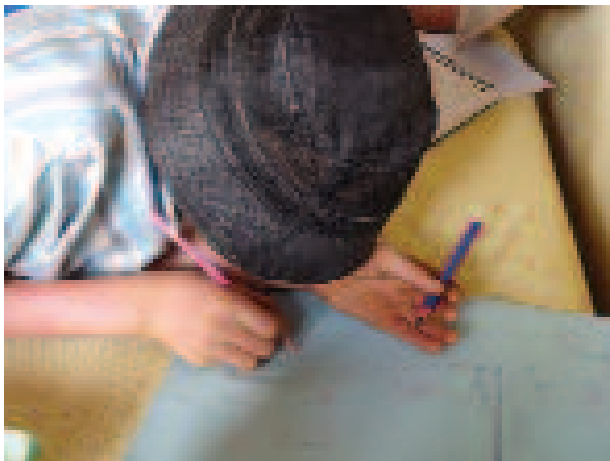
Albinism is found in all populations but has a relatively high frequency throughout sub-Saharan Africa, with a prevalence of 1 in 2–5,000³. It is a major cause of low vision at birth.

Educational strategies

The schooling of children with albinism differs between and within countries. In Zimbabwe, for example, they usually enter mainstream schools. In Zambia and South Africa, children either board at residential special schools or attend mainstream schools. In Malawi, some are in special schools established in the 1950s by missionaries for educating children who are blind or have low vision. Others are educated in residential resource centres attached to mainstream schools that were set up by international non-governmental organisations (INGOs) in the 1970s and are now

managed by the Ministry of Education, Science and Technology (MoEST). In the 1980s, a new system of delivery, the Malawi Integrated Education Programme (MIEP), was established to promote the integration of children with visual impairment into local schools and to reduce overcrowding in resource centres. On this scheme, itinerant teachers with some formal training in low vision education travel to mainstream schools and communities to support the education of visually impaired children, as well as their teachers and parents⁴.

Like many countries in sub-Saharan Africa, Malawi is struggling to meet the demands of surging numbers of enrolment following free primary education for all (FPE) and to convert these surges into high levels of progression in the early grades⁵. Given the very difficult conditions that 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 overcrowded classrooms with limited teaching and learning resources. A recent study in central Malawi, which was supported by the Commonwealth Secretariat, Sightsavers International, Coventry University and the University of Birmingham, explored simple and low-cost ways to support this vulnerable group through the use of inclusive educational practices. A participatory approach was adopted to encourage all those involved (children, young people, parents, as well as class, head and itinerant teachers) to talk about their experiences and to share their perspectives on albinism.



The low vision associated with albinism is not progressive, and children can see if allowed to get close to the book or paper



Example of the detailed drawings produced by children with albinism, demonstrating they can see and observe their environment even without access to spectacles or low vision aids

Outcomes of a Special Educational Needs (SEN) study

The majority (73 per cent) of visually impaired children on the MIEP programme in central Malawi had albinism, indicating that this condition is the major cause of low vision among children in this region. As albinism affects both sexes equally, the finding that there were twice as many boys as girls with albinism going to resource centres indicated significant gender inequality in accessing this service. This study also revealed worrying evidence that some children with albinism were not attending school due to bullying by peers, lack of understanding by teachers or insufficient parental support. However, attitudes towards the inclusion of pupils with visual impairment in mainstream schooling were generally supportive. Case studies (see box) highlight the experiences of those with albinism, demonstrating that although albinism cannot be cured, it can be managed effectively.

Evidence from children and young people with albinism, their teachers, parents and traditional leaders was gathered to share good practices and recommend ways to support the education of young people with albinism. The parents considered the role of the local school paramount in encouraging parents to send their children with albinism to school and in supporting them in class. Following a dialogue between the researchers and an advocacy group, The Albino Association of Malawi (TAAM), the following areas were prioritised:

- **Early identification** Those with albinism are easily identifiable due to their lack of pigment. They always have some degree of visual impairment, although this may initially go unrecognised.

Teachers should not wait for an 'expert' assessment of the children's vision, but observe them to assess their functional vision and adapt the environment to support them from the start of their school career.

