

4k. Health-related conditions – Albinism

Some of the learners in your Hub may have health-related conditions. Two conditions that may affect learners in your Hub are Albinism and Epilepsy. These are very different conditions; however, in both cases a major barrier to learners' educational success is stigmatisation.

Albinism

Albinism is a genetic condition which reduces the amount of pigment in a person's eyes, hair and skin. This means that children with albinism are often very pale in appearance and have low vision. Their skin is sensitive to the sun, so skin cancer is a significant issue for them. However, there is no learning disability or cognitive impairment associated with albinism.

Low vision occurs at birth and does not change with age. The degree of visual impairment varies between individuals, but they are not blind.

Albinism is associated with several types of eye conditions.

Strabismus or Squint	The girl's eyes may appear out of line with each other.
Astigmatism	Blurred or double vision
Photophobia	Eyes that are very sensitive to light and glare.
Nystagmus	Involuntary side to side movements, although the girl will see a stable image.
Myopia (short-sightedness):	Can see things when they are near to them.

Many children with albinism need to wear glasses or to hold objects and books close to their eyes to see them clearly. Bright light makes it difficult for them to see and some may have problem judging distance.



What can you do in your role to support girls with albinism?

There are several practical ways in which you can support girls with albinism in your Hub. These relate to addressing visual issues, skin sensitivity and stigmatisation. Following your initial conversations with the learner and their family, and your Hub observations, you can begin to develop an understanding of the girl's functional vision and how best to support her as an individual. The following are some helpful general strategies.

Physical

- Make sure the girl is feeling comfortable about where she is sitting, with regard to bright light and glare. As a general rule, avoid seating her or asking her to work in brightly lit spaces/direct sunlight. Allow her to move if the lighting in the Hub changes during the day.
- Generally, learners with albinism should sit near the front of the Hub if you are making a 'traditional' front of room presentation. The girl may adjust the angle of her head to reduce eye movements, and so may prefer to sit on the right, middle or left-hand side. Do not ask her to change the angle of her head, as it helps her vision. Discuss with her where she should sit and then observe how well she is learning in that particular place.
- She might hold books and objects close to her face. Show her, and the rest of the learners, that you are happy with this.
- If the girl has a low vision device then support her use of it. For example, you may need to provide a magnifier. Find out how she has been advised to use it and consult your School Head and/or Hub Development Committee.
- Learners do not require Braille.
- Some learners find a simple bookstand helpful and better to use than holding books for periods of time. A bookstand is anything that holds the book up in front of the learner.
- Sunglasses that protect against ultraviolet light are helpful. If a girl has some, then allow them to wear them inside the Hub if she wishes and always when in direct sunlight.
- Learners may require sunscreen lotion (check supplies with the School Head and/or Development Committee). Always request for additional supplies before they run out.

- Large font size in text may be preferred depending on individual needs and outcomes of assessments.
- Prescription glasses to correct refractive errors can be very helpful for many learners. In your initial meeting with the girl, check if she has some and support their use in the hub.
- Hats can be very helpful in reducing glare and protecting eyes, so allow the girl to wear a hat inside the Hub if she needs to do this. If she does not have a hat but is in need, please make a request to the School Head and/or Hub Development Committee.

Activities

Think about how to make tasks and materials more accessible, for example:

- When using a chalkboard use white chalk for contrast, use a clean board and always ensure your handwriting is legible to all learners.
- Describe verbally what you are writing.
- Plan to minimise activities where learners need to repeatedly switch their visual attention, for example, between their book and a display board or copying from a chalkboard.
- Allow them to write in a size that is legible for them. A black pen/pencil on white paper is helpful.
- Ensure the girl is always aware of changes in classroom set up to avoid her bumping into objects e.g. desks.

Social

- Use the girl's name before asking her to do something.
- Learners with low vision can find it hard to concentrate and follow teaching activities. Their eyes can become very tired and their posture strained, so give them frequent breaks from focused activities.
- If you are including outdoor activities think about when they occur, with regard to strong sunlight and shade.

Albinism is highly stigmatised and is associated with many common misconceptions. If you are asked about albinism, explain that it occurs across the world, is not a curse or disease, and cannot be 'caught' by touch. If learners are to succeed you will need to address name calling and teasing, and make them feel safe within your Hub. Your behaviour will act as a model for all and should express that those with albinism have the same potential and worth as all other learners.

References

Dart, Gareth and Lund, Patricia, Teachers' Toolkit for Supporting Students with Albinism in African Classrooms (AIMZ: Albinism in Malawi and Zambia, 2014) (<https://eprints.worc.ac.uk/3736/>)

Ero, Ikponwosa, Quick Guide for Teachers and Educators of Persons with Albinism: 4th edition (Under the Same Sun, 2014)

Kammer, Rebecca L., 'Low Vision Rehabilitation and Albinism' in Jennifer G.R. Kromberg and Prashiela Manga, eds. Albinism in Africa (Elsevier, 2018), 151-169

Lund, Patricia, Albinism in Africa: Information for Children (AIMZ: Albinism in Malawi and Zambia, 2014) (<https://curve.coventry.ac.uk/open/items/de7cc1f3-c446-4066-9351-d22f72d8b198/1/>)

Lund, Patricia, Massah, Bonface and Lynch, Paul, Albinism in Africa: Information for Teachers and Parents (The Albino Association of Malawi (TAAM), 2012) (<https://curve.coventry.ac.uk/open/file/5c501215-c908-ead9-1212-e9367731fd10/1/>)

Albinism -information for teachers and parents

Nystagmus Booklet for Teachers (The Nystagmus Network, 2016)

Albinism: An information booklet for teachers in Tanzania. Standing Voice (2019).

Acknowledgments

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<http://www.open.ac.uk/about/international-development/projects-and-programmes/gate-girls-access-education>

<https://www.open.edu/openlearncreate/course/view.php?id=2579>

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