- **Appropriate interventions** Simple interventions include allowing children with albinism to wear their hats inside, sit in the middle at the front of the class, have their own book even if others are sharing, and use low vision devices such as hand-held magnifiers (if available and acceptable to the child). Sun protection is crucial. Behavioural habits such as always wearing hats and protective clothes, as well as avoiding sun exposure during the middle of the day, should be encouraged and monitored. All interventions, such as the provision of low vision devices, should be monitored and their use evaluated frequently.
- **Inappropriate interventions** There is a mistaken belief that children with albinism will go blind in the future. This is sometimes used as a justification for teaching them Braille at school. This is not recommended, however, as albinism is not a progressive condition and does not lead to blindness.
- **Accessing information on albinism** When a child with albinism enters a school, the head teacher should immediately contact their District Education Manager to obtain information booklets on albinism from the Ministry of Education. In addition heads should obtain advice from their local advocacy group: for example, TAAM.
- **Nominated teachers** Each child with albinism should have a class or itinerant teacher with overall responsibility for supporting their education; for example, for training other teachers, liaising

Virginia's story: a young woman with albinism living in a rural village

At Virginia's birth, her mother was told by people in her village that she "will not grow and will die young". However, 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. The headmistress had said that she should attend a special school for the blind, but with the support of another teacher (a friend in their village), Virginia was subsequently enrolled. Her mother is proud that there is a photograph of Virginia at this school presenting her 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 three years, I thought that everyone had the same vision as I have."

Once she realised she was the only pupil in the class who could not see the blackboard, she requested and received extra help from her class teachers, who gave her additional lessons after school, and her peers, who allowed her to copy their notes.

With this support from family, peers and teachers, Virginia was always top of her class and went on to train as a teacher. She is keen to participate in advocacy, acting as a motivational speaker to inform schools and communities about albinism.

Virginia with her mother (left) and aunt (right); photo used with kind permission of Virginia and her family



with parents, and ensuring they have access to all available support, including large print examination scripts and protection from bullying and name calling.

- **Teacher training for classroom teachers** Class teachers who were coping with meeting the needs of children with albinism without any formal training were keen that basic information on albinism and appropriate strategies for educational inclusion should be integrated into the curriculum training for classroom teachers. This could be included in definitions of disability, early childhood education and low vision.
- **Teacher training for children with special educational needs (SEN)** Albinism and its associated visual impairment should be incorporated as a training topic for specialist SEN practitioners; this would involve training the lecturers at colleges responsible for delivering the training. Ways of adapting the classroom environment for children with albinism should also be discussed, rather than removing them from the classroom for special tuition. Trainees should be encouraged to conduct case studies on albinism to build up a local base of knowledge and experience.

Relevance to sub-Saharan countries

Facilities available in different countries to support the needs of children with albinism differ. In Tanzania, for example, protection from violence is a top priority, and schools are able to offer a refuge for those affected. In Namibia, meanwhile, with its country-wide network of optometrists, a support group, Sinasra (Support for Albinism Sufferers Requiring Assistance, www.sinasra.com), has found the use of donor-funded telescopic spectacles to be successful. These enable those with albinism to access learning materials and cope with classroom activities, thus facilitating their integration into mainstream education⁶. Such specialist devices are, however, prohibitively expensive, making such an intervention difficult to sustain and dependent on the availability of optometric services. The spectacles are not currently available in Malawi. Whatever the local resources, the simple but effective interventions that are outlined here will have a positive impact on the educational experience of this group of visually impaired children. Teacher training is key to achieving this⁷. In the words of one parent in Malawi: "Teachers should understand how to help a child with albinism."

Endnotes

- ¹ International Federation of Red Cross and Red Crescent Societies (2009). *Through Albino Eyes. The plight of albino people in Africa's Great Lake's region and a Red Cross response*. Advocacy report.
- ² Thuku, M. (2011). *Myths, Discrimination, and the Call for Special Rights for persons with albinism in sub-Saharan Africa*. Available at: http://www.underthesamesun.com/sites/default/files/MYTHS.Final_.pdf
- ³ Hong, E., Zeeb, H. and Repacholi, M. (2006). 'Albinism in Africa as a Public Health Issue'. *BMC Public Health* 6 (1), 212 Available at: <http://www.biomedcentral.com/1471-2458/6/212>
- ⁴ Lynch, P. and McCall, S. (2007). 'The role of Itinerant Teachers'. *Community Eye Health* 20 (62), 26-27 Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1906922/>
- ⁵ UNESCO (2011). Global Monitoring Report. *The Hidden Crisis: Armed conflict and education*.
- ⁶ *New Era* (newspaper) (20 October 2004). 'Namibia Amongst Highest Rate of Albinism'. Available at: <http://www.newera.com.na/article.php?articleid=3696&title>
- ⁷ Information booklets for children and teachers have been developed as an extension of this project. The next stage is to exploit radio broadcasts and mobile phones for large-scale community learning and teacher training.

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